



PATIENT  
COMMANDO

Empowering patient choice



# STATE OF **PATIENT ASSOCIATIONS** IN CANADA

Charitable organizations included in this report are defined as:

*Social purpose organizations that exclusively provide services, support, education, research, and/or advocacy to patients, caregivers and families in crisis or need, marginalized populations, at-risk and complex care needs, disabilities and those suffering from acute or chronic health challenges.*

## Acknowledgement

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# Executive Summary



# EXECUTIVE SUMMARY

In March 2020, Canada was caught up in the COVID-19 pandemic then spanning the globe.

As with all other elements of society, patient-focused charities that raise funds to support research, programs, and services aimed at helping patients and their families with specific diseases or conditions were hugely impacted, with the future of many such organizations being placed in doubt. This report provides a comprehensive overview of the status of these patient-focused charities in 2019, presenting a unique snapshot of a moment in time before things changed.

This is the first report to specifically analyze the financial, operational, and human resource capacity of 1004 patient-focused health charities in Canada. The report is based on data submitted to Canada Revenue Agency (CRA) in annual returns for the year prior to December 2019. It offers a baseline by which to compare the impact of COVID-19 on this sub-sector of charitable organizations as stakeholders emerge into a post-COVID-19 period and begin to reassess partner relationships in light of these organizations' capacity to continue their work.

The heterogeneous nature of patient-focused charities is one of the most noteworthy characteristics of this sector – comparable in many ways to the diversity of diseases and health conditions with which the charities are concerned. With each having more than \$100 million in income annually and hundreds of full-time employees, the Canadian Cancer Society and The Heart and Stroke Foundation of Canada dominate the sector. However, between these two charities and the many charities with few if any full-time employees who rely on volunteers and focus their efforts in a specific region or program, there lies a spectrum of many other organizations with a wide range of annual income and expenditures.



**The charitable sector in Canada was already facing challenges prior to 2020.**

While the COVID-19 pandemic is having a dramatic impact on patient-focused charities, the charitable sector in Canada was already facing challenges prior to 2020 with concerning trends in charitable donations and other organizational threats.

A report from the Senate noted that for charities “demand for services has increased, yet funding is constrained. In addition, technology has disrupted traditional models of service delivery and changed the way in which charities and non-profit organizations interact with volunteers and donors. A new roadmap is needed to enable the sector to continue to build on its strengths and adapt to new and emerging realities.”

## Revenue

There are over 86,000 registered charities in Canada whose total revenue in 2017 amounted to \$279 billion.<sup>1</sup> While making up 1.2% of the national total, patient-focused charities generated \$1.366 billion in revenue, only 0.49% of total charity revenue.

**The top 20 charities alone control 62% of all revenue with the remaining 38% of total revenue shared by the other 98% of the organizations.**

The number of groups earning under \$100,000 in revenue during the period evaluated totals 502, exactly 50% of those organizations under review. On the other end of the scale, there were 44 patient-focused charities with revenues over \$5 million or 4.4% the total, equivalent to the figure of 4% nationally across all 86,000 charities.

The top 20 patient-focused charities alone control 62% of all revenue with the remaining 38% of total revenue shared by the other 98% of the organizations. This disparity acutely

underscores the degree of competition for funding among these groups. With diminishing numbers of individual donors, there are a finite number of other sources — events, grants, sponsorships, etc. — available to this specific sector. Many of those funding sources also attract charities from outside the patient-focused sector which serves to inflame the competition. It also illustrates the intersectional nature of competition for funding.

The ability to issue official donation receipts is the most important benefit to Canadian registered charities and Canadian tax laws for charitable giving are arguably among the most generous among developed nations. The charities in the patient-focused sector issued tax receipts for 36.29% of total revenue. This contrasts starkly with the national percentage of 6.5% (2017) which would indicate a much higher dependency on this revenue source for the sustainability of the charities than the entire sector average.

Total government funding for the patient-focused groups was \$337,918,293 or just 24.73% of their revenue. By comparison, government funding of the entire charitable sector from all levels (federal, provincial/territorial and municipal) was in excess of \$183 billion in 2017, almost 66% of all funding.

For patient-focused charities, funding from the various levels of government was as follows:

- Federal funding accounts for only 1.46% of total revenue.
- Municipal funding was only 0.42% of total revenue.
- Provincial funding provided 30% of total revenue primarily in support of social service activity as agents of the government.

The term “earned income” is generally applied to activities that involve selling goods or services to customers. It is estimated that up to 75% of all charities have engaged in these activities. The range of goods and services is extremely broad, and includes products, expertise, processes, and intellectual property. The broad sector generated \$23.127 billion from the sale of goods and services which represents 8.5% of all revenue. Patient-focused charities, on the other hand, reported \$56,995,775 or 4.17% of revenue.

## Fundraising

Charities must report fundraising revenue and expenditures on their annual return. The fundraising ratio is a key measure that CRA uses to assess the fundraising activities of a charity. This ratio is calculated by adding up tax receipted gifts and non-tax receipted fundraising and then dividing by the total of fundraising expenditures. It is commonly believed that a ratio under 35% is unlikely to raise questions by CRA but if over 35% the opposite is possible.

About 40% of patient-focused organizations (399) reported total fundraising expenditures of \$301,555,342 or 22.61% of total expenditures. Their fundraising ratio is 41%, somewhat higher than the CRA test but dramatically higher than the broad sector which reported a ratio of 12.6%. This can be explained in part by the sums of government funding that government related charities receive, thus relieving them of a great deal of dependency on fundraising. The patient-focused charities however are far more dependent on fundraising.



Patient-focused charities however are far more dependent on fundraising.

There is a definite trend towards donating online in Canada. Online giving grew to \$144.8 million in 2017, a 17% increase from the year before, compared to a 6% increase in total giving in Canada.

Although over 16% of our groups still use collection plates and boxes, the trend to online activity is discernible with almost 30% of groups reporting fundraising activity on the internet.

Only 7% of patient-focused charities employed professional fundraisers who raised over \$64 million and were paid \$12.8 million.

## Expenses

The patient-focused group of charities spent \$1.33 billion or 97.61% of total revenue. By comparison broad sector expenditures amounted to \$261.7 billion or 93.5% of total revenue. The total sum of \$813,466,505 reported by the patient-focused groups on charitable activities represents

“Of all expenditures by charities, management and administration is probably the most publicized and scrutinized metric by the public, donors and media.

61% of total expenditures while the broad sector comes in with 76% of expenditures.

Of all expenditures by charities, management and administration is one of the most publicized and scrutinized metric by the public, donors and media. While there are many factors that influence this expenditure, such as size of organization, it is generally accepted that a ratio below 12.5% is considered excellent, and then ratios are further rated on a scale between 12.5% and 22.5%. Spending in this area accounted for 8.16% of expenditures for patient-focused charities.

Medical and scientific research is a key priority for many patient-focused charities and forms a foundational plank in their mission. The public is also very attentive to this fact as it is one of the major factors communicated to members as a reason to support the cause. The public is barraged by online and newspaper ads, billboard and transit advertising, direct mail campaigns, etc. all focusing on the theme of medical research to find a cure. A total of \$131,601,788 was reported as research grants and scholarships by 132 or 13.14% of the patient groups.

## Human resources

Patient-focused charities differ markedly in how many staff they employ, if any. While a few have many employees and are headed by an individual who is well-compensated, others have no full-time staff and are strictly run on a volunteer basis. Overall patient-focused charities employ 7435 full-time staff.


The review of human resources for these charities revealed the following:

- 56% have NO full-time employees
- 2 organizations employ 56% of all employees
- Full-time compensation is 32% of total revenue
- 27 organizations reported 39 employees earning between \$200,000 and \$350,000
- 5 organizations reported one employee earning over \$350,000

## Public policy activity

There is limited information available about the impact of Canadian patient organizations such as patient-focused charities on policy development. It has been demonstrated that patient involvement in policy areas such as Health Technology Assessment can have beneficial results and uncover insights into patient experience previously not widely known. But there is no significant evidence reporting the impact and influence of patient organizations across the policy landscape.

To address this important gap, we examined the public returns of the patient-focused organizations to identify how they describe their activities and what financial and human resources they devote to public policy activities. The data set represents the last complete reporting period under which charities were required to fully disclose political activities, including descriptions of the activities, resource deployment and amounts spent. The data clearly describes the degree of engagement and resource commitment charities gave to political activities. Under the rules by which charities operated during the period covered in this report, charities were prohibited from spending more than 10% of their revenue on political activities and were required to report on their activities and disclose their spending. Recent changes to the rules allow unlimited spending on what are termed Public Policy Dialogue and Development Activities (PPDDA) and no requirement to report expenditures or other details.



Total expenditures  
(on political  
activities) was  
\$5,135,878, .38% of  
revenue... fully 50%  
of that is accounted  
for by only 2 of the  
charities.

Out of the total of 1004 charities, only 31, or 3%, reported PPDDA expenditures. Total expenditures by this small number of organizations was \$5,135,878, representing 0.38% of total revenue of \$1.366 billion for the entire patient-focused sector. Of this spending fully 50% of that is accounted for by only 2 of the charities – the Canadian Cancer Society and Canadian Diabetes Association (now Diabetes Canada).

## Post-COVID era

The impact of the COVID-19 pandemic in the spring of 2020 on Canada's charitable sector including patient-focused charities was almost immediate and devastating. Organizations suddenly found themselves severely constrained in their revenue-generating activities while at the same time trying to maintain daily activities while direct person-to-person contact was discouraged or forbidden. Patient-focused charities also found themselves struggling to inform their constituents in the face of a

novel coronavirus whose signs and symptoms were soon found to impact several organ systems.

[An assessment<sup>2</sup>](#) of the impact of COVID-19 on the charitable sector conducted with more than 1400 charity leaders in late April, 2020 and published by Imagine Canada in May showed 30% of charities have already laid off staff and 55% say new or additional layoffs are a possibility. By the middle of July it was being reported that health charities expected “historic losses” and would only raise less than half of usual revenues in 2020 because of the COVID-19 pandemic. At the time of publication of this report, the course of the COVID-19 pandemic remains uncertain as does its impact on the charitable sector. The initiation of new programs or continuation of existing programs from the federal government to support charities will be somewhat dependent on the scope and speed of the economic recovery as we enter a “post-COVID” period.

As with for-profit and non-profit organizations it is probable some patient-focused charities will not be able to survive the economic challenges caused by the pandemic and will be forced to close their doors. Others will have to radically restructure in order to survive in whatever fund-raising environment they will have to function within under “new normal” conditions.

## **How patient-focused charities describe themselves**

Patient-focused organizations are asked to choose up to three program areas that describe their charitable activities. These program areas are pre-defined by CRA and the full list is in Appendix E. It affords a witness box perspective of how organizations view themselves, their work and their community.

These important data deliver insights to the interconnectivity of patient-focused charities with other charities in social services, community benefits such as human rights, culture, education, research, housing, transportation, or other support for the physically challenged.

It appears that patient-focused charities view themselves through a lens that spans a universe of needs including disease awareness, research, social determinants of health, advocacy, health literacy and psychosocial support among many others. With a preponderance of patient-focused charities describing themselves as involved in multiple program areas, the challenge and opportunity to potential stakeholders is to align themselves with the same multi-disciplinary, multi-dimensional perspective when it comes to establishing authentic partnerships.






# Introduction

# INTRODUCTION

If you have seen a television commercial or billboard advertisement exhorting people to help “find a cure” for a certain disease you have been exposed to a patient-focused charity. Similarly, if you have sought health information or care at a small regional centre you may be benefitting from the same type of charity.

 A new roadmap is needed to enable the sector to continue to build on its strengths and adapt to new and emerging realities. The charitable and non-profit sector has suffered from benign neglect for too long.

Canadian charities that focus on specific diseases and health conditions make up just a small percentage of all registered charities operating in Canada. However, in common with the larger sector of all charities, while the COVID-19 pandemic is putting unprecedented pressure on the many organizations, these charities were facing significant financial challenges and an uncertain future even before the pandemic. One of the most recent and comprehensive overviews of the charitable sector in Canada as a whole comes from a report titled [“Catalyst for Change: A Roadmap to a Stronger Charitable Sector”](#)<sup>3</sup> tabled by a special Senate committee in June, 2019. That report noted that an estimated 86,000 registered charities and 85,000 non-

profit organizations generate more than 7% of Canada’s gross domestic product and employ more than 2 million people.

The report stated:

*“Demand for services has increased, yet funding is constrained. In addition, technology has disrupted traditional models of service delivery and changed the way in which charities and non-profit organizations interact with volunteers and donors. A new roadmap is needed to enable the sector to continue to build on its strengths and adapt to new and emerging realities. The charitable and non-profit sector has suffered from benign neglect for too long. Legal rules have been*

*reformed in a piecemeal fashion; task force recommendations have gone unimplemented; and kind words have all too often served as a substitute for meaningful action. The time for real change has come.”*

The committee stated the sector relied on three main sources of funding: government funding, donations and earned income and that innovative approaches were needed in each of these areas to guarantee their future viability as sources of funding. It added “there is no single strategy or quick fix that would ensure the sector can continue to thrive and play its vital role at the heart of Canadian communities” but made a number of recommendations. “To continue its good work, the sector needs meaningful law and policy reform, as well as a renewed relationship with the federal government,” the report concluded.

“To continue its good work, the sector needs meaningful law and policy reform, as well as a renewed relationship with the federal government.

A report by Imagine Canada looking specifically at donations from Canadians to charities between 1985 and 2014 spotlighted another specific challenge facing charities – namely a decline in the number of people making donations. According to [Thirty Years of Giving in Canada](#):<sup>4</sup> “We estimate that in 2014, Canadians gave approximately \$14.3 billion in receipted and unreceipted donations to registered charities. Claimed donations have increased 150% in real terms since 1984. However, the proportion of taxfilers claiming donations has been falling steadily since 1990, which means that charities are relying on an ever-decreasing proportion of the population for donations.”

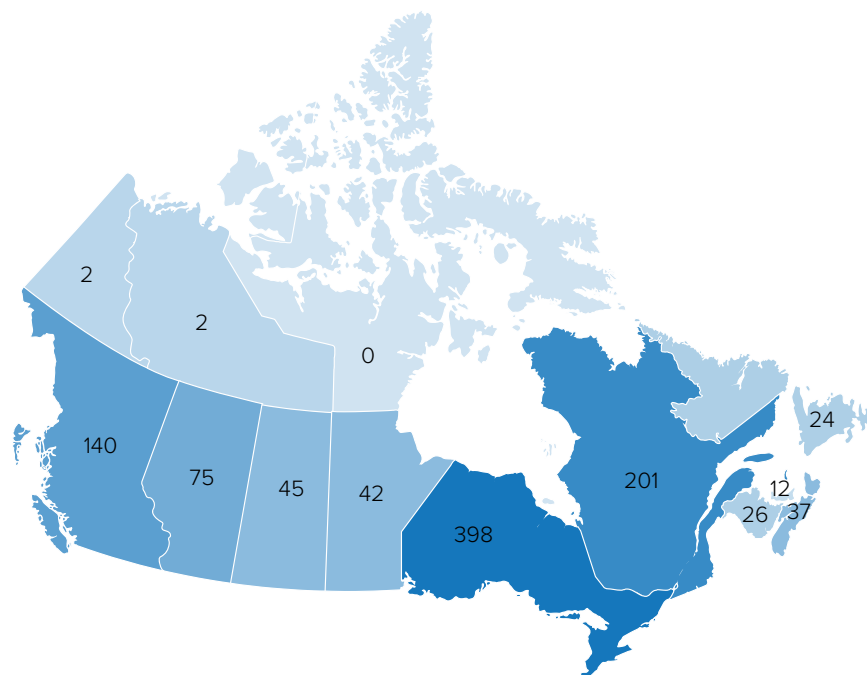
“Donors, as a group, have become much older and wealthier,” the report continued. “The giving behaviours of Generation Y are particularly worrisome; both the donation rates and average donations of this group are low and increasing very slowly...There is a limited amount of time left to tap into the philanthropic impulses of (the Baby Boomer generation) and it is unclear if younger generations will be willing or able to take their place.”

This uneasiness has also been expressed at the regional level. [A 2019 report](#)<sup>5</sup> from the Ontario Non-Profit Network representing charities and non-profit organizations in the province noted that “organizations aren’t just worried about having their funding streams cut, but also the speed and uncertainty of the decision-making process, as well as the lack of information, details, and engagement with the sector by the provincial

government. The responses from nonprofits underscore the challenges they face and the concern they have for the communities they serve.”

Imagine Canada describes health charities as organizations that “provide both in-patient care (e.g., hospitals, nursing homes) and a broad range of out-patient care and services including rehabilitation, mental health treatment, emergency medical services, crisis intervention, public health and wellness education.” The heterogeneous nature of patient-focused charities is one of the most noteworthy characteristics of this sector – comparable in many ways to the diversity of diseases and health conditions with which the charities are concerned. Each with more than \$100 million in income annually and hundreds of full-time employees, the Canadian Cancer Society and The Heart and Stroke Foundation of Canada dominate the sector. However, between these two charities and the many charities with few if any full-time employees who rely on volunteers and focus their efforts in a specific region or program, there lies a spectrum of many other organizations with a wide range of annual income and expenditures.

Many of the most well-known patient-focused charities are national in scope and concern themselves with common conditions such as cancer, heart disease or diabetes. Others focus their communications and fund-raising activities on diseases that are much less common such as genetic disorders with only a few dozen sufferers in Canada. Not surprisingly more than half of all patient-focused charities are based in either Ontario (40%), Quebec (20%) or British Columbia (14%) as these provinces have the largest populations and also serve as a natural home base for many national charities.



Patient-focused charities must compete for revenues and attention with a number of other organizations dealing with health issues ranging from non-profit patient advocate groups, to hospital foundations and

social enterprises working in the health sector. While patient-focused charities often have strong foundations and commendable reputations many people do not or cannot differentiate between them and other organizations when deciding who to support. The growth of the patient advocacy movement and creation of non-profit organizations to support this advocacy has made the field even more crowded. An environment which was already highly competitive and challenging was made much worse by the outbreak of the COVID-19 pandemic in the spring of 2020 creating a situation that will be explored in more depth at the conclusion of this report.

## Scope of report

This is the first report to specifically analyze the financial, operational, and human resource capacity of 1004 patient-focused health charities. The report is based on data submitted to Canada Revenue Agency (CRA) in annual returns for the year prior to December 2019 for charities designated as Charitable Organization (C) registered under the promotion of health (category codes 0100, 0110, 0120 and 0140). Just predating the onset of the COVID-19 pandemic, the report captures an accurate picture of the state of these organizations when it was “business as usual.” As such the report offers a baseline by which to compare the impact of COVID-19 on this sub-sector of charitable organizations as stakeholders emerge into a post-COVID-19 period and begin to reassess partner relationships in light of these organizations’ capacity to continue their work.

The report is based on the data submitted by charities to the CRA in their annual T3010 Registered Charity Information Return. The form collects key information including:

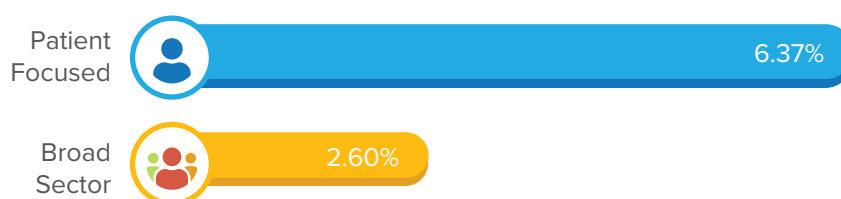
- Ongoing and new charitable programs the charity carried on during this fiscal period to further its purpose
- Descriptions of public policy dialogue and development activities
- Fund raising activities and expenditures, including the use of external fundraisers
- Financial position including assets and liabilities
- Revenue derived from tax receipted and non-tax receipted sources
- Revenue derived from all levels of government funding
- Compensation amounts and pay scales for senior executives, full-time and part-time employees
- Grants and other investments in research
- Expenditures on management, administration, advertising, staff training etc.

## How to use this report

This report provides a comprehensive overview of patient-focused charities operating in Canada up to the end of 2019. Data included in the report allow for a comparison of the various charitable organizations in terms of size and scope of operations and current activities of interest.

It should be noted that due to the nature of calendar year campaigning versus fiscal year spending, it sometimes appears that charities spend more than their income and appear to be operating in a deficit situation. It is important to compare a couple of years of data if a more granular look at an individual charity is required.

Throughout the report, where comparative data to the broad charitable sector are available, they are presented graphically to indicate how the patient-focused charities are performing relative to the rest of the sector.



## Defining qualifying organizations

The CRA charity database comprises over 16,000 health-related charities. This list has been reviewed to limit the report analysis to qualifying organizations based on specific criteria, which will be referred to as patient-focused organizations in this report. Charitable organizations included in the report are based on the following definition:

*Social purpose organizations that exclusively provide services, support, education, research, and/or advocacy to patients, caregivers and families in crisis or need, marginalized populations, at-risk and complex care needs, disabilities and those suffering from acute or chronic health challenges.*

The social determinants of health (SDOH) broadly help identify qualified organizations as they are unequivocally associated with health outcomes and managing illness successfully. Organizations addressing the special needs of single pregnant women, homeless persons, new immigrants, culturally sensitive communities, First Nations, remote and rural areas, housing and food insecurity, while not necessarily tackling patient-focused issues are, nonetheless, providing key support services to enhance the health outcomes of these populations and due to the isolated nature of



these cohorts and the general lack of more specific supports, are included within our definition.

However, they are not included in this report as we have concentrated on patient-focused organizations of which there are 1004 (see Appendix F). The next phase of this report will focus on organizations that represent the greater ecosystem of support available for patients including those referenced above.

## Exclusion criteria

Charitable organizations with the following characteristics or activities were excluded from the analysis:

- Those affiliated with religious organizations or groups.
- Activities focused on programs or populations outside of Canada.
- Hospital foundations or non-arm's length hospital charities such as hospital auxiliaries or community organizations whose only purpose is to raise money for equipment acquisition for local hospitals or long term care.
- Government Health authorities that deliver care.
- Professional membership-based organizations.
- Third-party care delivery organizations providing care in hospitals.
- Organizations that have discontinued operations due to lack of funding.
- Organizations focusing on Public Health versus the provision of patient or individual support.

There are a number of organizations in Canada that focus on patients and their families or caregivers but do not operate as charities but rather as non-profit organizations. These are not included in our study cohort but feature in some analysis detailed later in the report dealing with advocacy and public policy activities.



# Revenue

Where does it come from?

# REVENUE – WHERE DOES IT COME FROM?

A prominent area of due diligence for many donors is the relationship a charity has with its sources of funding. For donors it helps measure the diversity of income sources, any dependency on single sources and how that leaves the organization vulnerable if key sources withdraw or reduce their funding. For example, with government funding, changing policy environments can affect continued support and payment agreements with governments can impact whether cash flow is available in a timely manner. These inquiries serve to inform of implications regarding sustainability of funding and the subsequent impact on maintaining program continuity.

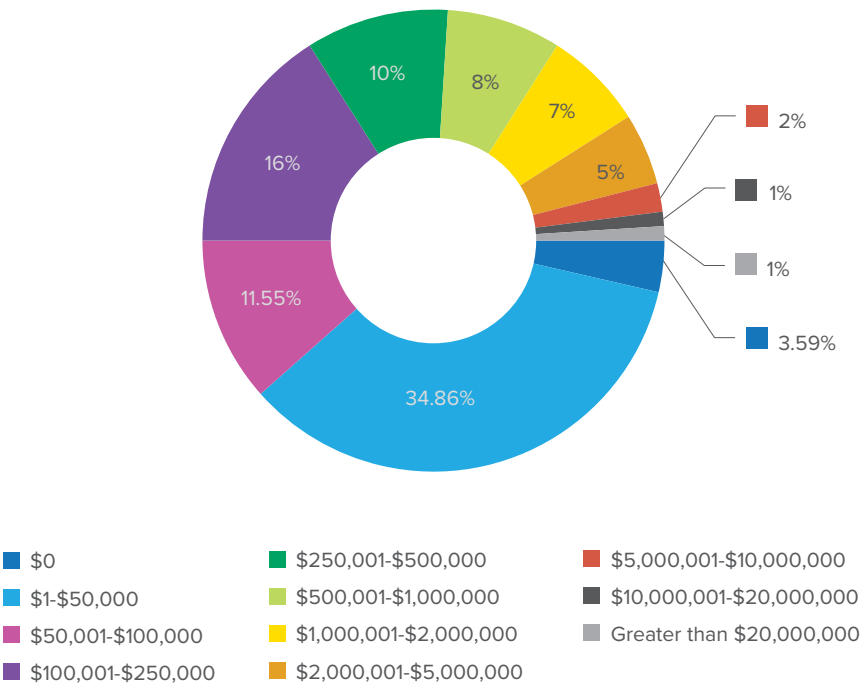
## Total revenue of all charities

There are over 86,000 registered charities in Canada whose total revenue in 2017 amounted to \$279 billion.<sup>6</sup> The subsector featured in this report numbers 1004 organizations, fewer than 1.2% of the national total. These groups generated \$1.366 billion in revenue, only 0.49% of total charity revenue.

**TABLE 1: NUMBER OF ORGANIZATIONS SEGMENTED BY REVENUE TOTALS**

Category	# of Charities	% of Total	Total Revenue	% of Total Revenue
\$0	36	3.59%	NIL	0
\$1-\$50,000	350	34.86%	\$6,082,979	0.45%
\$50,001-\$100,000	116	11.55%	\$8,413,171	0.62%
\$100,001-\$250,000	161	16%	\$26,076,194	1.91%
\$250,001-\$500,000	100	10%	\$34,994,275	2.56%
\$500,001-\$1,000,000	82	8%	\$59,964,740	4.39%
\$1,000,001-\$2,000,000	68	7%	\$94,456,756	6.91%
\$2,000,001-\$5,000,000	48	5%	\$140,433,876	10.28%
\$5,000,001-\$10,000,000	23	2%	\$164,995,968	12.07%
\$10,000,001-\$20,000,000	11	1%	\$157,893,474	11.56%
Greater than \$20,000,000	9	1%	\$673,121,823	49.26%
<b>Total:</b>	<b>1004</b>	<b>100%</b>	<b>\$1,366,433,256</b>	<b>100%</b>

CHART 1: PERCENTAGE OF ORGANIZATIONS BY REVENUE TOTALS



The number of groups earning under \$100,000 in revenue during the period evaluated totals 502, exactly 50% of those organizations under review. On the other end of the scale, there were 44 patient organizations with revenue over \$5 million or 4.4% of the total.

Table 2 identifies the top 25 organizations by revenue, their percentage of total revenue and the cumulative percentage of total revenue they represent as a group. This table illustrates the degree of domination of a small group of charities when it comes to revenue. For example:

- 62% of all revenue is controlled by only 2% of patient-focused charities.
- 38% of all revenue is shared by the remaining 98% of patient-focused charities.

This disparity acutely underscores the degree of competition for funding among these groups. With diminishing numbers of individual donors,<sup>7</sup> there are a finite number of other sources – events, grants, sponsorships, etc. – available to this specific sector. Many of those sources also attract charities from outside the patient-focused sector which serves to inflame the

“Patient-focused organizations have been heard to complain about this cross over competition, feeling short changed by the nature of the concrete offer that hospitals can make.”

competition. It also illustrates the intersectional nature of competition for funding sources. For instance, while this report has excluded hospital foundations, these organizations nevertheless serve as powerful competitors for funding. Patient-focused organizations have been heard to complain about this cross over competition, feeling short changed by the nature of the concrete offer that hospitals can make (e.g. tangibles such as MRI, CT, lab) versus the more abstract offer of investing in the remote hope for a cure – a fundamental pitch many disease charities use.

**TABLE 2: TOP 25 ORGANIZATIONS BY REVENUE**

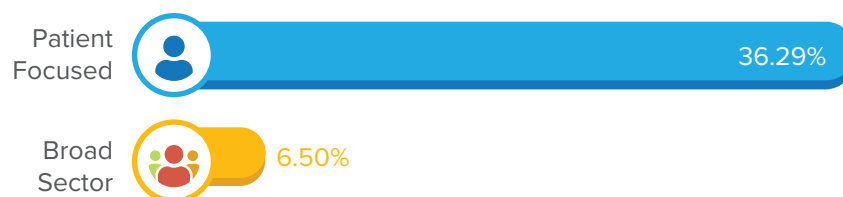
Charity	Revenue	% Total Revenue	Aggregate Total %
Canadian Cancer Society	\$187,804,352	12.71%	13%
Heart And Stroke Foundation Of Canada	\$169,462,000	11.47%	24%
Canadian National Institute For The Blind	\$92,399,362	6.25%	37%
British Columbia Transplant Society Branch	\$64,136,393	4.34%	42%
Multiple Sclerosis Society Of Canada	\$47,688,360	3.23%	45%
Canadian Diabetes Association	\$36,351,844	2.46%	47%
The Kidney Foundation Of Canada	\$27,996,642	1.89%	49%
The Arthritis Society	\$26,459,140	1.79%	51%
Juvenile Diabetes Research Foundation Canada	\$20,823,730	1.41%	52%
Alzheimer Society Of Canada	\$19,522,888	1.32%	54%
Cystic Fibrosis Canada	\$18,881,000	1.28%	55%
Movember Canada	\$18,189,734	1.23%	56%
Canadian Deafblind Association Ontario Chapter	\$15,036,388	1.02%	57%
Head Injury Rehabilitation Ontario	\$14,994,149	1.01%	58%
Crohn's And Colitis Canada	\$14,704,213	1.00%	59%
The Leukemia & Lymphoma Society Of Canada	\$12,837,620	0.87%	60%
Prostate Cancer Canada	\$12,428,912	0.84%	61%
Praxis Spinal Cord Institute	\$10,604,738	0.72%	62%
Parkinson Canada Inc.	\$10,400,951	0.70%	62%
Spinal Cord Injury Ontario	\$10,292,881	0.70%	63%
Pediatric Oncology Group Of Ontario	\$9,856,938	0.67%	64%
Alzheimer Society Of B.C.	\$9,728,822	0.66%	64%
Autism Society Ontario	\$9,718,412	0.66%	65%
Muscular Dystrophy Canada	\$9,649,909	0.65%	66%

## Amounts charities issued tax receipts

The ability to issue official donation receipts is the most important benefit to Canadian registered charities. Donations of cash, goods, land, or listed securities to a registered charity are eligible for a charitable tax credit which the taxpayer reports on his or her tax return. This tax benefit to donors incentivizes benevolence. Arguably, Canadian tax laws for charitable giving are among the most generous among developed nations. Tax receipted revenue is directly related to the relationship the organization has with its core supporters and individual donors.

The charities in our sector issued tax receipts for \$495,858,177 or 36.29% of total revenue. This contrasts starkly with the national percentage of 6.5% (2017) which would indicate a much higher dependency on this revenue source for the sustainability of the charities than the entire sector average.

CHART 2: PERCENTAGE OF REVENUE ISSUED AS TAX RECEIPTS



## Amounts received from other registered charities

There are three types of registered charities. Every registered charity is designated as one of the following:

- charitable organization
- public foundation
- private foundation

Inter-charity transfers represent amounts that are primarily coming from private or public foundations. For example, a hospital foundation may contribute funds to the hospital it supports, with both organizations being registered charities. Or a private foundation may contribute to a research project. This implies a co-dependency between organizations and the necessity for alignment to shared purpose.

While charitable foundations are allowed to accumulate assets, which total in excess of \$80 billion<sup>8</sup> for the

“...foundations are allowed to accumulate assets, which total in excess of \$80 billion for the full sector, they are restrained by regulation to a disbursement quota of 3.5% of assets.”



full sector, they are restrained by regulation to a disbursement quota of 3.5% of assets in any giving year. While this preserves the ability of foundations to be continuous sources of revenue, it also places strict boundaries on the amount of funding available. It goes without saying that foundation support comes with great due diligence by the foundation, making competition fierce and limiting the number of qualifying organizations. Sector leaders have advocated to increase the disbursement quota but no legislative change has as yet been enacted.

There are other types of transfers, including from a head or national office to a local affiliate, or vice versa. Some organizations raise funds to contribute to research or projects managed by other charities.

“Inter-charity revenue for patient-focused groups plays a much more important and growing role in funding programs than it does in the broad sector.

Inter-charity revenue for patient-focused health charities was \$87,038,101 or 6.37% of total revenue. With 45% of organizations reporting this revenue source, it demonstrates a high degree of interaction between organizations of shared purpose.

Consistent with other revenue disparities, this source is primarily dominated by a top tier of organizations with 23 organizations earning a minimum of \$1 million each from this source which is over 67% of the total received by all groups, leaving 95% of the remaining organizations competing for less than 33% of the revenue.

The broad sector reported inter-charity revenue in 2017 of \$7.262 billion or 2.6% of total revenue indicating that inter-charity revenue for patient-focused groups plays a much more important and growing role in funding programs than it does in the broad sector.

CHART 3: PERCENTAGE OF REVENUE RECEIVED FROM OTHER CHARITIES

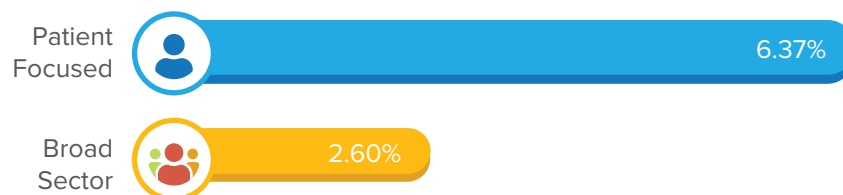


TABLE 3: ORGANIZATIONS REPORTING OVER \$1 MILLION OF INTER-CHARITY REVENUE

Organization	Inter-Charity Revenue	% of Total Revenue	Aggregate Total %
Praxis Spinal Cord Institute	\$7,516,053	8.64%	8.64%
Alzheimer Society of Canada	\$7,384,210	8.48%	17.12%
Canadian Cancer Society	\$4,653,232	5.35%	22.47%
Prostate Cancer Canada	\$4,648,913	5.34%	27.81%
The Multiple Sclerosis Scientific Research Foundation	\$4,213,046	4.84%	32.65%
Heart and Stroke Foundation of Canada	\$3,518,160	4.04%	36.69%
Juvenile Diabetes Research Foundation Canada	\$2,787,151	3.20%	39.89%
Canadian Diabetes Association	\$2,147,578	2.47%	42.36%
Heart and Stroke Foundation Canadian Partnership for Stroke Recovery	\$2,139,790	2.46%	44.82%
Multiple Sclerosis Society of Canada	\$2,095,607	2.41%	47.22%
The Canadian National Institute for the Blind	\$1,883,894	2.16%	49.39%
Heart and Stroke Foundation of Ontario	\$1,731,000	1.99%	51.38%
Ontario Society for Crippled Children	\$1,728,838	1.99%	53.36%
Canadian Lung Association	\$1,475,806	1.70%	55.06%
Amyotrophic Lateral Sclerosis Society of Canada	\$1,410,897	1.62%	56.68%
Alzheimer Society of B.C.	\$1,356,145	1.56%	58.24%
Starlight Children's Foundation Canada	\$1,279,754	1.47%	59.71%
Alzheimer Society of Toronto	\$1,179,226	1.35%	61.06%
Pediatric Oncology Group of Ontario	\$1,107,250	1.27%	62.34%
Alzheimer Society of Alberta and Northwest Territories	\$1,091,835	1.25%	63.59%
Canucks Autism Network Society	\$1,070,635	1.23%	64.82%
Crohn's and Colitis Canada	\$1,019,776	1.17%	65.99%
Trillium Childhood Cancer Support Centre	\$1,012,815	1.16%	67.16%

## Other gifts received for which a tax receipt was not issued

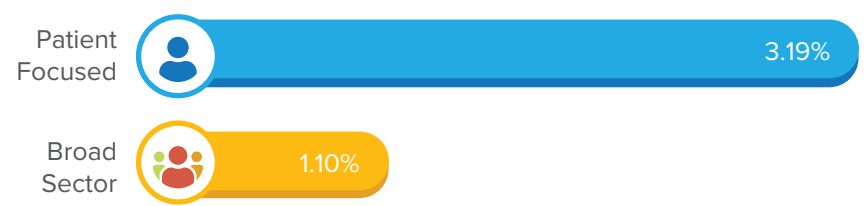
When is a gift not eligible for a tax receipt?<sup>9</sup> The simplest type of example would be anonymous donations collected by a coin box on a retail counter. Interestingly the Income Tax Act does not define "sponsorship". CRA takes the view that generally receipts cannot be issued for sponsorship fees because the sponsor receives something in exchange

and the fees are usually paid to support a charity event in return for some type of consideration. Contributions can also come from a company’s social responsibility (CSR) program. A business may deduct 100% of a sponsorship fee or CSR costs as a business expense so tax receipting the gift amounts would amount to compounding the tax benefit, something CRA frowns on.

Other types of gifts not eligible for receipts include<sup>10</sup> donations of services, gift cards and certificates, donations directed to specific individuals or families. Due to the unclear nature of these gifts, it is difficult to trace their origins to specific sources, hence they are lumped under the “Other” category and charities are left to allocate these revenues according to their usual practices.

In our group, 531 (53%) organizations earned \$43,616,337 or 3.19% of revenue from non-tax receipted gifts. This compares to 1.1%, or \$3.016 billion of total sector revenue implying a greater dependency on such gifts than the broad sector. Only 22 organizations reported non tax-receipted revenue of \$500,000 or more with Multiple Sclerosis Society the top earner with \$5,817,858.

CHART 4: PERCENTAGE OF REVENUE FOR WHICH A TAX RECEIPT WAS NOT ISSUED



### Government funding overview

Funding of the broad 86,000 charity sector from all levels of government, was in excess of \$183 billion in 2017, almost 66% of all funding. Total government funding for patient-focused charities was \$337,918,293 or 24.73% of revenue, which on the surface, appears to be a significant reduction from the broad sector. Government related charities include organizations such as hospitals, universities and colleges. Health and education account for the largest portion of the broad sector’s economic activity. The size and scope of these institutions account for the large investments by government. The numbers speak for themselves in 2017 with government transfers to the entire health charity sector amounting to \$98.75 billion, almost 54% of government funding available to all charities.

When breaking down the total of government funding to the respective levels, it is quickly evident which level is the primary source. For health funding, provincial governments provide the bulk of revenue, 90% nationally across the sector and 92% among patient-focused organizations.

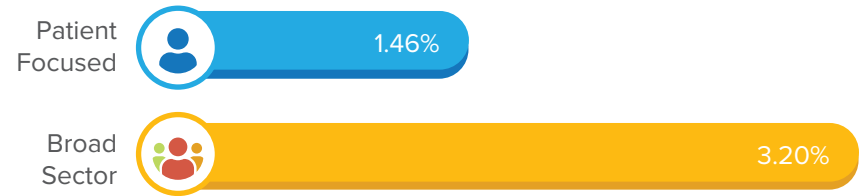
Government funding represents a substantial portion of the income for charities in the form of grants and reimbursement for delivering services. The role of the federal and municipal governments is statistically small compared to the provincial government. It would not be a stretch to consider the charities that are delivering services on behalf of provincial governments to have entered into a social contract in order to support the social fabric of society. They are however, for all intents and purposes, agents of the government and while structured as charities, must still conduct themselves under the rules and control of the governing regime.

**Revenue received from federal government.**

With only 1.46% (\$19,984,713) of total revenue coming from the federal government, it is a challenge for many of the patient-focused groups to devote resources to chasing this money. That only 17% of groups received any funding from the federal government underscores the challenge. From the top 10 list in Table 4 it can be seen that some of the largest groups are getting the majority of the money, with those on this list getting more than 60% of total federal funding.

The broad sector receives 3.2% of their funding from the federal government, over twice that of the patient-focused charities.

CHART 5: PERCENTAGE OF REVENUE FROM FEDERAL GOVERNMENT



The federal government is important because it controls the purse strings for a lot of research – a key purpose of many of these groups. It also creates national health policy and thus charities that have programs or a purpose that is aligned with critical government policy initiatives can sometimes slip stream behind the policy and receive valuable grants. It does require investment in political activities and given the nature of election cycles and unforeseen economic impacts, it is not always money that can be relied on annually.

TABLE 4: TOP 10 ORGANIZATIONS BY FEDERAL GOVERNMENT REVENUE RECEIVED AND THEIR PERCENTAGE OF THE TOTAL.

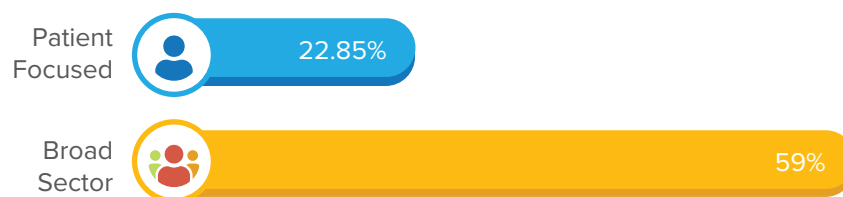
Organization	Amount	% of Total	Aggregate Total %
The Canadian National Institute for the Blind	\$3,136,912	15.70%	15.70%
Canadian Cancer Society	\$2,923,262	14.63%	30.32%
Childhood Obesity Foundation (COF)	\$1,228,619	6.15%	36.47%
Heart And Stroke Foundation of Canada	\$1,163,680	5.82%	42.29%
Community-Based Research Centre Society	\$862,086	4.31%	46.61%
Spinal Cord Injury Canada	\$684,313	3.42%	50.03%
Alzheimer Society Of Sarnia-Lambton	\$593,147	2.97%	53.00%
The Canadian Association of the Deaf	\$507,755	2.54%	55.54%
South Asian Autism Awareness Centre	\$465,144	2.33%	57.87%
Canadian AIDS Society	\$455,149	2.28%	60.15%

## Revenue received from provincial/territorial governments

Funding from provincial governments for patient-focused charities amounted to \$312,261,598 or 22.85% total revenue. The numbers for provincial funding are skewed somewhat due to the overwhelming amount by one organization, the British Columbia Transplant Society Branch with \$63,878,737, more than 20% of the total. It does indicate, however, the support provincial governments will give to critical health needs when there is a clear policy directive. It is also illustrative of the agency relationship that many of these charities have with their provincial masters.

The broad sector receives 59% of their funding from the provincial government, 2.5 times that of the patient-focused charities.

CHART 6: PERCENTAGE OF REVENUE FROM PROVINCIAL GOVERNMENT



This serves to highlight the critical social service role that these charities play in the delivery of health services to citizens. Our current sample includes 299 groups with over 50 organizations receiving \$1,000,000 or

more. It may not be immediately obvious that these groups are involved in social and community support of patients given the greater perception of them as advocacy organizations, many are active participants in supporting patients through a variety of programs that deliver social and care support such as social workers, respite for caregivers, etc. Conversely, those organizations who are not counted among this group as they are not patient-focused in their purpose, but are receiving the bulk of provincial funding of health, have intersecting interests with patient-focused organizations. These intersections and the alignment of shared purpose between organizations will be the subject of further investigation in our next report on social service agencies.

**TABLE 5: TOP 10 ORGANIZATIONS BY PROVINCIAL GOVERNMENT REVENUE RECEIVED AND THEIR PERCENTAGE OF THE TOTAL.**

Organization	Amount	% of Total	Aggregate Total %
British Columbia Transplant Society Branch	\$63,878,737	20.46%	20.46%
The Canadian National Institute for the Blind	\$32,792,655	10.50%	30.96%
Deafblind And Sensory Support Network of Canada	\$13,079,411	4.19%	35.15%
Head Injury Rehabilitation Ontario	\$12,513,875	4.01%	39.15%
Canadian Cancer Society	\$10,380,365	3.32%	42.48%
Spinal Cord Injury Ontario	\$8,256,222	2.64%	45.12%
Cerebral Palsy Parent Council of Toronto	\$8,089,502	2.59%	47.71%
Pediatric Oncology Group of Ontario	\$7,408,565	2.37%	50.09%
Autism Society Ontario	\$6,614,355	2.12%	52.20%
Brain Injury Community Reentry (Niagara) Inc	\$5,923,874	1.90%	54.10%

## Revenue received from municipal/regional governments

The municipal level of government supports charities focused on their local communities. However, with such a small sum available nationwide, only \$5.67 million, it takes just 10 organizations to corral over 65% of the funding. It is interesting to note that none of the large charities that have dominated other funding sources even appear on this top 10 list. From this list we can see that the local emphasis is on social support, ranging from supportive housing to relieving the burden on caregivers. Relationships with public health officials are critical as many municipal programs are conducted in partnership with, or funded by, public health, which are a local responsibility.



The broad sector receives 3.3% of their funding from municipal governments, almost 8 times that of the patient-focused charities.

#### CHART 7: PERCENTAGE OF REVENUE FROM MUNICIPAL GOVERNMENT



TABLE 6: TOP 10 ORGANIZATIONS BY MUNICIPAL GOVERNMENT REVENUE RECEIVED AND THEIR PERCENTAGE OF THE TOTAL.

Organization	Amount	% of Total	Aggregate Total %
Sidalys	\$1,122,342	19.79%	19.79%
Regional HIV/AIDS Connection	\$680,312	11.99%	31.78%
AIDS Committee of Toronto	\$533,089	9.40%	41.18%
AIDS Committee of Windsor	\$259,798	4.58%	45.76%
Société Alzheimer Rive-Sud	\$233,453	4.12%	49.88%
Société Alzheimer Outaouais / Alzheimer Society Outaouais	\$221,900	3.91%	53.79%
Epilepsy South Central Ontario	\$180,445	3.18%	56.97%
Alberta Caregivers Association	\$172,676	3.04%	60.01%
Africans In Partnership Against AIDS	\$172,520	3.04%	63.06%
Autisme De l'Est-Du-Québec	\$144,104	2.54%	65.60%

## Tax-receipted revenue for all sources outside of Canada

Charities in Canada may receive gifts from non-resident individuals and nonresident charities. As a general rule, such individuals and organizations would not be entitled to deduct such contributions for Canadian income tax purposes and therefore would not require an official income tax receipt from the Canadian charity.

Canada can be seen as an attractive charitable investment destination. The low value of the currency implies a lower cost of delivering on the mission of the organization. Foreign sources of revenue may be from governments, foundations, individuals or corporations.

As with all individuals and organizations in Canada, charities are responsible for making sure that they do not operate in association

“Charities are responsible for making sure that they do not operate in association with individuals or groups that are engaged in terrorist activities, or that support terrorist activities.”

with individuals or groups that are engaged in terrorist activities, or that support terrorist activities. CRA publishes a checklist for charities to prevent abuse of charities to fund terrorist organizations or charities being used for money laundering purposes.

It is a singular priority for a highly regulated industry to perform proper due diligence to know where support for charity partners comes from to be insulated against any connection to illegal activity, whether known or unknown to the charity partner.

Only 34 of our groups or 3% of the total reported tax-receipted foreign revenues, with the top 10 groups reaping over 92% of this revenue

source. The Canadian Cancer Society is the top earner with \$318,867, or 26% of the total but not a significant sum in comparison to the Society's revenue of \$187 million.

### **Non tax-receipted revenue for all sources outside of Canada**

As stated above, most foreign contributors would likely be ineligible for Canadian tax credits subverting the need for a tax receipt. There may be some international jurisdictions that have an exemption for certain countries, possibly including Canada, but it is by no means broadly applied and foreign contributors must abide by their local tax laws. It would be assumed that savvy international donors have processes in place to accommodate local circumstances.

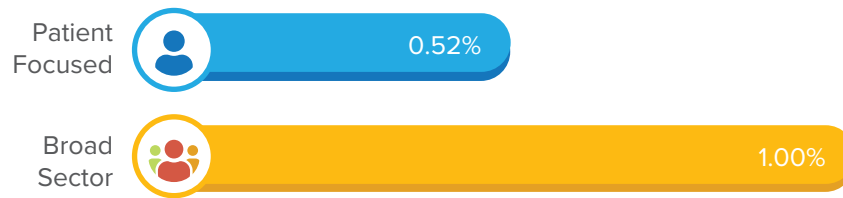
Our 5 top groups consume over 75% of all non tax-receipted revenue from outside of Canada with Crohn's and Colitis Canada the top earner with \$1,730,923.00, almost 30% of the total of this category.

Due to the way data has been made available, we have combined both receipted and non-receipted gifts to provide an accurate comparison to the broad sector.

“In a world where disease knows no borders this data raises some interesting question about the international relationships of national patient-focused organizations.”

Patient-focused charity total income from these two sources is \$7,057,295, only 0.52% of revenue. This compares with the broad sector total of all gifts from outside Canada, both receipted and non-receipted, of \$2.32 billion or less than 1% of sector revenue. Patient-focused groups appear marginally less dependent on foreign sources of revenue than the broad sector which we take to mean that the missions of patient-focused groups have an explicit pan-Canadian focus. It may be a reality experienced on a global basis by national and local patient organizations with very little in the way of international inter-dependency. In a world where disease knows no borders this data raises some interesting question about the international relationships of national patient-focused organizations.

CHART 8: PERCENTAGE OF REVENUE FROM OUTSIDE CANADA



It should also be noted that in compiling our database we explicitly excluded health charities with a focus on programs delivered outside of Canada.

## Interest and investment income received or earned

The entire issue of financial constraints imposed on charities by the regulatory regime can be confusing at the best of times. For instance, charities are permitted to have reserves – in fact having unrestricted

funds can be vital to manage fluctuations in income, different expenditure requirements and times of crisis such as the current pandemic. However, the public does not understand the difference between assets, endowments, perpetual endowments, reserves, cash, etc. They see funds listed as assets and many assume that these are freely available for expenditure by the charity. And while charities can have large reserves, the public may question the need to continue fundraising as opposed to drawing on the reserves.

“While charities can have large reserves, the public may question the need to continue fundraising as opposed to drawing on the reserves.”

The CRA has provided guidance on the matter, which in itself, contributes to the confusion:<sup>11</sup>

- 64. Canadian law requires that a registered charity be established and operated for charitable purposes and devote its resources to charitable activities. While the CRA recognizes that charities can, and often should, maintain reserves, fundraising that results in an unjustified level of reserves may indicate that the charity is failing to meet this requirement.

Apparently, then, there is the need to walk a fine line for those holding reserves or maintaining assets. Added to that is the scrutiny given to the investment of those assets. Assets are an indicator of financial strength and stability and the numbers demonstrate a wide range of possible outcomes that organizations may experience with their investments.

Over 42% (423) of our groups reported investment income that amounts to \$22,028,971 or 1.61% of total revenue. The top 10 organizations control over 71% of this revenue with the Heart and Stroke Foundation a clear leader with \$6,229,257 (28%) and Canadian Cancer Society a distant second with \$3,592,197 (16%). Like any investor, however, charities are subject to the whims of the market and the strength of their investment strategies. There are 13 groups that reported a loss with Canadian Diabetes Association declaring a loss of \$114,724 and Parkinson Canada reporting \$49,146 in losses.

The broad charitable sector reported \$5.379 billion in interest approximately 2% of total income. Compared to this data, the patient-focused 1.50% of total revenue is marginally weaker and provokes some questions relating to organizational sustainability for some.

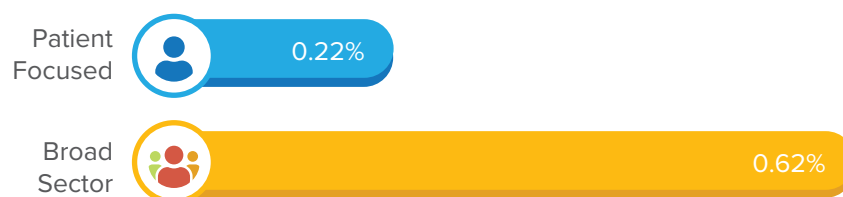
CHART 9: PERCENTAGE OF REVENUE FROM INTEREST AND INVESTMENT INCOME



## Non tax-receipted revenues received for memberships, dues and association fees

In 2017, the broad sector reported \$1.739 billion of revenue generated from memberships and dues, just 0.62% of total revenue. There is limited data available on membership fees but the trend over the last 13 years has witnessed a continued erosion in membership revenue from a potential high of 16% in 2007<sup>12</sup> to the current level of 0.62%.

CHART 10: PERCENTAGE OF REVENUE FROM MEMBERSHIP DUES



For patient-focused charities, the numbers are even more dismal. While 235 (24%) groups reported, the total revenue of \$3,030,252 only amounts to .22% of total revenue, arguably, a miniscule sum. Almost 69% of this revenue is accounted for by 15 charities with SHBC: Speech and Hearing BC Association topping the list with \$263,088 (8.7%). Contrary to expectations, the largest charities – Canadian Cancer Society, Heart and Stroke Foundation – do not appear on the list at all.

With donor trends changing over the last decade, donor relationships to causes are also changing and are less entrenched in brand loyalty. This leads to questions related to the ability of charities to recruit and maintain volunteers for program delivery and continuity of donor participation in programs such as annually recurring fundraising events.

## Non tax-receipted revenue from fundraising

The last time you attended a gala dinner and paid \$250 for the ticket, it is likely that you did not receive a tax receipt for the full amount of \$250. When a donation comes with a benefit to the contributor, the benefit is considered an “advantage” by CRA and must be deducted from the total to be tax receipted. In the case of the gala dinner, the advantages may be calculated at \$100 worth of food and entertainment leaving you with a tax receipt of only \$150. The balance is still accounted for by the charity as non tax-receipted revenue.

Non tax-receipted revenue from fundraising was reported by 564 (56%) patient-focused groups for a total of \$225,618,043 or 16.51% of total revenue. Leaders are once again Canadian Cancer Society with \$59,566,390 (26.40%), Heart and Stroke Foundation Of Canada \$34,000,190 (15.07%) and Canadian Diabetes Association \$11,306,203 (5.01%).

The broad sector reported \$3.052 billion or 1.1% of total revenues which seems to imply that the patient-focused sector has a much greater dependency on this revenue source than the broad sector. Events may seem to play an important role here for these charities as this type of revenue is often associated with them.

CHART 11: PERCENTAGE OF NON TAX-RECEIPTED REVENUE FROM FUNDRAISING



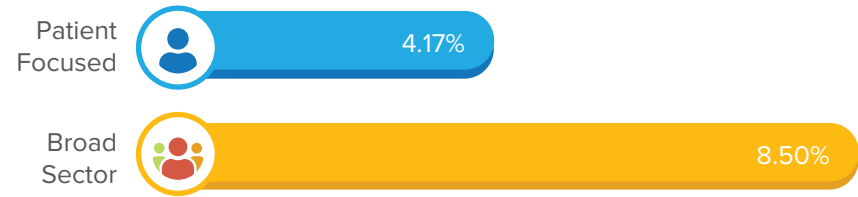
### Revenue from sale of goods and services

The term “earned income” is generally applied to activities that involve selling goods or services to customers. It is estimated that up to 75% of all charities have engaged in these activities. The range of goods and services is extremely broad, and includes products, expertise, processes, and intellectual property (Imagine Canada, 2013). Customers can be individuals, groups, businesses, or other charities.

It has become an important source of revenue and can be used to financially support the organization or a specific program. Not all earned income activities record a profit and the level of participation in earned income activities varies significantly according to the characteristics of a charity. Their amount of annual revenues and whether they employ full-time staff are key determinants that shape an organization’s approach. For some organizations it can represent more than one-third of total revenue.

The broad sector generated \$23.127 billion from the sale of goods and services which represents 8.5% of all revenue. The patient-focused sector, on the other hand, has reported \$56,995,775 or 4.17% of revenue. As this is less than 50% of the percentage achieved by the broad sector it indicates this revenue source could be an area due for improvement.

CHART 12: PERCENTAGE OF REVENUE FROM SALE OF GOODS AND SERVICES



Whether engaging earned income by operating a social enterprise or as part of their range of activities, charities have demonstrated that there is capacity to manage these enterprises which can be significant contributors to the financial sustainability of an organization.

As seen in some of the earlier analyses, the concentration of revenue is dominated by a small number groups. The Canadian National Institute for the Blind is the clear leader with \$18,764,986, almost one-third of all earned revenue. Canadian Diabetes Association is a distant second with \$4,054,849.

There are some unexpected organizations in Table 7 which account for over 71% of all earned income. Cerebral Palsy Association in Alberta reported \$1,965,186 which is 64% of their total revenue. Meanwhile Diabete Drummond Inc. reports \$1,518,541 which constitutes almost 98% of their revenue. Whether engaging earned income by operating a social enterprise or as part of their range of activities, charities have demonstrated that there is capacity to manage these enterprises which can be significant contributors to the financial sustainability of an organization.

There is much room for performance improvement in this revenue source for patient-focused charities and much to be learned and shared from those who are doing it successfully.

TABLE 7: TOP 10 EARNERS OF REVENUE FROM THE SALE OF GOODS AND SERVICES.

Organization	Amount	% of Total Earned Income	Aggregate Total %
The Canadian National Institute for the Blind	\$18,764,986	32.92%	32.92%
Canadian Diabetes Association	\$4,054,849	7.11%	40.04%
Western Institute for the Deaf and Hard of Hearing	\$3,881,291	6.81%	46.85%
Heart and Stroke Foundation of Canada	\$3,100,110	5.44%	52.29%
Canadian Cancer Society	\$3,004,070	5.27%	57.56%
Cerebral Palsy Association in Alberta	\$1,965,186	3.45%	61.01%
Head Injury Rehabilitation Ontario	\$1,781,689	3.13%	64.13%
Diabete Drummond Inc.	\$1,518,541	2.66%	66.80%



Organization	Amount	% of Total Earned Income	Aggregate Total %
Integrated Services for Autism and Neurodevelopmental Disorders	\$1,468,648	2.58%	69.37%
Deafblind and Sensory Support Network of Canada	\$1,251,558	2.20%	71.57%

## Other revenue

“Other” revenue accounts for all other sources of revenue that do not fall into any of the above categories. These sources can range from conference fees to bequests to amortization of deferred capital. While many appear related to events, there are also some that are purely administrative in nature. Organizations are required to describe these “other” activities and from the selection provided in Table 8 of the most popular reported sources, it becomes clear that it constitutes quite a variety.

Patient-focused groups reported \$41,755,208 or 2.74% of total revenue. This compares with the broad sector reporting \$26.92 billion, 9.6% of total revenue.

CHART 13: PERCENTAGE OF REVENUE FROM OTHER REVENUE



Surprisingly, there are some unexpected organizations reporting significant “Other” revenue that aren’t normally on any of the top 10 lists. Hypertension Canada reported \$1,020,382 which is 73% of their total revenue. The description for these funds was “sponsorships / grants”. The Save Your Skin Foundation reported \$1,267,475 which is 95% of their revenue. And Obesity Canada reported \$997,517, over 97% of their total revenue.

Whatever the source, it appears that patient-focused organizations still have room to grow in this revenue category and perhaps learn from some of these unexpected leading and perhaps innovative organizations.

TABLE 8: TYPES OF OTHER REVENUE

Administration	Misc. Fundraising	Events
Amortization of Deferred Capital	Bequests	Walk, swim, bike, marathon
Gain on sale of capital asset	Community grants - United Way	AGM registration fees
GST/HST recovery	Summer job grants	Conference registration fees
Recycling fees	Research grants	Conference sponsorship fees
	Other grants	Bingo
		Camp fees
		Golf tournament
		Other sponsorships
		Advertising
		Speaking honorarium



# Fundraising

# FUNDRAISING

Clearly, charities rely on fundraising in order to fund their activities and the CRA acknowledges this dependency as necessary for the sustainability of the charitable sector. At the same time CRA expects charities to be transparent and operate within specific legal parameters.


While the CRA does provide guidance on what is appropriate fundraising, it also explicitly defines what is not acceptable fundraising.<sup>13</sup> This is especially important to understand for potential donors and sponsors who are entering into relationships with specific charities:

- a purpose of the charity (a collateral, non-charitable purpose)
- delivering a more than incidental private benefit (a benefit that is not necessary, reasonable, or proportionate in relation to the resulting public benefit)
- illegal or contrary to public policy
- deceptive
- an unrelated business

Charities must report fundraising revenue and expenditures on their annual return. The fundraising ratio is a key measure that CRA uses to assess the fundraising activities of a charity. This ratio is calculated by adding up tax receipted gifts and non-tax receipted fundraising and then dividing total by the total fundraising expenditures. It is commonly believed that a ratio under 35% is unlikely to raise questions by CRA but if over 35% the opposite is possible. Should a ratio hit upwards of 70% CRA reacts like a 4 alarm fire. It is no secret that charities may try to move a portion from non tax-receipted gifts to the non tax receipted fundraising to lower the ratio or they may transfer sponsorship monies and income from cause related campaigns.

## Total expenditures on fundraising

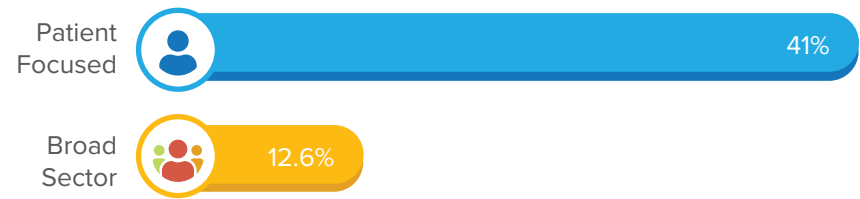
About 40% of organizations (399) reported total fundraising expenditures of \$301,555,342 or 22.61% of total expenditures. The ratio for the patient-focused sector is 41% ( $301,555,342 / (495,853,772 + 225,618,043)$ ), somewhat higher than the CRA test but dramatically higher than the broad sector which reported a ratio of 12.6%. This can be explained in part by the



Is it any wonder then that there is a public perception that these charities, especially the larger ones, seem to be fundraising machines, existing more for the purpose of fundraising than supporting patients?

huge sums of government funding the government related charities receive, thus relieving them of a great deal of dependency on fundraising.

CHART 14: RATIO OF FUNDRAISING COSTS TO REVENUE



The patient-focused charities however are far more dependent on fundraising than the broad sector and appear to invest heavily in it. Is it any wonder then that there is a public perception that these charities, especially the larger ones, seem to be fundraising machines, existing more for the purpose of fundraising than supporting patients? We must assume that the CRA has considered this matter and has recognized the great disadvantage that these organizations suffer and that they likely compare organizations against their peers rather than the broad sector when assessing fundraising expenditures.

### What fundraising tools are organizations employing?

There is a definite trend towards donating online in Canada.

Online giving grew to \$144.8 million in 2017, a 17% increase from the year before, compared to a 6% increase in total giving in Canada. As for the devices people use, donations from mobile users are outpacing donations from desktop users.

All this speaks to the fundraising tactics charities use. Although over 16% of our groups still use collection plate and boxes, the trend to online activity is discernible with almost 30% of groups reporting fundraising activity on the internet.

The old standards of targeted corporate donations and fundraising dinners/galas were reported by 38% and 35% of groups respectively. With the rising trend in corporate social responsibility, it is unusual that cause-related marketing was reported by so few, only 7.57%.

As the technology trends continue, expect to see the “Mail Campaigns” increasingly turn into “e-Mail” campaigns.

TABLE 9: FUNDRAISING TOOL UTILIZATION

Tool	Number of Groups	% of Groups
2500 Advertisements/print/radio/TV commercials	236	23.51%
2510 Auctions	196	19.52%
2530 Collection plate/boxes	167	16.63%
2540 Door-to-door solicitation	27	2.69%
2550 Draws/lotteries	223	22.21%
2560 Fundraising dinners/galas/concerts	357	35.56%
2570 Sales	212	21.12%
2575 Internet	297	29.58%
2580 Mail campaigns	236	23.51%
2590 Planned-giving programs	125	12.45%
2600 Targeted corporate donations/sponsorships	389	38.75%
2610 Targeted contacts	245	24.40%
2620 Telephone/TV solicitations	56	5.58%
2630 Tournament/sporting events	258	25.70%
2640 Cause-related marketing	76	7.57%
2650 Other	228	22.71%
2660 Specify_____	219	21.81%

### Most popular “Other” event fundraisers

Examination of this category shows disease-related charities used a wide variety of event fundraising approaches. However, Walk-A-Thons top the list by a wide margin with 73 organizations reporting using this tactic.

Overall, the category of sports events dominates this type of fundraising. However, gaming is an old standby with consistent revenues and a tried and true tradition. With online and virtual gaming gaining steam expect charities to respond with new and innovative gaming offerings for the public. It is gratifying to see events directly tied to organizational purpose with Patient Conferences reported by 5 groups.

TABLE 10: MOST POPULAR OTHER EVENT FUNDRAISERS

Sports		Gaming		Donations		Misc Events		Meetings And Conferences	
Walk-A-Thon	73	Bingo	13	Donations	4	Events	9	Patient Conference	5
Run	8	Casino	7	Bottle Deposit, Return It Recycling	4	Festivals	2	Information Sessions	1
Swimathon/ Safeway Cards	2	Raffles	3	Membership Dues	3	Car Shows	2		
Activités	2	Provincial Nevada	2	Memorials	3				
Marathon	2	Gaming	1	Social Media	2				
Skating Fund Raiser	1			Website	2				
Bike	1			Donations For Use Of Equipment	1				
Bowling	1			Member Donations	1				
Dragon Boat Races	1								
Motorcycle Ride	1								
Night At Races	1								
Sledge Hockey	1								
Wheelchair Relay	1								

## Charities that paid external fundraisers

Almost 10 years ago CBC ran a story headlined “Charities paid \$762M to private fundraisers”.<sup>14</sup> This expose detailed how Canadian registered charities paid \$762 million to third-party fundraisers between 2004 and 2008. In more than 200 cases, more than 50% of the donations were paid to external fundraisers. Their report found that less than 1% of charities hired external fundraisers. Among our patient-focused charities, 70 reported using external fundraisers, 7% of our total.



## Gross revenue collected by external fundraisers

Two important questions were raised by the CBC investigation: how much revenue do these fundraisers actually generate, and, are they operating ethically. While we do not have the capacity to make a judgement on the ethical relationships patient groups have with external fundraisers, we can defer to CRA's perspectives on the subject. CRA guidance stipulates that a charity must:

- Demonstrate that the cost is an investment that will reduce costs at a later stage
- Make an assessment of fair market value for services
- Has measures in place to control costs
- Be transparent and disclose costs to the public.


Gross revenue from using external fundraisers was \$64,144,394. Only 47 organizations reported such revenue which represents 4.69% of total revenue earned by this sector. On face value it appears that this is a fairly significant source of revenue in light of the small number of charities that engage in it.

**TABLE 11: TOP 10 EARNERS OF REVENUE BY EXTERNAL FUNDRAISERS**

Organization	Amount	% of Total	Aggregate Total %
Canadian Cancer Society	\$32,130,842	50%	50%
Heart and Stroke Foundation of Canada	\$17,487,430	27%	77%
The Canadian Council of the Blind	\$2,107,718	3%	81%
The Arthritis Society	\$1,851,619	3%	84%
Canadian Liver Foundation	\$1,581,844	2%	86%
The Canadian National Institute for the Blind	\$1,516,676	2%	88%
Western Institute for the Deaf and Hard of Hearing	\$1,108,149	2%	90%
Fondation Quebecoise du Cancer Inc.	\$1,106,074	2%	92%
Canadian Down Syndrome Society	\$1,088,600	2%	94%
Shine Through the Rain Foundation	\$680,849	1%	95%

## Amounts paid to external fundraisers

At the end of the day, are these fundraisers worth their price? The total paid by 46 groups is \$12,853,744 which represents less than 1% of total expenditures. Given the nature of fundraising campaigns operating over extended periods of time, it is quite possible that the apparent profit from these engagements of more than \$51.3 million may be somewhat inflated. This is likely accounted for due to the calendar year nature of



The sector as a whole could benefit from a deeper understanding of how to spread and scale an ethical professional fundraising collaboration.

campaigns conflicting with fiscal reporting periods, making a profit of 80% a very attractive outcome. More analysis of previous and subsequent reporting periods is required to be more accurate. With that in mind this is still a promising outcome and the sector as a whole could benefit from a deeper understanding of how to spread and scale an ethical professional fundraising collaboration.



# Expenses

Where does it all go?

# EXPENSES –WHERE DOES IT ALL GO?

## Total operating expenses of patient-focused charities

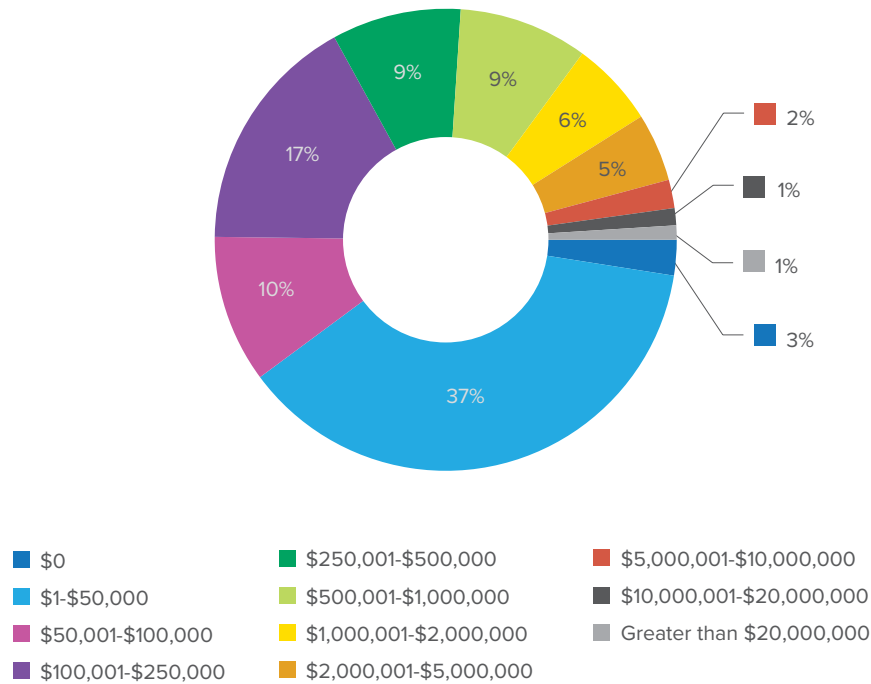
Expense categories parallel those of revenue as most charities spend most or all of their income in pursuit of their mission. Actual spending on charitable purposes, a specific category that CRA will be looking at, is a measure whose value is debated by sector stakeholders but it is still a focal point of CRA measurement and will be looked at separately. Charities are not required to spend all of their income and can accumulate reserves. Also, due to the nature of calendar year campaigning vs fiscal year spending it sometimes appears that charities spend more than their income and appear to be operating in a deficit situation. It is important to compare a couple of years of data if a more granular look at an individual charity is required.

The patient-focused group of charities spent \$1.33 billion or 97.61% of total revenue. By comparison, broad sector expenditures amounted to \$261.7 billion or 93.5% of total revenue. Given the variances in reporting periods the difference here is not significant.

**TABLE 12: NUMBER OF ORGANIZATIONS SEGMENTED BY OPERATING EXPENSE TOTALS**

Category	# of Charities	% of Total	Total Expenditures	% of Total Expenditures
\$0	25	2.49%	\$0.00	0.00%
\$1-\$50,000	376	37.45%	\$6,193,961	0.46%
\$50,001-\$100,000	104	10.36%	\$7,655,977	0.57%
\$100,001-\$250,000	169	16.83%	\$27,576,885	2.07%
\$250,001-\$500,000	91	9.06%	\$31,852,663	2.39%
\$500,001-\$1,000,000	91	9.06%	\$65,793,947	4.93%
\$1,000,001-\$2,000,000	60	5.98%	\$84,885,611	6.36%
\$2,000,001-\$5,000,000	48	4.78%	\$137,767,084	10.33%
\$5,000,001-\$10,000,000	20	1.99%	\$142,374,260	10.67%
\$10,000,001-\$20,000,000	12	1.20%	\$161,331,384	12.10%
Greater than \$20,000,000	10	1.00%	\$668,308,258	50.11%
<b>Total:</b>	<b>1004</b>	<b>100%</b>	<b>\$1,333,740,030</b>	<b>100%</b>

CHART 15: PERCENTAGE OF ORGANIZATIONS SEGMENTED BY OPERATING EXPENSE TOTALS



## Total expenditures on charitable activities

The data made publicly available by CRA requires charities to re-categorize some of their expenses in order to provide clarity on spending for the actual charitable purposes of an organization. This might make a charity's financial statements appear different from these data. This is the proportion of a charity's total spending that it spends on its end cause, as opposed to other things it might need or choose to spend money on. People sometimes confuse this with the proportion of donations that are spent on the end cause – they're not the same thing, because many charities, especially larger ones, also have other sources of money than donations. So while there is some debate around the value and interpretation of this metric, it is nevertheless one of the more frequent ones under examination.

“Heavy investment from provincial governments in broad sector charities disadvantages the patient groups sector.”

When regrouping data from financial statements to accommodate the CRA form, the objective for charities is to have the highest amount reported as charitable activities expenditures. High amounts recorded in fundraising and management and administration will raise flags. While there is limited guidance from CRA on this reporting item, they do advise that charities apply consistent practices from year to year.

The total sum of \$813,466,505 for charitable activities reported by the patient-focused groups represents 61% of total expenditures while the broad sector comes in with 76% of expenditures. Seemingly alarming by comparison, the aforementioned heavy investment from provincial governments in broad sector charities disadvantages the patient groups sector by inflating the charitable activities component of its beneficiaries.

**CHART 16: PERCENTAGE OF EXPENDITURES ON CHARITABLE ACTIVITIES**



## Total expenditures on management and administration

Of all expenditures by charities, management and administration is one of the most publicized and scrutinized metrics by the public, donors and media. This includes all expenditures related to the overall management and administration of a charity. Other examples of expenditures include:

- holding meetings of the board of directors;
- accounting, auditing, personnel, and other administrative services;
- purchasing supplies and equipment, and paying occupancy costs for offices;
- applying for grants or other types of government funding, and/or for gifts from other charities.

Some expenditures can be considered partly charitable and partly management and administration, such as salaries and occupancy costs. In these cases, there is a transfer of amounts between charitable purposes and management. These expenditures need to be reported on a consistent basis.

Complicating the use of this metric is whether a charity has full-time employees or is entirely volunteer driven. It can be seen in our revenue categories that 50% of the patient groups earn less than \$100,000. A full-time employee in an organization of this size can skew management numbers significantly. Larger organizations with greater numbers of

**Management and administration is one of the most publicized and scrutinized metrics by the public, donors and media.**

employees may reallocate certain salary costs to charitable activities thereby reducing administration costs.

This is not a perfect metric by any means. However, guidance comes from a small charity, Charity Intelligence Canada which provides a rating methodology for donors. Their ratings cover cost ratios primarily between 12.5% and 22.5%.

While there are many factors that influence this expenditure, such as size of organization, Charity Intelligence scores a ratio below 12.5% very high, and then ratios are further rated on a scale between 12.5% and 22.5% with no scoring for those over 22.5%. Patient-focused spending in this expense area accounted for 8.16% of expenditures for patient-focused charities and is equivalent to the broad sector which comes in with 8%.

Table 13 lists some selected charities from different revenue categories to illustrate the ranges of management and administration ratio.

**CHART 17: PERCENTAGE OF EXPENDITURES ON MANAGEMENT AND ADMINISTRATION**



**TABLE 13: MANAGEMENT AND ADMINISTRATION EXPENSE RATIO FOR SELECTED GROUPS.**

Organization	Management Expenses	Revenues	Ratio
Canadian Cancer Society	\$6,581,000	\$174,777,417	3.77%
Mitocanada Foundation	\$12,193	\$340,283	3.58%
Alzheimer Society of Canada	\$718,966	\$18,939,604	3.80%
Epilepsy Toronto	\$110,582	\$2,123,687	5.21%
Canadian Cancer Survivor Network	\$28,369	\$517,338	5.48%
Bladder Cancer Canada	\$80,239	\$963,109	8.33%
Crohn's and Colitis Canada	\$1,299,177	\$14,209,274	9.14%
Canadian Hemophilia Society	\$301,545	\$1,780,443	16.94%
Rare Disease Foundation	\$149,778	\$874,158	17.13%
Juvenile Diabetes Research Foundation Canada	\$4,786,098	\$20,775,081	23.04%
Spina Bifida and Hydrocephalus Association of Canada	\$51,349	\$216,354	23.73%
Canadian Organization for Rare Disorders (CORD)	\$211,933	\$749,248	28.29%



Organization	Management Expenses	Revenues	Ratio
Ottawa Regional Cancer Foundation	\$1,303,166	\$4,393,490	29.66%
The Canadian Society for Mucopolysaccharide & Related Diseases	\$55,790	\$145,008	38.47%
Sickle Cell Association of Ontario	\$14,553	\$25,197	57.76%

## Total expenditures on education and training for staff and volunteers

The persistent challenge presented by budget constraints often forces organizations to choose between funding programs and training employees. Since training falls under management and administrative spending, the extreme scrutiny that this expense category often claims employee and volunteer training as a victim. There are many good reasons to train staff and volunteers which are dependent upon organizational goals. A charity may need to recruit a strong board, increase fundraising, win more grants, or retain more volunteers to meet its goals.

There is no requirement that charities disclose what training programs they conduct which leaves researchers having to rely on anecdotal evidence. It is thought that a major spending area is in sending staff to conferences and educational symposia. It is harder to isolate any singular activity for volunteers other than any specific training volunteers may need to participate in a particular program. An example of this is the Simulated Patient program conducted by Alzheimer Society which requires specialized training for volunteers.

Just under 30% of patient groups (294) reported total spending on education of \$5,626,845 which is less than 0.5 of one percent of total revenue. There is no comparable data for the broad sector. Table 14 lists the top 10 organizations that invested in education along with the percentage of revenue. While many of the expected revenue leaders appear here by simple virtue of revenue size, there is an outlier here identified by the amount spent as a percentage of the charity's revenue and that is The Charles H. Best Diabetes Centre. They spent \$171,213 which is 11.48% of their total revenue while the others spending ranged from 0.16% to 2.85% of their revenue.

As charities enter the post-COVID era, staff and volunteer training in new technologies and methods of program delivery will become a more critical and demanding priority.

TABLE 14: TOP 10 ORGANIZATIONS REPORTING EMPLOYEE AND VOLUNTEER EDUCATION AND TRAINING.

Organization	Education Expense	% of Total	% of Charity Revenue
Multiple Sclerosis Society of Canada	\$772,642	13.73%	1.62%
The Canadian National Institute for the Blind	\$328,348	5.84%	0.36%
Canadian Cancer Society	\$307,029	5.46%	0.16%
Muscular Dystrophy Canada	\$274,557	4.88%	2.85%
Cystic Fibrosis Canada	\$183,702	3.26%	0.97%
The Charles H. Best Diabetes Centre	\$171,213	3.04%	11.48%
Heart And Stroke Foundation of Canada	\$143,304	2.55%	0.08%
Ontario Lung Association	\$141,837	2.52%	1.52%
Crohn's and Colitis Canada	\$137,332	2.44%	0.93%
Juvenile Diabetes Research Foundation Canada	\$134,137	2.38%	0.64%

## Total research grants and scholarships

It is hard to contest that medical research is a key priority for many patient-focused charities and forms a foundational plank in their mission. The public is also very attentive to this fact as it is one of the major factors communicated to members as a reason to support the cause.

The public is barraged by online and newspaper ads, billboard and transit advertising, direct mail campaigns, etc. all focusing on the theme of medical research to find a cure. A total of \$131,601,788 was reported as research grants and scholarships by 132 or 13.14% of the patient groups. Of course, no comparable data is available for the broader charitable sector as medical research does not extend beyond the health sector.

Most people would agree that research is vital, but when it takes an average of 17 years to develop a new idea into a medical product available to the public, how can medical research charities show the difference they make? The Association of Medical Research Charities (AMRC) in the UK released a report in 2017 that identified 4 key areas of impact:<sup>15</sup>

- Generating new knowledge
- Translating research ideas into new products and services
- Creating evidence that will influence policy or other stakeholders
- Stimulating further research via new funding or partnerships
- Developing the human capacity to do research

Table 15 identifies the 12 organizations that spent over \$1 million each and whose spending comprises 91% of all of the available research

“As donors look for concrete outcomes from their donations, it can be seen from this chart that patient groups devote from 9% to 78% of total revenue to research.

funds. As donors look for concrete outcomes from their donations, it can be seen from this chart that patient groups devote from 9% to 78% of total revenue to research in fulfillment of their mission and their explicit promise to donors. There is one unusual report here; The Multiple Sclerosis Scientific Research Foundation which contributed 271% of revenue to medical research. It appears that there was a disposition of assets that accounts for this anomaly. Otherwise, the highest percentage contribution belongs to Heart and Stroke Foundation Canadian Partnership for Stroke Recovery with over 78% of revenue committed to research.

TABLE 15: ORGANIZATIONS SPENDING OVER \$1 MILLION ON MEDICAL RESEARCH.

Organization	Research Expense	% of Total Research Funding	% of Organization Revenue
Canadian Cancer Society	\$44,099,203	33.51%	23.48%
Heart and Stroke Foundation of Canada	\$28,753,631	21.85%	16.97%
The Multiple Sclerosis Scientific Research Foundation	\$12,029,356	9.14%	271.13%
Crohn's and Colitis Canada	\$6,285,805	4.78%	42.75%
Cystic Fibrosis Canada	\$5,371,873	4.08%	28.45%
Prostate Cancer Canada	\$5,252,796	3.99%	42.26%
Multiple Sclerosis Society of Canada	\$4,162,686	3.16%	8.73%
Heart and Stroke Foundation Canadian Partnership for Stroke Recovery	\$4,007,499	3.05%	78.62%
The Arthritis Society	\$3,983,888	3.03%	15.06%
Alzheimer Society of Canada	\$3,308,651	2.51%	16.95%
Amyotrophic Lateral Sclerosis Society of Canada	\$1,525,268	1.16%	19.16%
Huntington Society of Canada	\$1,022,232	0.78%	23.85%



# Human Resources

**What are they getting paid?**

# HUMAN RESOURCES – WHAT ARE THEY GETTING PAID?

## Total number of permanent compensated positions

The subject of employees and compensation is often top of mind for the public and many donors. This perspective is often shaped by our concept of volunteerism. Despite the fact that the charitable sector delivers important social services and vital support to vulnerable people, many people believe it should be a purely voluntary activity. This is

“It is sometimes perceived that major charities have bloated bureaucracies, excessive salaries, and pampered executives.”

particularly true in health care. Our contemporary model of care is based on a medieval delivery of care by faith based organizations that was conducted as an act of charity.

In addition, donors are looking for concrete outcomes for their investments in charitable activities and view any costs incurred beyond the hard costs of program delivery as suspect. It is sometimes perceived that major charities have bloated bureaucracies, excessive salaries, and pampered executives.

Adding fuel to the fire is the lack of in-depth human resource data for this sector. Unlike other sectors like mining, construction, or agriculture there is no comprehensive national labour market data for the charitable sector. So donors and sponsors do not have enough information to understand the labour needs of their beneficiaries, and the sector has no way of planning a human resources strategy in order to identify and fulfill sector needs. The Human Resources Council for the Voluntary & Non-profit Sector was created in 2005 with a mandate to bring employers and employees together to provide leadership, build knowledge, and develop strategies on issues related to employment and by extension to provide the data necessary to inform these decisions. It was shut down in 2013 when it lost its funding.

There is hope for change. Recommendation 7 of the Senate report Catalyst for Change: A Roadmap to a Stronger Charitable Sector is: “That the Government of Canada, in consultation with the charitable and non-profit sector, reinstate the Human Resources Council for the Voluntary Sector, or a similar body by which the sector can collaborate with government to fulfill aspects of the human resources renewal plan.” It is vital for all stakeholders – governments who are major funders of charities, charitable organizations, donors, sponsors, and employees.

Are negative public perceptions accurate? Highlights from Charity Village's 2019 Canadian Nonprofit Sector Salary & Benefits Report, shed light on compensation realities:

- Cash compensation continues to grow slowly for many. From 2011 to 2018, compensation grew at an average rate of 0.4% to 1.8% per year, depending on the level. For many that growth was too slow and in fact stagnant for many.
- Sector focus impacts average compensation. Compensation is organizationally dependent with arts based organizations having dramatically different frameworks than health related organizations. While health based charities are among the leaders in cash compensation, this is most likely due to the high concentration of highly paid professionals in institutions such as hospitals and research.
- Larger charities generally offer larger salaries. Geography matters. Charities located in the larger metropolitan centres pay higher salaries especially at the most senior levels.
- Benefits continue to be an important part of the compensation package. While health benefits are an important perk, the more dominant one is retirement benefits, again especially important at the most senior levels.
- Education is highly valued by organizations and employees. This is a highly educated work force.
- Pay gap remains significant but is slowly shrinking. The gender related pay gap is most notable in larger organizations in the larger cities. Men tend to be more concentrated in higher paid jobs in larger cities with women having the same roles at lower pay in smaller organizations and smaller cities.

Patient-focused charities employ 7435 full-time staff serving patients and families across the country.

Charities differ markedly in how many staff they employ, if any. While a few have many employees and are headed by an individual who is well-compensated, others have no full-time staff and are strictly run on a volunteer basis.

The review of human resources for patient-focused charities revealed the following:

- 56% have NO full-time employees
- 22 organizations employ 56% of all employees
- Full-time compensation is 32% of total revenue
- 27 organizations reported 39 employees earning between \$200,000 and \$350,000
- 5 organizations reported one employee earning over \$350,000

It may seem shocking to some that 56% of charities do not have any full-time employees but it is consistent with the 58% total seen across the broad sector of all charities.

Similarly, the segment comprising organizations with more than 50 full-time employees contains only 22 patient groups or 2.2% of the total of patient-focused groups which is comparable to the broad charitable sector with 2.8% of charities.

“56% of charities do not have any full-time employees.”

These 22 organizations employ 4182 full-time people which is 56% of all full-time employees for patient-focused charities.

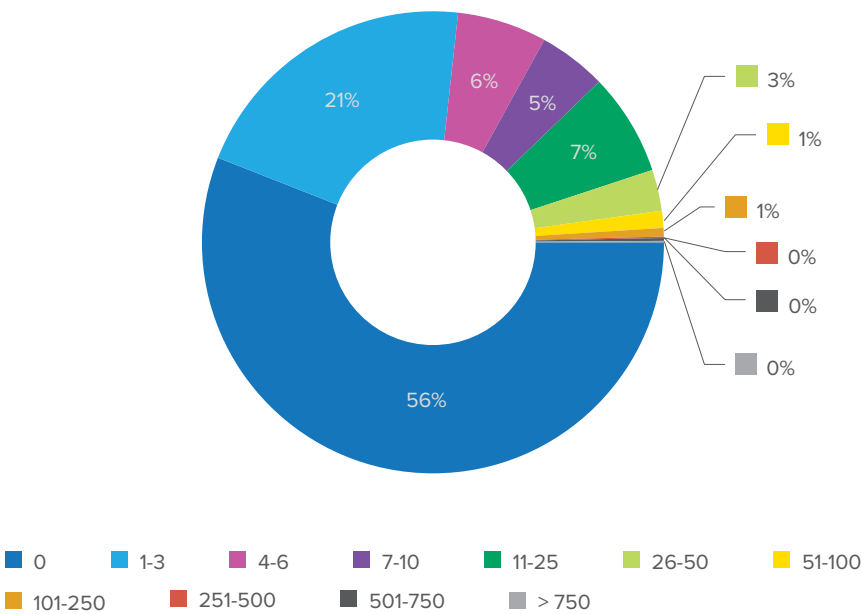
Another interesting segment includes those with 11-50 employees. There are 2223 employees or 30% of the total work force of 7435, spread among 101 groups or 10% of total groups, which is higher than the broad sector at 7%.

**TABLE 16: ORGANIZATIONS SEGMENTED BY NUMBER OF EMPLOYEES**

Number of Employees	# of Groups	% of Total Groups	# of Full-time Employees
0	563	56.08%	0
1-3	209	20.82%	337
4-6	63	6.27%	306
7-10	48	4.78%	387
11-25	72	7.17%	1188
26-50	29	2.89%	1035
51-100	12	1.20%	822
101-250	6	0.60%	943
251-500	1	0.10%	315
501-750	2	0.20%	1249
> 750	1	0.10%	853
	<b>1004</b>	<b>100%</b>	<b>7435</b>



CHART 18: PERCENTAGE OF ORGANIZATIONS BY NUMBER OF EMPLOYEES



Total expenditure on all compensation

Looking at the entire patient-focused sector, expenditure for all compensation, full-time and part-time totals \$525,130,656 which is 38.43% of total revenue. That compares against the broad sector with 53% of total revenue. Are these patient-focused groups offering lower wages or running leaner? The data from the Charity Village report indicates that health related charities are supposed to have higher wages. Perhaps greater investigation is necessary to get a clearer idea whether patient-focused groups are disadvantaged in comparison to the rest of the health charity sector.

Total expenditure on full-time compensation

Total Compensation Expenditures	\$525,130,656	38.43%
Total Part-time Expenditures	\$86,947,977	6.36%
Full-time Expenditures	\$438,182,679	32.07%

The CRA does not break out full-time compensation from total compensation, but only breaks out part-time compensation. By deducting part-time compensation from the total we see that full-time compensation is 83.4% of all compensation and 32% of total revenue. By comparison the broad sector full-time compensation is 42% of total revenue.

## CHART 19: PERCENTAGE OF EXPENDITURE ON FULL-TIME COMPENSATION



This may be significant because part-time staff numbers are more likely to fluctuate according to a number of factors including economic trends and program load while the full-time numbers may remain stable over a longer period of time. An erosion or explosion of these full-time numbers can be an indicator of financial strength or weakness. The top 15 compensation budgets are listed in Table 17.

TABLE 17: TOP 15 COMPENSATION BUDGETS.

Organization	Total Compensation	# Full-time Employees	Total Revenue
Canadian Cancer Society	\$64,456,759	651	187,804,352
Heart And Stroke Foundation of Canada	\$50,752,097	598	169,462,000
The Canadian National Institute for the Blind	\$32,786,582	853	92,399,362
Canadian Diabetes Association	\$17,496,170	234	36,351,844
Multiple Sclerosis Society of Canada	\$15,634,229	315	47,688,360
British Columbia Transplant Society Branch	\$14,088,112	35	64,136,393
The Arthritis Society	\$13,694,304	131	26,459,140
Head Injury Rehabilitation Ontario	\$12,097,200	165	14,994,149
Deafblind And Sensory Support Network of Canada	\$11,243,859	172	15,036,388
The Kidney Foundation of Canada	\$9,046,583	136	27,996,642
Juvenile Diabetes Research Foundation Canada	\$7,959,982	105	20,823,730
Spinal Cord Injury Ontario	\$7,636,529	86	10,292,881
Cerebral Palsy Parent Council of Toronto	\$7,202,939	80	8,862,710
Cystic Fibrosis Canada	\$6,397,230	80	18,881,000
Alzheimer Society of B.C.	\$5,768,743	72	9,728,822

## The ten (10) highest compensated, permanent, full-time positions

There is no Sunshine List for the charitable sector comparable to lists for government and public sector employees which publicly disclose salary, benefit and severance information for all employees earning over \$100,000 annually. Such lists are intended to shed light on government spending and provide accountability and transparency.

For donors and sponsors concerned about potentially bloated payrolls, charities that are agents of the government, such as hospitals or universities, do disclose their salary information on the provincial Sunshine List, if the province publishes one. For all charities, the CRA requires disclosure of the ten highest compensated, permanent, full-time positions. Note the limit of 10 which, while intriguing, does not complete the full salary picture if an organization employs more than 10 people.

**The broad sector data implies that the patient group is bottom heavy in the lower wage brackets.**

Among the patient-focused groups, these shortcomings become readily apparent. The limit of the CRA disclosure restricts the data to only 32% of the full-time workforce. The largest segments are those earning between \$40,000 and \$79,999 with 15.47% of the total and those earning less than \$40,000 representing over 9% of all employees. To provide some comparative data, we captured the similar percentages from the

broad sector. Taken at face value the broad sector data implies that the patient group sector is bottom heavy in the lower wage brackets but must be considered in light that the data only represents 11% of the broad sector work force vs 32% for the patient groups. If anything, this highlights the difficulty donors and sponsors have in getting useful data to inform their decisions when trying to isolate strategies to support charitable missions or organizational requirements. Nevertheless, for those for whom the issue of compensation is a critical component of decision making, these disclosure structures provide a method that can be applied to specific charitable organizations without restriction to the top 10 as prescribed by CRA.

TABLE 18: THE TEN (10) HIGHEST COMPENSATED, PERMANENT, FULL-TIME POSITIONS BY SALARY CATEGORY.

Full-time Employee Salary	# Groups	# Positions	% of Positions	Broad Sector %
\$1 – \$39,999	243	685	9.21%	5.52%
\$40,000 to \$79,999	329	1150	15.47%	3.73%
\$80,000 to \$119,999	152	336	4.52%	1.02%
\$120,000 to \$159,999	65	123	1.65%	0.32%
\$160,000 – \$199,999	28	49	0.66%	0.14%
\$200,000 – \$249,999	13	19	0.26%	0.09%
\$250,000 - \$299,999	11	14	0.19%	0.05%
\$300,000 – \$349,999	3	6	0.08%	0.04%
\$350,000 and over	5	5	0.07%	0.05%
	<b>849</b>	<b>2387</b>	<b>32.10%</b>	<b>10.95%</b>

## The Sunshine List

As stated earlier, the lack of sufficient data makes it difficult to fully assess the salary grades of employees in our patient-focused groups. To satisfy what seems to be a high level of curiosity among the general public and especially donors and sponsors, we have compiled our own sunshine list from publicly available data provided by CRA. We caution, of course, that the limitations of this data do not provide a fully accurate picture.

TABLE 19: THE SUNSHINE LIST

Salary Category	Organization	Total
> \$350,000	Canadian Cancer Society	1
	Heart And Stroke Foundation Of Canada	1
	Ontario Lung Association	1
	Prostate Cancer Canada	1
	The Canadian National Institute For The Blind	1
\$300,000 to \$350,000	Juvenile Diabetes Research Foundation Canada	1
	The Arthritis Society	1
	Heart And Stroke Foundation Of Canada	4
\$250,000 to \$300,000	Alzheimer Society Of Canada	1
	Crohn's And Colitis Canada	1

Salary Category	Organization	Total
	Cystic Fibrosis Canada	1
	Multiple Sclerosis Society Of Canada	1
	Ottawa Regional Cancer Foundation	1
	Praxis Spinal Cord Institute	1
	Starlight Children's Foundation Canada	1
	The Canadian National Institute For The Blind	1
	Canadian Cancer Society	2
	Canadian Diabetes Association	2
	Heart And Stroke Foundation Of Canada	2
\$200,000 to \$250,000	Alzheimer Society Of Toronto	1
	Amyotrophic Lateral Sclerosis Society Of Canada	1
	Association Du Diabete Du Quebec Inc	1
	Heart And Stroke Foundation Canadian Partnership For Stroke Recovery	1
	Parkinson Canada Inc.	1
	Pediatric Oncology Group Of Ontario	1
	Prostate Cancer Canada	1
	The Arthritis Society	1
	Canadian Cancer Society	2
	Multiple Sclerosis Society Of Canada	2
	The Canadian National Institute For The Blind	2
	The Kidney Foundation Of Canada	2
	Heart And Stroke Foundation Of Canada	3
\$160,000 to \$200,000	Alberta Lung Association	1
	Alzheimer Society Of B.C.	1
	Association Du Diabete Du Quebec Inc	1
	British Columbia Lung Association	1
	British Columbia Transplant Society Branch	1
	Canadian Lung Association	1
	Childhood Cancer Canada Foundation	1
	Deafblind And Sensory Support Network Of Canada	1
	Fondation Quebecoise Du Cancer Inc.	1
	Huntington Society Of Canada	1
	Hypertension Canada	1

Salary Category	Organization	Total
	Movember Canada	1
	Muscular Dystrophy Canada	1
	Osteoporosis Canada	1
	Ottawa Regional Cancer Foundation	1
	Ovarian Cancer Canada	1
	Pediatric Oncology Group Of Ontario	1
	Praxis Spinal Cord Institute	1
	Spinal Cord Injury Ontario	1
	The Foundation Fighting Blindness	1
	The Leukemia & Lymphoma Society Of Canada	1
	Cystic Fibrosis Canada	3
	Juvenile Diabetes Research Foundation Canada	3
	Multiple Sclerosis Society Of Canada	3
	The Canadian National Institute For The Blind	4
	Canadian Cancer Society	5
	Canadian Diabetes Association	5
	The Arthritis Society	5
\$120,000 to \$160,000	Advanced Coronary Treatment (ACT) Foundation Of Canada, Inc.	1
	AIDS Committee Of Toronto	1
	Alberta Lung Association	1
	Alzheimer Society Of B.C.	1
	Alzheimer Society Of Brant, Haldimand Norfolk, Hamilton Halton	1
	Alzheimer Society Of Calgary	1
	Alzheimer Society Of London And Middlesex	1
	Alzheimer Society Of Manitoba Inc.	1
	Alzheimer Society Of Saskatchewan Inc	1
	Alzheimer Society Of Toronto	1
	Amyotrophic Lateral Sclerosis Society Of BC	1
	Asthma Canada	1
	Autism Society Ontario	1
	Canadian Aids Society	1
	Canadian Cancer Survivor Network	1
	Canadian Liver Foundation	1

Salary Category	Organization	Total
	Canadian Spinal Research Organization	1
	Canucks Autism Network Society	1
	Cardiac Health Foundation Of Canada	1
	Ch.I.L.D. Foundation	1
	Dystonia Medical Research Foundation Canada	1
	GI (Gastrointestinal) Society	1
	Head Injury Rehabilitation Ontario	1
	Hope Air	1
	Integrated Services For Autism And Neurodevelopmental Disorders	1
	Lung Cancer Canada	1
	Lymphoma Foundation Canada	1
	Mitocanada Foundation	1
	Ontario Society For Crippled Children	1
	Pancreatic Cancer Canada Foundation	1
	Parkinson Society British Columbia	1
	Prostate Cancer Canada	1
	Rethink Breast Cancer Canada	1
	Société Canadienne De La Sclérose En Plaques (Division Du Québec)	1
	Spinal Cord Injury Association Alberta	1
	Spinal Cord Injury Ontario	1
	The Association For The Rehabilitation Of The Brain Injured	1
	The Foundation Fighting Blindness	1
	The Lung Association Of Saskatchewan Inc.	1
	Transforming Faces	1
	Western Institute For The Deaf And Hard Of Hearing	1
	Alzheimer Society Of Alberta And Northwest Territories	2
	Heart And Stroke Foundation Of Ontario	2
	Muscular Dystrophy Canada	2
	Osteoporosis Canada	2
	Ovarian Cancer Canada	2
	The Arthritis Research Centre Society Of Canada	2
	The Canadian National Institute For The Blind	2
	Canadian Diabetes Association	3

Salary Category	Organization	Total
	Crohn's And Colitis Canada	3
	Heart And Stroke Foundation Canadian Partnership For Stroke Recovery	3
	Movember Canada	3
	Ontario Lung Association	3
	Parkinson Canada Inc.	3
	Pediatric Oncology Group Of Ontario	3
	Praxis Spinal Cord Institute	3
	The Arthritis Society	3
	Juvenile Diabetes Research Foundation Canada	4
	Multiple Sclerosis Society Of Canada	4
	Starlight Children's Foundation Canada	4
	Amyotrophic Lateral Sclerosis Society Of Canada	5
	Cystic Fibrosis Canada	5
	The Kidney Foundation Of Canada	5
	The Leukemia & Lymphoma Society Of Canada	5
	British Columbia Transplant Society Branch	9

## Revenue per full-time employee

Revenue per Full-time Employee is an important ratio that measures approximately how much money each employee generates for a company. The revenue-per-employee ratio is most useful when comparing it against that of other companies in the same industry. It is a meaningful analytical tool because it measures how efficiently a particular firm utilizes its employees. Ideally, a company wants the highest ratio of revenue per employee possible because a higher ratio indicates greater productivity. Revenue per employee also suggests that a company is using its resources—in this case, its investment in human capital—wisely by developing workers who are very productive.

While it is understood that a charity is not a profit driven enterprise, the notion of efficient use of human resources is one that management of any type of enterprise pays attention to. It also allows donors and sponsors an opportunity to use a ratio they are familiar with in their own enterprise or as investors as they consider relationships with charities.

The ratio by itself is of little use without any frame of reference but to date that data has not been available. The intention of this ratio is to provide key evidence for those who dwell on the efficient utilization of the



voluntary sector work force, providing meaningful evidence to establish a foundation for future analysis and assessment of work force efficiency.

Here are some examples of the revenue per employee ratio from some well-known brands:

Facebook	\$1,928,831
Twitter	\$681,914
General Motors	\$718,953
Toyota Motor	\$638,522
Royal Bank of Canada	\$782,635
Bank of Montreal	\$844,396
Rogers Communications	\$595,771
Bell Canada	\$459,962
Home Depot	\$265,155
McDonalds	\$102,812
Starbucks	\$76,594

Based on the available data, the revenue per full-time employee for patient groups and the broad sector has been computed as follows:

#### CHART 20: REVENUE PER FULL-TIME EMPLOYEE



It may appear that the sector as a whole, and the patient-focused groups in particular, perform admirably against other labour intensive service sectors, however we did not include part-time workers in the analysis. This would require extensive study to be able to convert part-time data to the full-time equivalent, and in the absence of solid data that task is outside of the scope of this report. The presentation of this data is made on the expectation that those who are concerned deeply about measuring the efficiency of the charitable work force have an entry to a point of inquiry.

Table 20 illustrates the range of this ratio across charities from all of the revenue categories of charities earning over \$100,000. It can be expected that the larger charities would have higher ratios but that is not necessarily the case. Examples like the National Indigenous Diabetes Association Inc. and Kidney Cancer Canada demonstrate that smaller organizations

can operate efficiently in comparison to their much larger competitors. It speaks to their agility and resilience and may offer insight into their ability to withstand the pressures of economic and political crises.

This data does not necessarily set any bench marks for assessment, but rather is a starting point for anyone who needs to do a labour market analysis of the charitable sector, and in particular the patient-focused groups that exclusively support patients and their families.

“  
Smaller  
organizations can  
operate efficiently  
in comparison to  
their much larger  
competitors.”

TABLE 20: EXAMPLES OF REVENUE PER FULL-TIME EMPLOYEE FROM DIFFERENT REVENUE CATEGORIES

Organization	Total Revenue	# FT Employees	Rev / FTE
Canadian Cancer Society	187,804,352	651	\$288,486
Heart And Stroke Foundation of Canada	169,462,000	598	\$283,381
Crohn's And Colitis Canada	\$14,704,213	58	\$253,521
Parkinson Canada Inc.	\$10,400,951	72	\$144,458
Osteoporosis Canada	\$7,500,466	51	\$147,068
Canadian Liver Foundation	\$6,920,260	26	\$266,164
Huntington Society of Canada	\$4,286,307	18	\$238,128
Alzheimer Society of York Region	\$3,109,590	27	\$115,170
The AIDS Committee of Ottawa	\$1,136,214	14	\$81,158
Young Adult Cancer Canada Inc.	\$1,033,354	7	\$147,622
Kidney Cancer Canada Association	\$976,405	4	\$244,101
Lung Cancer Canada	\$764,683	5	\$152,937
Scleroderma Society of Ontario	\$312,047	5	\$62,409
National Indigenous Diabetes Association Inc.	\$268,825	1	\$268,825
National Gaucher Foundation of Canada	\$188,677	1	\$188,677

## Total number of part-time employees

Only 400 (40%) patient groups reported employing 6,060 part-time employees. The ratio of part-time to full-time is 81.5% while the broad sector reports a ratio closer to 1:1. The top 15 employers of part-time

employees are listed in Table 21. There are some new names that have not appeared on previous lists.

**TABLE 21: TOP 15 EMPLOYERS OF PART-TIME EMPLOYEES.**

Organization	# Part-time
Canucks Autism Network Society	478
The Canadian National Institute for the Blind	331
Canadian Diabetes Association	306
Deafblind And Sensory Support Network of Canada	203
Autism Services of Saskatoon Inc.	196
Ontario Society for Crippled Children	193
Canadian Cancer Society	191
Trillium Childhood Cancer Support Centre	170
Heart And Stroke Foundation of Canada	162
Autism Society Ontario	155
Head Injury Rehabilitation Ontario	126
Cerebral Palsy Parent Council of Toronto	102
Brain Injury Community Reentry(Niagara) Inc	94
The Kidney Foundation of Canada	91
Société Alzheimer Rive-Sud	88

## **Total expenditure on compensation for part-time employees**

Patient-focused groups spent \$86,947,977 on part-time compensation which was 6.36% of total revenue. The broad sector comparable figure is 10.4% possibly indicating much higher employment levels of part-time people or higher rates of pay. The fluctuating nature of this segment of the workforce due to seasonal and program load influences can also account for the variance.



# Public Policy Activity

# PUBLIC POLICY ACTIVITY

Our data set represents the last complete reporting period under which charities were required to fully disclose public policy activities, including descriptions of the activities, resource deployment and amounts spent. The data clearly describe the degree of engagement and resource commitment charities gave to these activities. As such it serves as a vital benchmark as the sector moves into a post-pandemic era where strategic priorities for charities may dramatically change.

The Income Tax Act has recently changed the treatment of “political activities” by registered charities. It is now covered under the category of Public Policy Dialogue and Development Activities (PPDDA). This refers to all non-partisan activities a charity may do to influence laws, regulations, or government policies at any level, either in Canada or abroad. This would include opposing, changing, or rescinding old or new laws and policies; participating in process through written submissions or committee work; meeting with elected officials to advocate for change, and rallying the public for support of a specific issue. There remains the prohibition against charities engaging in *partisan* political activities—i.e. direct or indirect support of, or opposition to, any political party or candidate for public office.

Under the rules by which charities operated during the period covered in this report, charities were prohibited from spending more than 10% of their revenue on political activities and were required to report on their activities and disclose their spending. The new rules allow unlimited spending on PPDDA and no requirement to report expenditures or other details.

“...representatives of patients do not always feel able to really influence decision-making processes.

Organizations that support patient-focused populations are commonly referred to as “advocacy” groups. Advocacy is a term broadly applied in the context of the charitable mission of these groups. While the implication is that these groups are actively lobbying government to advance the interests of those they serve, there is another form of advocacy attached to the charitable mission of disease awareness and education. This manifests itself in activities such as programs directed at health care

professionals, public awareness campaigns, and building the capacity of individual patients to advocate for their own care throughout the patient journey. While we recognize this broader context, this analysis is restricted to the consideration of public policy activities, or PPDDA.

Research indicates a complicated state of affairs in the matter of public policy “when participation takes place through patient organizations:

representatives of patient organizations may also be manipulated, and representatives of patients do not always feel able to really influence decision-making processes”.<sup>16</sup> Indeed there has been discussion that patient organizations should professionalize and discard the veneer of volunteerism in order to increase their level of participation beyond what can often be considered as tokenism. There is further evidence that impact of patient organization participation in health policy decision-making can be quite low as is the case in Italy and France.<sup>17</sup>

Adding to the challenges that patient organizations face, there are no clear standards for equitable participation in policy decisions. For example, according to the European Patients Forum (EPF) there is no agreement on best practices for patient involvement in Health Technology Assessment (HTA) and there are severe limitations to the practice of engagement. At the international level, the Health Technology Assessment International (HTAi) Patient and Citizens’ Sub-Group is working to promote methodologies to incorporate patients’ perspectives in HTA, but there is as yet no clear consensus in this policy area among HTA organizations leaving patient organizations still waiting to be invited to the table.<sup>18</sup>

“According to the European Patients Forum (EPF) there is no agreement on best practices for patient involvement in Health Technology Assessment (HTA).”

“There is no significant evidence reporting the impact and influence of patient organizations across the policy landscape...”

There is limited information available about the impact of Canadian patient organizations on policy development. It has been demonstrated that patient involvement in policy areas such as HTA can have beneficial results and uncover insights into patient experience previously

undisclosed.<sup>19</sup> It is for this reason that organizations such as Health Quality Ontario embedded patient feedback into their HTA process. But there is no significant evidence reporting the impact and influence of patient organizations across the policy landscape.

To address this important gap, we examined the public returns of the patient-focused organizations to identify how they describe their activities and what financial and human resources they devote to public policy activities.

## Definition of public policy dialogue and development activities (PPDDA)

The CRA describes PPDDAs as “activities a charity carries on to participate in the public policy development process, or facilitate the public’s participation in that process”, while “public policy means the laws, policies, or decisions of a government, in Canada or a foreign country.”<sup>20</sup>

## Total expenditures on public policy activities

Out of the total of 1004 charities, only 31, or 3%, reported PPDDA expenditures. Total expenditures by this small number of organizations was \$5,135,878, representing 0.38% of total revenue of \$1.366 billion for the entire patient-focused sector. Under rules operational at the time, this amount leaves 96.5% unspent out of the eligible \$146 million that the patient-focused health charities could have collectively spent under the old rules.

“96.5% unspent out of the eligible \$146 million.”

TABLE 22: PUBLIC POLICY HIGHLIGHTS

ORGANIZATIONS REPORTING	31
% OF ALL ORGANIZATIONS (1004)	3.1%
TOTAL EXPENDITURES	\$5,135,878
POLICY DOMINATED BY 2 ORGANIZATIONS	50% OF ALL EXPENSES
CANADIAN CANCER SOCIETY	\$1,728,220
CANADIAN DIABETES ASSOCIATION	\$801,686

There are a number of possible reasons why there is so much money left on the table when it comes to public policy activities. Clearly, the size of the organization and its ability to devote resources, including financial and human resources, is a key determinant. As we also see in the following section detailing the description of activities, there appears to be limited number of issues that actually resonate with the mandates of these organization. It would seem to indicate that even with some disease states represented by multiple organizations, the siloed nature of these groups appears to restrict collective action on issues that cross patient-focused boundaries.

One exception to this is the Health Charities Coalition of Canada founded in 2000 with the mandate to “advocate for sound public policy on health issues and promoting the highest quality health research.” The largest of the patient-focused health charities in Canada belong to this coalition. Among the resources offered by the Coalition is the [Canadian Consensus](#)



[Framework for Ethical Collaboration](#), outlining a set of ethical standards to guide collaboration among patient organizations, health care professionals and the pharmaceutical industry.

While new rules were enacted in early 2019 allowing charities to spend up to 100% of their revenue on PPDDA, charities have not yet had time to develop new programs and PPDDA campaigns. PPDDA must be in support of the charitable purposes of the organization and there is still some confusion on the interpretation of this limitation in that political activity as a sole focus is not a charitable purpose but a political purpose.<sup>21</sup>

Interestingly, the lack of impact implied by the relatively minimal expenditure by this sector is amplified with the disclosure that of the \$5.135 million spent, fully 50% of that is accounted for by only 2 of the charities – Canadian Cancer Society and Canadian Diabetes Association (now Diabetes Canada).

**TABLE 23: TOTAL EXPENDITURES ON PUBLIC POLICY ACTIVITIES REPORTED BY ORGANIZATION**

Organization	Amount	Total Revenue	% of Total Revenue
Canadian Cancer Society	\$1,728,226	\$187,804,352	0.92%
Canadian Diabetes Association	\$801,686	\$36,351,844	2.21%
Parkinson Canada Inc.	\$344,181	\$10,400,951	3.31%
Amyotrophic Lateral Sclerosis Society of Canada	\$326,196	\$7,960,369	4.10%
Juvenile Diabetes Research Foundation Canada	\$318,674	\$20,823,730	1.53%
Heart And Stroke Foundation of Canada	\$279,000	\$169,462,000	0.16%
Alzheimer Society of Canada	\$192,103	\$19,522,888	0.98%
Rethink Breast Cancer Canada	\$149,285	\$2,110,426	7.07%
The Arthritis Society	\$148,327	\$26,459,140	0.56%
Cystic Fibrosis Canada	\$147,656	\$18,881,000	0.78%
Ovarian Cancer Canada	\$139,772	\$3,806,035	3.67%
Childhood Obesity Foundation (COF)	\$86,207	\$2,837,407	3.04%
Société Canadienne de la Sclérose en Plaques (Division du Québec)	\$73,154	\$5,585,101	1.31%
Huntington Society Of Canada	\$60,351	\$4,286,307	1.41%
Ottawa Regional Cancer Foundation	\$59,307	\$4,435,335	1.34%
Canadian Cancer Survivor Network	\$51,423	\$518,139	9.92%
Allergies Québec / Allergy Québec	\$43,058	\$952,184	4.52%



Organization	Amount	Total Revenue	% of Total Revenue
Alberta Lung Association	\$36,855	\$2,073,279	1.78%
Prostate Cancer Canada	\$34,052	\$12,428,912	0.27%
Ontario Lung Association	\$33,478	\$9,302,005	0.36%
Crohn's and Colitis Canada	\$31,131	\$14,704,213	0.21%
Alzheimer Society of B.C.	\$17,019	\$9,728,822	0.17%
The Lung Association of Saskatchewan Inc.	\$9,463	\$2,525,736	0.37%
Autism Society Ontario	\$6,163	\$9,718,412	0.06%
Asthma Canada / Asthme Canada	\$5,428	\$773,555	0.70%
New Brunswick Lung Association Inc.	\$3,866	\$728,058	0.53%
Diabétiques de Lanaudière Inc.	\$2,873	\$144,155	1.99%
Pulmonary Hypertension Association of Canada	\$2,444	\$566,749	0.43%
Association des Personnes Handicapees Visuelles du Bas St-Laurent	\$2,000	\$161,906	1.24%
Alzheimer Society of Manitoba Inc.	\$1,500	\$2,505,404	0.06%
Parkinson Québec	\$1,000	\$1,717,687	0.06%

## Description of public policy activities

While 31 organizations disclosed expenditures related to public policy activities, there are 35 groups that provided descriptions of public policy activities. The discrepancy in disclosure can be attributed to the type of activity carried out and what resources if any – e.g. volunteers, social media – were deployed.

Seven key themes emerge from these descriptions:

- 1. Access to Care.** Fifteen organizations included access to high quality care as a key anchor of their activities. This includes access to specific medical equipment such as sleep apnea equipment and non-invasive ventilation and also more comprehensive care such as palliative and hospice access.
- 2. Access to new drug and device therapies.** Twelve groups noted that they had participated as contributors of patient input to Canadian processes for assessing new drugs and devices such as Common Drug Review (CDR) applications, Pan Canadian Pharmaceutical Alliance (pCPA) policy review, Health Technology Assessment (HTA) for new devices and drugs, as well as advocating for including new drugs in provincial formularies.
- 3. Public Health and Quality of Life.** Improving Quality of Life for their constituency forms a core part of the mission of 10 groups.

There is an implicit relationship for some between their members' needs and the public health responsibility of government. This is illustrated by objectives to, for example, educate and inform about food allergies, provide adapted accommodation for those with disabilities, remove the stigma associated with genetic testing and support a cancer care coaching pilot.

- 4. Burden of Illness.** This is an explicitly powerful component of activity for 9 groups. It manifests itself in educational and awareness programs, lobby day action on Parliament Hill, and informing members of parliament about the physical, emotional, social and financial cost that illness places on patients.
- 5. Policy and Legislation.** There was mention of advocacy activities around specific policies or legislation by 9 groups. This included a tax on sugary drinks, changes to the Disability Tax Credit, accessibility, smoke free environments and Bill 222 amendments to the Human Rights Code regarding genetic characteristics.
- 6. Funding research.** Eight groups indicated that advocating for increased funding for scientific research for their disease was vital to their work, and it would appear, part of the commitment they make to their members. It is tied to the theme of a "hope for a cure" that forms the basis of a relationship with members for many organizations.
- 7. Caregiver support.** While only 4 groups highlighted this need, it is significant that this issue has risen to the level of political activity. Over the last few years there has been increased activity at various levels of government on the topic of caregiver support. For example, the non-profit Ontario Caregiver Organization has been created in Ontario and think tanks like the Change Foundation have made caregiver support a key focus of their work.

There is minimal mention of pan-Canadian activity with only a couple of organizations devoting resources to coast-to-coast activities. Work by the Alzheimer Society to advocate for a national dementia strategy is one example.

There are also a few examples of collaborations between groups to advance specific common issues. Heart and Stroke and Childhood Obesity Foundation have partnered in Stop Marketing for Kids (Stop M2K!) Coalition. In Quebec there is a coalition of progressive neurological and neuromuscular groups called Neuro Partners. Finally, an example of a cross-sectoral collaboration by Asthma Canada in the Clean Economy Alliance demonstrates that common policy interests aren't necessarily restricted to patient-focused policies. It represents an understanding and awareness that the health outcomes of patients are affected by many factors including environmental and social determinants of health.

A full description of the public policy activities undertaken by those patient-focused groups who reported them is detailed in Appendix A.

## Resources and methods used for public policy activities

Charities are required to identify what tactics and tools they used to participate in or carry out public policy activities. Table 24 identifies each one of the methods used with the number of groups reporting their deployment and the percentage of the groups who disclosed from 35 groups that reported.

Table 24 highlights the top 3 methods used by organizations: the Internet, letter writing campaigns, and conferences. The Internet is the most popular tool listed for supporting these activities. While able to reach large numbers of people, and especially a younger demographic, the use of social media for these purposes has often been referred to as “passive activism” or “slacktivism” due to the low level of commitment required of the target audience to engage with the cause. Conventional letter writing campaigns continue to be deployed, generally due to the perceived ability to physically flood the mailbox of a member of parliament in order to draw attention to a cause. There is still considerable use of conferences and seminars to inform and educate. These methods align well with some of the themes that emerged in the previous section that described the public policy activities of organizations.

**TABLE 24: HUMAN AND FINANCIAL RESOURCES USED FOR PUBLIC POLICY ACTIVITIES**

Line	Description	Staff		Volunteers		Financial		Property	
		#	%	#	%	#	%	#	%
700	Media releases and advertisements	11	28.21%	9	23.08%	19	48.72%	0	0.00%
701	Conferences, workshops, speeches, or lectures	15	38.46%	12	30.77%	22	56.41%	2	5.13%
702	Publications (printed or electronic)	11	28.21%	10	25.64%	17	43.59%	0	0.00%
703	Rallies, demonstrations, or public meetings	5	12.82%	4	10.26%	8	20.51%	0	0.00%
704	Petitions, boycotts (calls to action)	4	10.26%	2	5.13%	6	15.38%	0	0.00%
705	Letter writing campaign (printed or electronic)	16	41.03%	10	25.64%	17	43.59%	0	0.00%
706	Internet (website, social media (Twitter, YouTube))	17	43.59%	11	28.21%	24	61.54%	0	0.00%
707	Gifts to qualified donees for political activities	1	2.56%	1	2.56%	0	0.00%	0	0.00%
708	Other (specify):	5	12.82%	3	7.69%	8	20.51%	0	0.00%

## Non-profit groups without charitable status

Registered charities are not the only patient-focused organizations dedicated to supporting patients with specific conditions. There are numerous groups incorporated as non-profit organizations that resemble the registered charities and have similar missions. But there are differences.

While non-profit groups can accept donations and grants, they are not able to issue tax receipts. Unlike charities, non-profits are not required to file annual information returns that will be posted publicly. Additionally, they have not had the same restrictions inhibiting their range of public policy activities that registered charities did. While these charitable restrictions were revised in early 2019, the new regulations are too recent to have generated much change in the way that charities conduct these activities. The full description of the differences between registered charities and non-profits is detailed in Appendix D.

A limitation of the report is the lack of publicly available financial data for the non-profit patient-focused organizations that do not have charitable status. We have identified 46 of these groups (full list in Appendix C) from public sources such as member lists of national and provincial health advocacy coalitions as well as participants in public hearings and consultations. This list is not exhaustive. From a review of websites, publications and events, they have been deemed to qualify as meeting the criteria for patient-focused organizations.

A predominant characteristic of these groups is that they are volunteer driven with only a select few having full-time employees, to the best of our determination. There can be a number of reasons these groups have chosen a non-profit structure over a charitable one with cost of becoming a registered charity, the ongoing regulatory burden, and the absence of restrictions on public policy advocacy being three of them.

“It is understood how vulnerable and fragile many of these non-profit groups are and how dependent they are on a limited base of support.”

At the same time, it is understood how vulnerable and fragile many of these non-profit groups are and how dependent they are on a limited base of support, a small cadre of committed volunteers, a lack of donor incentive from a tax receipted donation, and the need to focus on narrow issues in order to be impactful.

Despite lacking charitable status, these non-profit organizations compete with patient-focused and other health charities for public attention and often delegate significant attention and resources to public policy advocacy. For these

reasons the interface between patient-focused charities and non-profit organizations merits attention within this chapter - Public Policy Activity - of this report.

How patient-focused charities and non-profit organizations working with patient, families and caregivers approach certain advocacy or public policy issues differently may be seen in the emphasis each category - non-profit or charity - places on engaging with the process of funding new drugs in Canada.

Many patient groups, whether charities or non-profits, include the issue of access to medication as a key part of their mission as pointed out earlier in the section Description of Public Policy Activities. Once a new drug is approved by Health Canada as safe and marketable in Canada, the next step in the journey takes it to the CADTH Common Drug Review (CDR) where it is assessed and recommendations provided to public drug plans, except Quebec, on the value of providing coverage for the product. The CDR process invites input from patients and patient groups when new applications are received from manufacturers. These submissions by patient groups are meant to provide the CDR expert committees with a deeper appreciation of the lived experience of patients.

Out of 107 publicly named patient input contributors to CADTH CDR and pCODR April 2013 - Oct 2017, 62 of the patient-focused charities contributed to CADTH during that time period (Table 26). This represents just 6% of all patient-focused charities.

In contrast, 44% (20) of the 46 non-profit organizations identified in Appendix C appear among the 107 publicly named patient input contributors to CADTH (Table 25). Comparing the two types of organizations with this limited data, non-profit groups appear to contribute to the task of patient input to CDR at a rate of participation almost 7 times higher than the larger cohort of patient-focused charities. Without data to concretely support this disparity, it is difficult to conclude why this imbalance between organization types exists.

**TABLE 25: NON-PROFIT GROUPS CONTRIBUTING TO CDR AND PCODR**

- Action Hepatitis Canada
- Arthritis Consumer Experts
- Bladder Health BC
- Canadian Arthritis Patient Alliance
- Canadian Association of Psoriasis Patients (CAPP)
- Canadian Pituitary Tumours & Related Diseases Network (PTN)
- Canadian PKU & Allied Disorders Inc.
- Canadian Psoriasis Network
- Canadian Skin Patient Alliance
- Canadian Spondylitis Association

- Canadian Treatment Action Council
- Canadian Women with Fibroids
- Centre for ADHD Awareness Canada (CADDAC)
- Chronic Myelogenous Leukemia Society of Canada
- Consumer Advocare Network
- COPD Canada
- Familial Hypercholesterolemia Patient Network
- HAE Canada Inc.
- International Federation of Aging
- Pacific Hepatitis C Network

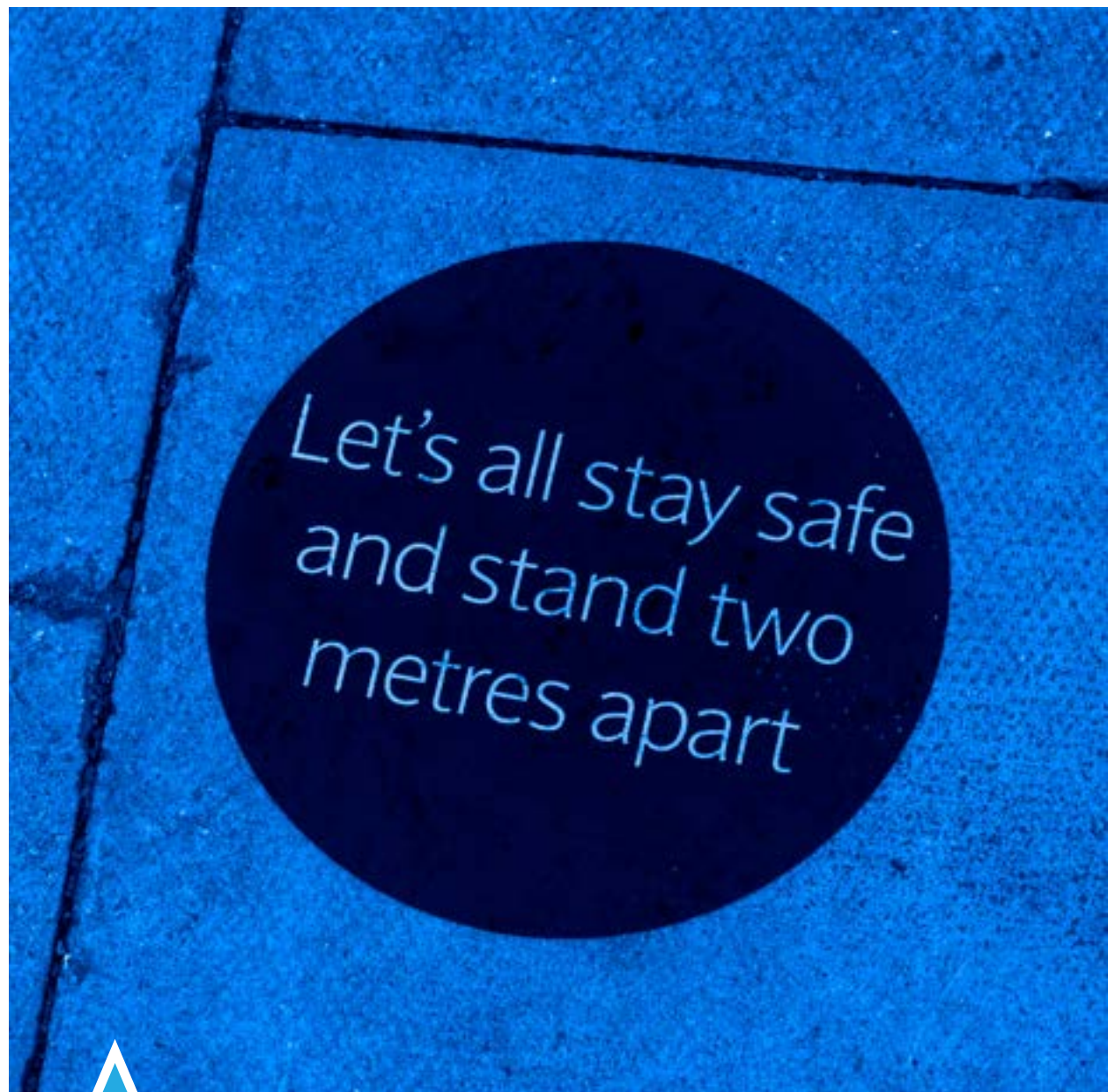
**TABLE 26: REGISTERED CHARITIES THAT CONTRIBUTED TO CDR AND PCODR 2013-2017**

- AboutFace Craniofacial Family Society
- Arthritis Society
- Asthma Society of Canada
- BC Epilepsy Society
- British Columbia Lung Association
- Canadian Breast Cancer Network
- Canadian Cancer Survivor Network
- Canadian Continence Foundation
- Canadian Council of the Blind
- Canadian Diabetes Association
- Canadian Liver Foundation
- Canadian National Institute for the Blind
- Canadian Organization for Rare Disorders (CORD)
- Canadian PBC Society
- Canadian Pulmonary Fibrosis Foundation (CPFF)
- Canadian Society for Mucopolysaccharide and Related Diseases
- Cardiac Health Foundation of Canada
- Centre d'Aide aux Personnes Atteintes d'Hépatite C (CAPAHC)
- Colorectal Cancer Association of Canada
- Craig's Cause Pancreatic Cancer Society
- Crohn's and Colitis Foundation of Canada
- Cystic Fibrosis Canada
- Diabetes Canada
- Dravet.ca
- Dystonia Medical Research Foundation of Canada
- Epilepsy Newfoundland and Labrador
- Epilepsy Nova Scotia
- Epilepsy Ontario
- Epilepsy Toronto
- Foundation Fighting Blindness (FFB)

- Gastrointestinal (GI) Society
- Heart and Stroke Foundation of Canada
- HeartLife Foundation
- Hepatitis C Education and Prevention Society (HepCBC)
- Isaac Foundation for MPS Treatment and Research
- Kidney Cancer Canada
- Kidney Foundation
- Leukemia & Lymphoma Society of Canada (The)
- Lung Association of Saskatchewan
- Lung Association, Alberta & NWT (TLA)
- Lung Cancer Canada
- Lymphoma Canada
- Melanoma Network of Canada
- Multiple Sclerosis Society of Canada
- Myeloma Canada
- National Gaucher Foundation of Canada
- New Brunswick Lung Association
- Ontario Lung Association
- Osteoporosis Canada
- Ovarian Cancer Canada
- Parkinson Society of Canada
- Polycystic Kidney Disease (PKD) Foundation of Canada
- Prostate Cancer Canada
- Pulmonary Hypertension Association of Canada
- Rethink Breast Cancer
- Sarcoma Cancer Foundation of Canada
- Save Your Skin Foundation
- Scleroderma Society of Canada
- Soft Bones Canada
- Thalassemia Foundation of Canada
- Thyroid Cancer Canada
- Tuberous Sclerosis Canada Sclerose Tubereuse

TOTAL: 62





# Post-COVID Implications

**for the health charity sector**

# POST-COVID IMPLICATIONS FOR THE HEALTH CHARITY SECTOR

The impact of the COVID-19 pandemic in the spring of 2020 on Canada's charitable sector including patient-focused charities was almost immediate and devastating.

Organizations suddenly found themselves severely constrained in their revenue-generating activities while at the same time trying to maintain daily activities while direct person-to-person contact was discouraged or forbidden. Patient-focused charities also found themselves struggling to inform their constituents in the face of a novel coronavirus whose signs and symptoms were soon found to impact several organ systems.

The pandemic also touched many patient groups beyond the coronavirus itself, as a group of 16 health charities outlined in [an April report](#)<sup>22</sup> summarized here:

*“A key finding of the report is the impact of COVID-19 on Canadians with chronic diseases or an underlying medical condition. For example, Canadians with diseases that affect their ability to breathe, such as lung disease, cystic fibrosis and muscular dystrophy, are at severe health risk, as COVID-19 attacks the lungs. People with Crohn’s disease and diabetes, who rely on medications that suppress their immune system, are vulnerable to contracting COVID-19. People needing to have a cancerous tumour removed are on hold indefinitely, along with those requiring diagnostic services and transplants, as hospitals and critical care services redirect their resources to COVID-19 efforts.”*


On the advocacy front, patient advocates and caregivers found themselves excluded from the decision-making processes for hospitals and long-term care homes as these groups battled to “flatten the curve” and prevent widespread transmission of COVID-19. Policies were determined at the highest levels without input from patients or caregivers. (It took a few months for it to be acknowledged that even with COVID-19 the patient perspective remained essential and that family caregivers were also a key part of patient-care teams).

On March 24, an Emergency Coalition of Canadian charities - which included some of Canada's biggest health charities - wrote to Prime Minister Trudeau and his senior ministers requesting "urgent financial aid and federal action to prevent our organizations from irreparable collapse amid the COVID-19 pandemic, at a time when more and more Canadians and vulnerable families throughout the world will be in desperate need of our services."

According to the Health Charities Coalition of Canada, "the ongoing COVID-19 crisis has created an unprecedented challenge for Canada's health care system as well as the organizations that are actively supporting patients affected by cancer, ALS, heart disease, diabetes and many other debilitating diseases and conditions. As a result of efforts to bend the curve and impacts from the volatile economy, these essential health charities are reporting more than a 50% reduction in donation revenues."

[Global surveys<sup>23</sup>](#) of charitable organizations (including those focusing on healthcare) conducted over the summer months by CAF America showed that "while nonprofits worldwide are demonstrating great ingenuity in adapting their operations and programs, over 90% of the responding organizations in each survey ... during the past three months report being negatively impacted by the coronavirus global pandemic". A third of the 414 organizations polled in these surveys estimated they would have to close down within 12 months if their financial situation remained unchanged.

In Canada in April, Prime Minister Trudeau announced measures including a \$350 million fund to support the charitable sector serving vulnerable populations affected by COVID-19 but this fell far short of the \$10 billion stabilization fund requested by the emergency coalition. Patient-focused charities who had a mandate to fund research dealing with their condition also found themselves facing the prospect of not having sufficient funds to continue financing Canadian researchers. The Health Charities Coalition of Canada sent [a letter<sup>24</sup>](#) to the Prime Minister on May 21 signed by more than 1000 researchers explaining the essential role of funding from health charities "to the continuation of their ground-breaking and life-saving work." The coalition requested direct investments of up to \$28 million per month to allow organizations to continue their work in funding research.



**A third of the 414 organizations polled in these surveys estimated they would have to close down within 12 months if their financial situation remained unchanged.**

One of the most comprehensive pictures of the impact of COVID-19 on charities (including patient-focused charities) and non-profit organizations in Canada comes from Imagine Canada, which advocates on behalf of both charities and non-profits.

In an April 30 [blog post](#),<sup>25</sup> Emily Jensen, co-ordinator of network engagement for Imagine Canada, noted that revenue loss was threatening both charities and non-profit organizations.

*“Across the country, fundraising galas are cancelled or postponed, charity runs and golf tournaments have been called off, and with many feeling the pinch on their own personal finances, individual donations are down.”*

*“When it comes to earned revenues, the sector is subject to the same challenges faced by the retail market. Many organizations rely on the sale of goods and services for income, but social distancing measures have made many revenue generating activities impossible.”*

A major focus of Imagine Canada over the spring and summer of 2020 was the call for a Sector Resilience Grant Program to provide \$3.75 billion in funding to cover core operating costs for charities not covered by the Canada Emergency Wage Subsidy program.

In late April, the largest health charities represented by the Health Charities Coalition of Canada had [outlined a number of steps](#)<sup>26</sup> taken by these organizations to meet the needs of their vulnerable populations. These included:

- Transitioning services to virtual platforms to respond to need for disease-specific information for patients and their families in understanding risks, managing disease, and maintaining health in this new context.
- Convening virtual support groups, connecting individuals living with disease to their care team and to each other during this time of social isolation.
- Meeting the increased demand for health charities to supplement care, such as social workers and physical therapists due to the lack of capacity in the healthcare system.
- Advocating for the needs of their communities in the midst of the triage of health care resources.
- Elevating issues of access to community-based personal support workers and respiratory therapists.
- Raising awareness of the need for personal protective equipment in community-based settings.

- Working to pivot significant aspects of their revenue models – from seasonal in-person fundraising activities to virtual events.

[An assessment<sup>27</sup>](#) of the impact of COVID-19 on the charitable sector conducted with more than 1400 charity leaders in late April, 2020 and published by Imagine Canada in May contained the following findings:

- 30% of charities have already laid off staff and 55% say new or additional layoffs are a possibility.
- 49% reported difficulty engaging volunteers in current working conditions and 33% said volunteers were less available.
- 20% believe they will be able to continue their current level of operations for 3 to 6 months; 25% for 6 to 12.

In looking at health charities specifically, this assessment found 9% of charities surveyed had ceased or suspended operations while 14% had cancelled programs due to lack of demand. Health-related charities were also significantly more likely than other types of charities (except those in education) to have moved their existing programs online.

“Canadian Cancer Society expected a drop of between \$80 and \$100 million in donations this year as well as being forced to cancel hundreds of events.

By the middle of July it was being reported that health charities expected “historic losses” and would only raise less than half of usual revenues in 2020 because of the COVID-19 pandemic. A [CBC report<sup>28</sup>](#) noted that the Canadian Cancer Society expected a drop of between \$80 and \$100 million in donations this year as well as being forced to cancel hundreds of events. Its annual Relay for Life event, which was “reimagined” as a virtual Relay At Home version, only raised \$4.2 million compared to more than \$20 million in each of the last two years. The report also said smaller charitable organizations like

the Sickle Cell Association of Ontario also faced a tough year and the \$2,000 a month it usually received in donations has dropped to \$400 since March.

At the time of publication of this report, the course of the COVID-19 pandemic remains uncertain as does its impact on the charitable sector. The initiation of new programs or continuation of existing programs from the federal government to support charities will be somewhat dependent on the scope and speed of the economic recovery as we enter a “post-COVID” period. As with for-profit and non-profit organizations it is probable some patient-focused charities will not be able to survive the economic challenges caused by the pandemic and will be forced to close their doors. Others will have to radically restructure in order to survive in

whatever fund-raising environment they will have to function within under “new normal” conditions.

In 2017, Christopher Barry who was working as an interim CEO to support not-for-profit organizations experiencing revenue challenges and transformational change wrote a column for The Globe and Mail Report on Business on the characteristics of successful charities. While pre-dating COVID-19, Barry’s four points seem to provide a useful roadmap for patient-focused charities hoping to thrive in the months and years to come:



Forge new  
relationships with  
digital donors and  
volunteers.

1. Execute and deliver to the organization’s mission.
2. Adapt to change in stakeholders’ expectations.
3. Address competition and declining revenue.
4. Forge new relationships with digital donors and volunteers.





# How Patient-Focused Charities Describe Themselves



# HOW PATIENT-FOCUSED CHARITIES DESCRIBE THEMSELVES

Organizations are asked to choose up to three program areas that describe their charitable activities and to estimate the percentage of total time and resources (human and financial) allocated to each area. These program areas are pre-defined by CRA and readers can see the full list in Appendix E. Limitations of this data are that 265 organizations did not complete the form and the percentage allocated to resources is subject to some degree of guesswork. Nevertheless, it affords a witness box perspective of how organizations view themselves, their work and their community.

These important data deliver insights to the interconnectivity of patient-focused charities with other charities in social services, community benefits such as human rights, culture, education, research, housing, transportation, or other support for the physically challenged. While our next report will explore in greater detail the intersections these organizations share between them, these data offer a useful starting point from the perspective of the patient-focused charities themselves.

The program area codes for charitable purposes are listed below for Health only.

**F1** - Hospitals

**F2** - Nursing homes

**F3** - Clinics

**F4** - Services for the sick

**F5** - Mental-health services and support groups

**F6** - Addiction services and support groups

**F7** - Other mutual-support groups (for example, cancer patients)

**F8** - Promotion and protection of health, including first-aid and information services

**F9** - Specialized health organizations, focusing on specific diseases/conditions

As a reminder to readers, the selection criteria for patient-focused organizations excluded F1 - Hospitals, F2 - Nursing homes, and F3 - Clinics from the groups under review in this report. While not included in the current cohort of patient-focused organizations, F5- Mental-health services and F6 – Addiction services will be part of the ecosystem of patient support that will be analyzed in the next report. Nevertheless 27 patient-focused organizations selected F5 – Mental-health services with an average commitment of 48% of resources to this program area.

Table 27 illustrates the wide range of charitable activity these organizations engage in while still maintaining clear focus on the patient population they serve. From this overview, the relationships between health and the social determinants of health begin to emerge. Organizations can select multiple area codes and assign a percentage of the mission to each area.

Field code prefixes for each category relate to program groups – Social services, Education and Research, Culture, Health, Other Community Benefits. They range from a strictly health focus, such as F4 - Services for the sick, to the top of mind A1 - Housing (seniors, low-income persons, and those with disabilities) and to the more advocacy oriented H12 - Human rights.

Expectedly, 309 organizations identified as F9 - Specialized health organizations, focusing on specific diseases/conditions. At the same time less than half (147) of them dedicated 100% of their energy to this one area. The remaining 156 groups that are 100% dedicated to a single

program area are spread among 15 areas, only 5 of which are in the Health category. The areas outside of Health include research, scholarships, family and crisis counselling, literacy programs, senior's services, and Children and youth services/housing. Two Alzheimer groups selected A6 - Seniors' services as their sole program area.

A7 - Services for the physically or mentally challenged has the third highest number of selections with an average resource allocation of 70%. This is the strongest indicator of the interconnection between disease specific conditions and the social determinants of health. Services can include supportive housing, transportation, and food security.

F5 - Mental-health services and support groups is in the top ten bringing a strong highlight on the need for greater appreciation of the impact chronic illness can have on mental health. With population mental health getting so much exposure lately, patient-focused charities providing peer support programs are aligned in shared purpose with organizations whose exclusive focus is mental health.

Finally, H8 - Summer camps remind us that even patients can have fun and that the pursuit of joy in life is a valid charitable activity.

“Services for the physically or mentally challenged...is the strongest indicator of the interconnection between disease specific conditions and the social determinants of health.”

In summary, it seems that patient-focused charities view themselves through a prismatic lens, one that addresses the needs of the individual, their local community, and the wider national society within which we all live. This lens spans a universe of needs including disease awareness, research, social determinants of health, advocacy, health literacy and psychosocial support among many others, all of which highlights how non-linear the actual patient journey is. With a preponderance of patient-focused charities describing themselves as involved in multiple program areas, the opportunity and challenge to potential stakeholders is to see these charities from the same multi-disciplinary, multi-dimensional perspective when it comes to establishing authentic partnerships with them.

**TABLE 27: TOP 20 PROGRAM AREAS FOR PATIENT-FOCUSED CHARITIES**

Category	Total Respondents	Average Resource allocation %	Reported Area at 100%
F9 - Specialized health organizations, focusing on specific diseases/conditions	309	73%	147
F7 - Other mutual-support groups (for example, cancer patients)	201	55%	60
A7 - Services for the physically or mentally challenged	125	70%	51
F8 - Promotion and protection of health, including first-aid and information services	113	38%	12
C10 - Public education, other study programs	97	31%	0
C11 - Research (scientific, social science, medical, environmental, etc.)	69	38%	6
F4 - Services for the sick	27	64%	9
F5 - Mental-health services and support groups	27	48%	4
A11 - Family and crisis counselling, financial counselling	25	31%	1
C1 - Scholarships, bursaries, awards	16	27%	2
H12 - Human rights	15	18%	0
A1 - Housing (seniors, low-income persons, and those with disabilities)	10	36%	0
H15 - Support and services for charitable sector	10	43%	2
A6 - Seniors' services	9	46%	2
H8 - Summer camps	8	15%	0
F3 - Clinics	6	29%	0

Category	Total Respondents	Average Resource allocation %	Reported Area at 100%
A5 - Other services for low-income persons	5	70%	2
C7 - Vocational and technical training (not delivered by universities/colleges/schools)	5	35%	0
A3 - Employment preparation and training	4	30%	0
B5 - Literacy/education/training programs	4	41%	0
D2 - Festivals, performing groups, musical ensembles	3	23%	0



# Appendix A:

**Organizations reporting public policy  
dialogue and development activities**

# APPENDIX A: ORGANIZATIONS REPORTING PUBLIC POLICY DIALOGUE AND DEVELOPMENT ACTIVITIES

## ALBERTA LUNG ASSOCIATION

To engage lung disease patients, care givers and medical representatives to inform and educate government about the issues facing Albertans with lung disease and their families. By developing relationships and informing key political representatives who have oversight for research funding, supporting early detection efforts and providing additional support and treatment options for patients with lung diseases. Our efforts seek to keep these issues top of mind for those key decision makers in government.

## ALLERGIES QUÉBEC / ALLERGY QUÉBEC

Travail effectué pour la conception d'un projet de loi encadrant la prise en charge des étudiants allergiques. Ceci est en lien avec la mission de promouvoir la sécurité et améliorer la qualité de vie de ceux et celles avec des allergies alimentaires. et sensibiliser à ce problème de santé publique.

## ALZHEIMER SOCIETY OF B.C.

The Alzheimer Society of B.C. works in partnership with the Government of B.C. to fund and deliver First Link® dementia support, a referral program for healthcare providers and care partners to connect people affected by dementia to the Society's support services. Quarterly data reports on First Link® are provided to the Ministry of Health and regional health authorities. On occasion, the Society meets with B.C. MLAs to inform them about the healthcare and social needs of people living with dementia and their care partners. At the request of MLAs, the Society will also present information about dementia at the B.C. Legislature and at public constituency events. A Society web-based guide provides information to people affected by dementia about how to inform their MLA about their experience with the disease. The Society liaises with staff from the Ministry of Health in respect of Ministry Policy initiatives affecting people with dementia and their care partners. The Society submits reports when invited, to Legislative Committees such as Finance and Health.

## ALZHEIMER SOCIETY OF CANADA

In fiscal 2018-19 the Alzheimer Society of Canada's political activities with the Government of Canada were largely focused on development of the national dementia strategy and funding in federal Budget 2019 to support

its implementation. This pan-Canadian strategy will increase awareness, scale up best practices and introduce measures which address stigma. The specific activities included meetings and communications with the Ministers of Health, Finance and Seniors, Members of Parliament, Senators, and with senior officials at the Public Health Agency of Canada and Department of Finance. Representations were also made to the Government on legislative and policy issues associated with the Accessible Canada Act, Genetic Non-Discrimination Act and Framework on Palliative Care.

#### ALZHEIMER SOCIETY OF MANITOBA INC.

Wrote letters to government organizations advocating for persons with dementia and their family care providers. Meet and communicate with elected officials and senior government advisors.

#### ALZHEIMER SOCIETY OF SIMCOE COUNTY

The Alzheimer Society of Simcoe County shared information with the public and local MPPs about the impact of Alzheimer's disease and other dementias on the people of Ontario, and issued a call to action to support continued investments in dementia care and supports. This activity relates to the organization's goal to improve the quality of life of persons who are directly affected by dementia.

#### AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA

ALS Canada is responsible for the national ALS research program, federal advocacy and directly responsible for support and services for people affected by ALS in Ontario. Aligned with the mission, ALS Canada advocated to the federal government to increase awareness of ALS and the needs of Canadians and their families living with this terminal disease, ALS specific research funding, and issues relating to access for emerging therapies. Within Ontario, advocacy efforts were also undertaken for these issues as well as access to non-invasive ventilation in long-term care facilities.

#### ASSOCIATION DES PERSONNES HANDICAPEES VISUELLES DU BAS ST-LAURENT

Participation aux comités consultatifs pour l'accessibilité des services publics et privés aux personnes handicapées visuelles

#### ASTHMA CANADA

As a member of the Clean Economy Alliance, Asthma Canada, along with 60 other member organizations signed onto a letter addressed to Ontario's Minister of the Environment, Conservation and Parks, calling for an effective plan to deal with climate change in Ontario and

fought against a roll-back to existing climate change initiatives. We also participated in the development of the provincial Make It Better Campaign, which is focused on building a unified approach to children's health and climate change in Ontario. We continued our letter writing campaign on national pharmacare, streamlining our submission platform and publishing community letters. This campaign gives members of the asthma community the opportunity to get involved by sending letters to their government representatives on the impacts of OHIP + and the new Ontario Lung Act. Working alongside other key stakeholders, we successfully played a role in getting valved-holding chambers covered for those aged 12 and under. As a chronic disease with no cure, having varied and innovative treatment options available is vital to ensuring that all Canadians are able to control their asthma. This year, we made submissions to both CADTH (Canada's national drug review body) and British Columbia's Pharmacare Review in support of the biologic treatment benralizumab (Fasenra). Asthma Canada responded to a CADTH Request for Advice regarding all currently available biologic medications used to treat severe eosinophilic asthma. We made a number of recommendations regarding criteria for eosinophil levels, reversibility, and on preventing wastage, ensuring patient and physician choice, age indications, ensuring equal access throughout Canada and ensuring that those with asthma who smoke are not disqualified from accessing required treatments. We also made another submission to British Columbia's Pharmacare Review for Aermony Respiclick and Arbesda Respiat. By making submissions to CADTH and provincial drug review bodies, we work to ensure that patient input is taken into consideration when new treatments are being reviewed, helping improve access and advocating for increased treatment coverage.

#### AUTISM SOCIETY ONTARIO

Participation by invitation at meetings with various Government of Ontario committees (working groups, legislative committees, etc.) dealing specifically with government programs or policies that affect ASD and/or their families. Writing responses papers to requests for input on relevant government initiatives with ASD. Topics include: housing, education, Disability Tax Credit and RDSPs/ Also responding to media requests for input on ASD public policy matters and to actively promote our work and participation on these matters. Providing non-partisan resources for voters to inform them on ASD related matters when speaking with local candidates during election times.

#### AUTISME DE L'EST-DU-QUÉBEC

L'organisme effectue de la représentation et de la défense des droits avec d'autres organismes communautaires. Aussi, par la sensibilisation et l'information, il défend les droits des personnes ayant un TSA ainsi que leurs familles.



## CANADIAN CANCER SOCIETY

The Canadian Cancer Society (CCS) supports healthy public policy at all levels of government (including federal, provincial, territorial, municipal, First Nations and Internationally) to advance the CCS mission to eradicate cancer and to improve the lives of people living with cancer, CCS advocates to advance its mission on issues such as asbestos, indoor tanning, tobacco control, healthy eating, physical activity, radon, occupational and environmental exposure to carcinogens, access to drugs, access to treatment/health care, support for family caregivers, palliative and end of life care, cancer control strategies, research funding, lottery regulation, charitable tax credits, and others. As appropriate, CCS advocates internationally such as on matters related to the WHO Framework Convention on Tobacco Control and the UN High Level Declaration on Non-Communicable Diseases.

## CANADIAN CANCER SURVIVOR NETWORK

CCSN is established to advance education by organizing and participating in conferences and speaking engagements to the public on topics related to cancer. These included: A Federal Legislative Reception on June 2018 to raise awareness on immunotherapy for cancer treatments. Ontario Legislative Reception on October 2018 to raise awareness on biologics and biosimilars and patient choice. The legislative reception is a non-partisan activity with speakers including patients, oncologists, members of every party, and members of several cancer organizations. An All-party Cancer Caucus in the Ontario legislature on March and November 2018, as well as an All-party Cancer Caucus in the Alberta legislature on May 2018. Both cancer caucuses provided education on the use of cancer rehabilitation for patients and survivors. The caucus is a non-partisan activity with speakers including patients, survivors, and members of every party. To undertake activities ancillary and incidental to the attainment of CCSN's charitable purposes CCSN organizes questions on priority issues of cancer patients and survivors, sent to every candidate of every party in federal and provincial elections, and the answers are posted on the CCSN website.

## CANADIAN DIABETES ASSOCIATION

We routinely engage in a non-partisan fashion in methods such as those listed below to educate policy and decision makers about the burden that diabetes imposes on people with the disease, our economy, healthcare system, government and potential measure to address this.

## CHILDHOOD OBESITY FOUNDATION (COF)

Marketing to Kids: The World Health Organization and health organizations worldwide are leading efforts to ensure children everywhere are protected against food and beverage marketing. The

Stop Marketing for Kids (Stop M2K!) Coalition, founded by the Heart and Stroke Foundation in collaboration with the Childhood Obesity Foundation, recommends restricting the commercial marketing of all food and beverages to children and youth age 16 years and younger. This policy recommendation aligns with Childhood Obesity Foundation's mission to lead a societal shift toward healthy eating and active lifestyles to promote childhood healthy weights and the resulting physical and emotional benefits. We have not made any gifts to qualified donees intended for political purposes.

Reduction of Sugary Drinks: The Rethink Sugary Drinks Coalition is a provincial coalition co-led by the Childhood Obesity Foundation and BC Alliance for Healthy Living. The mission of this coalition is to work collaboratively to oversee the development and implementation of a multi-pronged approach to decrease sugary drinks consumption in BC. The Childhood Obesity Foundation also participates on a national working group of stakeholders who work together to decrease sugary drink consumption across Canada. There is a strong scientific consensus that excessive Sugary Sweetened Beverage (SSB) intake is a major risk factor for the development of unhealthy weights. As such, a primary goal of both of these groups is to advocate for a tax on sugary drinks. This policy recommendation aligns with the Childhood Obesity Foundation's mission to lead a societal shift toward healthy eating and active lifestyles to promote childhood healthy weights and the resulting physical and emotional benefits. We have not made any gifts to qualified donees intended for political purposes.

#### CROHN'S AND COLITIS CANADA

1. 'No Forced Switch' Campaign Crohn's and Colitis Canada encouraged its patient community to engage in the organization's digital letter-writing tool to voice their concerns to their provincial representative and Minister of Health regarding a considered, but not yet formally proposed, Ministry of Health policy to switch Crohn's or colitis patients currently stable on a biologic to a biosimilar.
2. 'Increase Washroom Access' Campaign Crohn's and Colitis Canada encouraged its patient community to engage in the organization's digital letter-writing tool to ask their federal representative and the federal Minister of Persons with Disabilities to ensure that washroom access within federal government buildings would be included in the upcoming Canadians with Disabilities Act. These activities align with our Mission which includes a statement indicating that Crohn's and Colitis Canada will raise funds to advocate to governments and stakeholders on behalf of those affected by Crohn's and colitis.

#### CYSTIC FIBROSIS CANADA

The charity's political activities were primarily focused on advocating for (1) cystic fibrosis newborn screening in Quebec, and (2) access to medicines

to treat cystic fibrosis. Other activities included payments to organizations that support the charity's advocacy, public policy and government relations priorities. These organizations include the Health Charities Coalition of Canada, Research Canada, the Public Policy Forum and the C.D. Howe Institute Health Policy Council. Throughout the year, the charity's program expenditures included public service announcements and news releases related to advocacy priorities. Cystic Fibrosis Canada's mission is to end cystic fibrosis (CF). We will help all people living with CF by funding targeted world-class research, supporting and advocating for high-quality individualized CF care and raising and allocating funds for these purposes.

#### EATING DISORDER FOUNDATION OF NL INC.

Our political activity relates to communication with the provincial government and regional health authorities to ensure eating disorder services are in place. We also lobby government to increase grants to us to allow us to offer our programs & services.

#### HEART AND STROKE FOUNDATION OF CANADA

- Calling on elected officials to support and complete the federal healthy eating strategy. As diet is a significant risk factor for heart disease stroke and other co-morbidities, these asks are directly related to our charitable purpose of preventing disease. We asked elected officials to achieve this by -including restrictions on food and beverage marketing to children (bill s-228) -complete cg2 for front-of-package nutrition labeling; invest in a healthy eating initiative such as a school nutrition program -coordinate action on restaurant menu labeling.
- Calling on elected officials for an interim order and strong regulations on vaping. This is directly related to our charitable purpose of preventing disease.
- Calling on elected officials to support a universal national pharmacare program.
- Calling on elected officials to renew and augment funding for heart & stroke's federally funded "advancing women's heart & brain health initiative".
- Calling on elected officials to ensure that sex and gender-based analysis and reporting are required for all federally-funded health research.
- Calling on elected officials to prevent death from cardiac arrest by - investing in a public awareness campaign - promoting placement of defibrillators in areas under federal jurisdiction - engage with indigenous organizations and leaders to facilitate discussions on cardiac arrest rates among indigenous people with the goal of improving resuscitation outcomes.

- Calling on elected officials to address dementia by implementing a national strategy to address dementia in order to facilitate these calls to action, our activities included the following tactics:
  - Media releases and advertisements
  - Op-eds
  - Reception for elected officials on parliament hill focusing on women's health
  - Letter writing campaign, electronic
  - Social media promotion
  - Collaborating with partners/stakeholders
  - Meetings with mps and other government/public officials
  - Surveying political parties leading up to the general election regarding their stance on various issues key to our charitable mission. - Posting all responses on our website in a non-partisan manner.

#### HUNTINGTON SOCIETY OF CANADA

HSC advocates for genetic fairness on behalf of Canadians living with Huntington disease. HSC advocates at both the Federal and Provincial levels of government to end discrimination and create a safe environment for people to participate in genetic testing and to benefit from their own genetic information without being discriminated against because of it.

#### JUVENILE DIABETES RESEARCH FOUNDATION CANADA

JDRF is committed to delivering a cure for Type 1 Diabetes (T1D) and its complications through the support of research. To this end, we engage directly with federal and provincial representatives and encourage our supporters to do the same to raise awareness about the financial and human costs of the disease-for our health care system and the people who live with it in order to make the case that these may be reduced through investment in research aimed at curing, preventing and treating the disease. Political outreach in 2018, included direct outreach by staff, volunteer board members and a two-day lobbying event Kids for a Cure Lobby Day where youth delegates and their parents travelled to Ottawa for the purposes of meeting with Members of Parliament and Senators. The purpose of this activity was to secure renewed federal funding for research undertaken by the JDRF Canadian Clinical Trial Network. All engagement undertaken was strictly non-partisan and using the methods set out below in Section 2.

#### MULTIPLE SCLEROSIS SOCIETY OF CANADA

The goal of government relations and advocacy is to support the mission of the MS Society of Canada by advocating for improvements to governmental policies and legislation and relevant non-governmental practices, actions and attitudes. These non-partisan efforts are designed

to increase responsiveness that will deliver meaningful benefit to the greatest possible number of primary clients and are likely to be successful. The MS Society is focused on ensuring Canadians living with MS and their families have the opportunity to participate fully in all aspects of life. We are advocating for policy changes that: Improve income and employment security; and enhance access (accessibility legislation, access to treatments, and comprehensive home care); and accelerate research.

#### NEW BRUNSWICK LUNG ASSOCIATION INC.

Met with NB Minister of Health regarding Lung Transplant Program. Met with NB Minister of Environment on woodstove smoke issues and electric vehicles. With partners, prepared a white paper of recommendations for B26 Chemical Management Program, are presented that to Health Canada. Total time spent on advocacy = 15 days.

#### ONTARIO LUNG ASSOCIATION

1. Meetings with elected officials and their staff.
2. Letter writing campaigns aimed at MPP's.
3. Asking supporters to sign a petition.
4. Meet with Ministry officials. To support legislation and programs that will improve lung health and prevent lung disease.

#### OTTAWA REGIONAL CANCER FOUNDATION

During the fiscal year, the Charity's political activities were focused on building strategic relationships at the provincial and federal levels of government in order to identify additional funding opportunities to further the Charity's ability to provide non-medical programming to meet cancer patients' survivorship needs. Additionally the Charity sought to highlight the struggles faced by cancer patients to galvanize members of government to provide funding for a cancer coaching pilot to help support these individuals.

#### OVARIAN CANCER CANADA

Ovarian Cancer Canada conducted activities to raise awareness of elected federal and provincial representative for the need of:

1. Funding for ovarian cancer research
2. Funding for new ovarian cancer treatment

#### PARKINSON CANADA INC.

Parkinson Canada's advocacy activities reflects the priorities of the Parkinson's community and includes working with all levels of government on federal and pan-Canadian initiatives, mobilizing members of the Parkinson's community to effect positive change, and raising awareness

about Parkinson's disease. Through these efforts, Parkinson Canada is working to improve the quality of life of people living with Parkinson's, increase support for caregivers, protect people affected by Parkinson's from poverty and increase funding for neurodegenerative research to improve treatment and help find a cure.

#### PARKINSON QUÉBEC

Participation à une table de réflexion sur les besoins et enjeux des personnes qui vivent avec une maladie neurologique évolutive et préparation d'un mémoire commun, dans le cadre des Partenaires Neuro. Les << Partenaires Neuro >> regroupent 5 organismes sans but lucratif dédiés à la recherche et au soutien des personnes atteintes d'une maladie neurologique ou neuromusculaire évolutive. Les membres de ce regroupement sont:

- Fédération québécoise des Sociétés Alzheimer;
- Société canadienne de la sclérose en plaques, division du Québec;
- La Société SLA du Québec; -Parkinson Québec;
- Dystrophie musculaire Canada.

Préparation d'une représentation à l'Assemblée nationale qui s'est tenue le 27 février 2019 Présentation d'une proposition de formation aux personnels du réseau de la santé, au Ministère de la Santé et Services Sociaux.

#### PROSTATE CANCER CANADA

Prostate Cancer Canada is the champion for the cause of prostate cancer, ensuring that governments across the country provide Canadian men with equitable and timely access to testing and therapies. We support healthy public policy at all levels of government.

#### PULMONARY HYPERTENSION ASSOCIATION OF CANADA

Lead a public awareness campaign to encourage provincial drug plans to provide reimbursement for new treatment options for pulmonary hypertension.

#### RETHINK BREAST CANCER CANADA

Rethink advocated for continuing monitoring of the pan-Canadian Pharmaceutical Alliance (pCPA) set of crucial benchmarks that improve transparency and timelines when negotiating the price of cancer medications. This involved a media campaign and social media campaign of blog posts, tweets and Facebook posts. We brought a group of young breast cancer patients and advocates to fill the gallery during Question Period at Queen's Park in October. Rethink organized a workshop for

young women with metastatic breast cancer to gather feedback and input on patient values and the role patient values play in health Technology Assessment. These activities were related to our charitable purpose of fighting breast cancer through supporting young women concerned about or affected by breast cancer in Canada.

#### SOCIÉTÉ CANADIENNE DE LA SCLÉROSE EN PLAQUES (DIVISION DU QUÉBEC)

Nos efforts dans le domaine des relations avec les gouvernements et de la défense des droits et des intérêts ont pour but de soutenir la mission de la Société canadienne de la SP grâce à la promotion d'améliorations portant sur des politiques gouvernementales et des lois ainsi que sur des pratiques, des actions et des positions non gouvernementales pertinentes. Ces activités non partisans visent à accroître la réceptivité des gouvernements, des autorités locales, des entreprises et d'autres organismes concernés relativement aux questions d'intérêt en lien avec la Société de la SP. Dans le domaine de la défense des droits et des intérêts, la Société de la SP s'affaire essentiellement à obtenir des résultats qui profiteront concrètement au plus grand nombre possible de personnes atteintes de SP en menant des activités qui sont conçues en fonction de leurs chances de succès. Selon les réponses reçues à l'occasion d'un sondage d'envergure mené auprès des Canadiens touchés par la SP, l'organisme a déterminé les domaines d'intervention suivants: sécurité de l'emploi et du revenu, soutien aux proches aidants, mise en place d'un système coordonné de soins et de soutien continu, recherche sur la SP progressive, hébergement adapté, financement des cliniques de SP, accès aux médicaments.

#### THE ARTHRITIS SOCIETY

The issues focused on relate to ensure that arthritis patients have timely access to the care they need, to maintain medical cannabis access for patients, implementation of an allied health professional support program, supporting policy decision-making for the introduction of biosimilars, and advocating for shorter wait times for joint replacement surgeries. We have been focused on educating and engaging the public on the issues, providing tools for them to share their views and communicate with political candidates and officials and formal submissions to government.

#### THE KIDNEY FOUNDATION OF CANADA

- a. Supported Bill 222 - an amendment to the Human Rights Code re: Genetic Characteristics (Genetic Discrimination)
- b. Volunteers and staff presented to the government's special committee on Organ Donation

#### THE LUNG ASSOCIATION OF SASKATCHEWAN INC.

Advocacy to all local levels of government for Outdoor Smoke Free Spaces, Smoke Free Social Housing and changes to the Sleep Apnea program. Outdoor smoke free spaces and smoke free social housing will reduce exposure to tobacco and improve respiratory health. Ensuring access to CPAP machines for individuals with Sleep Apnea falls into our charitable purposes of respiratory health. The Lung Association, Saskatchewan has developed a Provincial Lung Health Alliance partnering with industry, members of the public and the Saskatchewan government to develop Lung Health Strategy for the province of Saskatchewan.





# Appendix B:

**Spending on public policy activities  
of every reporting organization**

## APPENDIX B: SPENDING ON PUBLIC POLICY ACTIVITIES OF EVERY REPORTING ORGANIZATION

Canadian Cancer Society / Société Canadienne du Cancer	\$1,728,226
Canadian Diabetes Association / Association Canadienne du Diabète	\$801,686
Parkinson Canada Inc.	\$344,181
Amyotrophic Lateral Sclerosis Society of Canada / Société Canadienne de la Sclérose Latérale Amyotrophique	\$326,196
Juvenile Diabetes Research Foundation Canada / Fondation de la Recherche sur le Diabète Juvenile Canada	\$318,674
Heart and Stroke Foundation of Canada / Fondation des Maladies du Cœur et de L' AVC du Canada	\$279,000
Alzheimer Society of Canada / Societe Alzheimer du Canada	\$192,103
Rethink Breast Cancer Canada	\$149,285
The Arthritis Society / La Societe D'arthrite	\$148,327
Cystic Fibrosis Canada / Fibrose Kystique Canada	\$147,656
Ovarian Cancer Canada / Cancer de L'ovaire Canada	\$139,772
Childhood Obesity Foundation (COF)	\$86,207
Société Canadienne de la Sclérose en Plaques (Division du Québec)	\$73,154
Huntington Society of Canada	\$60,351
Ottawa Regional Cancer Foundation / Fondation du Cancer de la Region D'ottawa	\$59,307
Canadian Cancer Survivor Network	\$51,423
Allergies Québec / Allergy Québec	\$43,058
Alberta Lung Association	\$36,855
Prostate Cancer Canada	\$34,052
Ontario Lung Association	\$33,478
Crohn's and Colitis Canada / Crohn et Colite Canada	\$31,131
Alzheimer Society of B.C.	\$17,019
The Lung Association of Saskatchewan Inc.	\$9,463
Autism Society Ontario	\$6,163
Asthma Society of Canada	\$5,428

New Brunswick Lung Association Inc. / Association Pulmonaire du Nouveau Brunswick Inc.	\$3,866
Mouvement Santé Mentale Québec	\$2,963
Pulmonary Hypertension Association of Canada	\$2,444
Association des Personnes Handicapées Visuelles du Bas Saint-Laurent	\$2,000
Alzheimer Society of Manitoba Inc.	\$1,500
Parkinson Québec	\$1,000



# Appendix C:

**Disease specific non-profit groups  
without charitable registration**

## APPENDIX C: DISEASE SPECIFIC NON- PROFIT GROUPS WITHOUT CHARITABLE REGISTRATION

- Acne and Rosacea Society of Canada
- Action Hepatitis Canada
- ACTION Ontario for People with Neuropathic Pain
- aHUS Canada
- Alberta Community Council on HIV
- Alberta Society of Melanoma
- Alliance for Open Access to Psychiatric Medications
- Arthritis Consumer Experts
- Be the Choice
- Bladder Health BC
- Canadian Arthritis Patient Alliance
- Canadian Association of Pompe (CAP)
- Canadian Association of Psoriasis Patients (CAPP)
- Canadian Association of Scarring Alopecias
- Canadian Burn Survivors Community
- Canadian Cystic Fibrosis Treatment Society
- Canadian MPN Network
- Canadian Pituitary Tumours & Related Diseases Network (PTN)
- Canadian PKU & Allied Disorders Inc.
- Canadian Psoriasis Network
- Canadian Skin Patient Alliance
- Canadian Spondylitis Association
- Canadian Treatment Action Council
- Canadian Women with Fibroids
- Centre for ADHD Awareness Canada (CADDAC)
- Chronic Lymphocytic Leukemia Patient Advocacy Group
- Chronic Myelogenous Leukemia Society of Canada
- CLLSLL at Groups.io
- Consumer Advocare Network
- COPD Canada
- Dense Breasts Canada
- Familial Hypercholesterolemia Patient Network
- Fibromyalgia Society Of Edmonton & Area
- HAE Canada Inc.
- HS Aware
- International Federation of Aging

- Life Saving Therapies Network
- Metastatic Breast Cancer Atlantic
- Millions Missing Canada
- Olive Us Care
- Pacific Hepatitis C Network
- Prevent Cancer Now
- The Canadian CML Network
- Wounds Canada
- Coalition Priorité Cancer au Québec / Quebec Cancer Coalition
- Canadian Psychedelic Association



# Appendix D:

**The differences between a registered charity and a non-profit organization**

## APPENDIX D: THE DIFFERENCES BETWEEN A REGISTERED CHARITY AND A NON-PROFIT ORGANIZATION

We are sharing CRA's information in full on the differences between a registered charity and a non-profit organization as their descriptions are clear and concise.<sup>29</sup>

“Registered charities and non-profit organizations (NPOs) both operate on a non-profit basis, however they are not the same. This page explains the differences between them.

### Registered charities

Registered charities are charitable organizations, public foundations, or private foundations that are created and resident in Canada. They must use their resources for charitable activities and have charitable purposes that fall into one or more of the following categories:

- the relief of poverty
- the advancement of education
- the advancement of religion
- other purposes that benefit the community

### Examples of registered charities

Some examples of registered charities under each of the four categories:

- relief of poverty (food banks, soup kitchens, and low-cost housing units)
- advancement of education (colleges, universities, and research institutes)
- advancement of religion (places of worship and missionary organizations)
- purposes beneficial to the community (animal shelters, libraries, and volunteer fire departments)

#### NOTE:

If you are operating as a charity and want to issue official donation receipts and not have to pay income tax, you have to apply to be a registered charity. If you are not registered, you do not qualify for these advantages.



## Non-profit organizations

Non-profit organizations are associations, clubs, or societies that are not charities and are organized and operated exclusively for social welfare, civic improvement, pleasure, recreation, or any other purpose except profit.

### Examples of non-profit organizations

Here are a few types of non-profit organizations and examples of each:

- social, recreational, or hobby groups (bridge clubs, curling clubs, and golf clubs)
- certain amateur sports organizations (hockey associations, baseball leagues, and soccer leagues)
- certain festival organizations (parades and seasonal celebrations)

Topic	Registered charity	NPO
Purposes	<ul style="list-style-type: none"> <li>• must be established and operate exclusively for charitable purposes</li> </ul>	<ul style="list-style-type: none"> <li>• can operate for social welfare, civic improvement, pleasure, sport, recreation, or any other purpose except profit</li> <li>• cannot operate exclusively for charitable purposes</li> </ul>
Registration	<ul style="list-style-type: none"> <li>• must apply to the CRA and be approved for registration as a charity</li> </ul>	<ul style="list-style-type: none"> <li>• does not have to go through a registration process for income tax purposes</li> </ul>
Charitable registration number	<ul style="list-style-type: none"> <li>• is issued a charitable registration number once approved by the CRA</li> </ul>	<ul style="list-style-type: none"> <li>• is not issued a charitable registration number</li> </ul>
Tax receipts	<ul style="list-style-type: none"> <li>• can issue official donation receipts for income tax purposes</li> </ul>	<ul style="list-style-type: none"> <li>• cannot issue official donation receipts for income tax purposes</li> </ul>
Spending requirement (disbursement quota)	<ul style="list-style-type: none"> <li>• must spend a minimum amount on its own charitable activities or as gifts to qualified donees</li> </ul>	<ul style="list-style-type: none"> <li>• does not have a spending requirement</li> </ul>
Designation	<ul style="list-style-type: none"> <li>• is designated by the CRA as a charitable organization, a public foundation, or a private foundation</li> </ul>	<ul style="list-style-type: none"> <li>• does not receive a designation</li> </ul>
Returns	<ul style="list-style-type: none"> <li>• must file an annual information return (Form T3010) within six months of its fiscal year-end</li> </ul>	<ul style="list-style-type: none"> <li>• may have to file a T2 return (if incorporated) or an information return (Form T1044) or both within six months of its fiscal year-end</li> </ul>
Personal benefits to members	<ul style="list-style-type: none"> <li>• cannot use its income to personally benefit its members</li> </ul>	<ul style="list-style-type: none"> <li>• cannot use its income to personally benefit its members</li> </ul>

Topic	Registered charity	NPO
Tax exempt status	<ul style="list-style-type: none"> <li>• is exempt from paying income tax</li> </ul>	<ul style="list-style-type: none"> <li>• is generally exempt from paying income tax</li> <li>• may have to pay tax on property income or on capital gains</li> </ul>
GST/HST	<ul style="list-style-type: none"> <li>• generally must pay GST/HST on purchases</li> <li>• may claim a partial rebate of GST/HST paid on eligible purchases</li> <li>• most supplies made by charities are exempt</li> <li>• calculates net tax using <a href="#">the net tax calculation for charities</a></li> </ul>	<ul style="list-style-type: none"> <li>• must pay GST/HST on purchases</li> <li>• may claim a partial rebate of GST/HST paid on eligible purchases only if it receives significant government funding</li> <li>• few supplies made by NPOs are exempt</li> <li>• calculates <a href="#">net tax</a> the regular way</li> </ul>



# Appendix E:

## Program areas and field codes

# APPENDIX E: PROGRAM AREAS AND FIELD CODES<sup>30</sup>

## Social services in Canada

- A1** - Housing (seniors, low-income persons, and those with disabilities)
- A2** - Food or clothing banks, soup kitchens, hostels
- A3** - Employment preparation and training
- A4** - Legal assistance and services
- A5** - Other services for low-income persons
- A6** - Seniors' services
- A7** - Services for the physically or mentally challenged
- A8** - Children and youth services/housing
- A9** - Services for Aboriginal people
- A10** - Emergency shelter
- A11** - Family and crisis counselling, financial counselling
- A12** - Immigrant aid
- A13** - Rehabilitation of offenders
- A14** - Disaster relief

## International aid and development

- B1** - Social services (any listed under A1-A13 above)
- B2** - Infrastructure development
- B3** - Agriculture programs
- B4** - Medical services
- B5** - Literacy/education/training programs
- B6** - Disaster/war relief

## Education and research

- C1** - Scholarships, bursaries, awards
- C2** - Support of schools and education (for example, parent-teacher groups)
- C3** - Universities and colleges
- C4** - Public schools and boards
- C5** - Independent schools and boards
- C6** - Nursery programs/schools
- C7** - Vocational and technical training (not delivered by universities/colleges/schools)
- C8** - Literacy programs

- C9** - Cultural programs, including heritage languages
- C10** - Public education, other study programs
- C11** - Research (scientific, social science, medical, environmental, etc.)
- C12** - Learned societies (for example, Royal Astronomical Society of Canada)
- C13** - Youth groups (for example, Girl Guides, cadets, 4-H clubs, etc.)

## Culture and arts

- D1** - Museums, galleries, concert halls, etc.
- D2** - Festivals, performing groups, musical ensembles
- D3** - Arts schools, grants and awards for artists
- D4** - Cultural centres and associations
- D5** - Historical sites, heritage societies

## Religion

- E1** - Places of worship, congregations, parishes, dioceses, fabriques, etc.
- E2** - Missionary organizations, evangelism
- E3** - Religious publishing and broadcasting
- E4** - Seminaries and other religious colleges
- E5** - Social outreach, religious fellowship, and auxiliary organizations

## Health

- F1** - Hospitals
- F2** - Nursing homes
- F3** - Clinics
- F4** - Services for the sick
- F5** - Mental-health services and support groups
- F6** - Addiction services and support groups
- F7** - Other mutual-support groups (for example, cancer patients)
- F8** - Promotion and protection of health, including first-aid and information services
- F9** - Specialized health organizations, focusing on specific diseases/conditions

## Environment

- G1** - Nature, habitat conservation groups
- G2** - Preservation of species, wildlife protection
- G3** - General environmental protection, recycling services

## Other community benefits

- H1** - Agricultural and horticultural societies
- H2** - Welfare of domestic animals
- H3** - Parks, botanical gardens, zoos, aquariums, etc.
- H4** - Community recreation facilities, trails, etc.
- H5** - Community halls
- H6** - Libraries
- H7** - Cemeteries
- H8** - Summer camps
- H9** - Day care/after-school care
- H10** - Crime prevention, public safety, preservation of law and order
- H11** - Ambulance, fire, rescue, and other emergency services
- H12** - Human rights
- H13** - Mediation services
- H14** - Consumer protection
- H15** - Support and services for charitable sector

## Other

- I1** - Write a description if this category applies



# Appendix F:

**Patient-focused charities included  
in the report**

# APPENDIX F: PATIENT-FOCUSED CHARITIES INCLUDED IN THE REPORT

- “Stop Diabetes” Foundation Inc.
- “Women Alike” (Breast Cancer Survivors) Society
- A Port in the Storm Inc.
- A.C.P.D. - Action Committee of People with Disabilities Society
- Aaron’s Apple Inc.
- Aboutface Craniofacial Family Society
- Abreast in the Rockies Dragonboat Assoc.
- Acoustic Neuroma Association of Canada
- Action Autisme
- Action CIND
- Adam’s Hope (A Quinte Learning Resource for Children with Autism)
- Adhd Association of Greater Edmonton
- Advanced Coronary Treatment (Act) Foundation of Canada, Inc.
- Africans in Partnership Against AIDS
- AIDS Coalition of Nova Scotia
- AIDS Committee of Toronto
- AIDS Committee (Durham)
- AIDS Committee of Newfoundland and Labrador Inc.
- AIDS Committee of North Bay and Area / Comite du SIDA de North Bay et de la Region
- AIDS Committee of Thunder Bay
- AIDS Committee of Windsor
- AIDS New Brunswick Sida Nouveau-Brunswick
- AIDS Programs South Saskatchewan Inc.
- AIDS Saskatoon Inc.
- Alberta Caregivers Association
- Alberta Chapter Canadian Foundation for Poliomyelitis and RE
- Alberta Lung Association
- Alberta Lymphedema Association
- Alberta Pituitary Patient Society
- Alberta Society for the Visual Impaired Edmonton District
- Alberta Society for the Visually Impaired Calgary District
- Alberta Society of the Deaf Blind
- Allergies Québec / Allergy Québec
- Alliance for South Asian AIDS Prevention
- Alpha-1 Antitrypsin Deficiency Canada Inc.
- ALS Society of Alberta
- ALS Society of Newfoundland & Labrador Corporation
- ALS Society of Prince Edward Island Inc.
- Alstrom Syndrome Canada
- Alstrom Syndrome International Society
- Alzheimer Society Chatham-Kent
- Alzheimer Society Foundation of Brant, Haldimand Norfolk, Hamilton Halton
- Alzheimer Society Lanark Leeds Grenville
- Alzheimer Society of Alberta and Northwest Territories
- Alzheimer Society of B.C.
- Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton
- Alzheimer Society of Calgary
- Alzheimer Society of Canada / Societe Alzheimer du Canada
- Alzheimer Society of Dufferin County
- Alzheimer Society of Durham Region
- Alzheimer Society of Grey-Bruce
- Alzheimer Society of Hastings-Prince Edward
- Alzheimer Society of Huron County Incorporated
- Alzheimer Society of Kenora / Rainy River Districts
- Alzheimer Society of KFLA&A Kingston, Frontenac, Lennox and Addington
- Alzheimer Society of London and Middlesex
- Alzheimer Society of Manitoba Inc.
- Alzheimer Society of Muskoka
- Alzheimer Society of New Brunswick Inc. / Societe Alzheimer de Nouveau Brunswick Inc.
- Alzheimer Society of Newfoundland and Labrador, Inc
- Alzheimer Society of Niagara Region
- Alzheimer Society of Nova Scotia
- Alzheimer Society of Oxford
- Alzheimer Society of PEI Ltd



- Alzheimer Society of Perth County
- Alzheimer Society of Peterborough, Kawartha Lakes, Northumberland and Haliburton
- Alzheimer Society of Sarnia-Lambton
- Alzheimer Society of Saskatchewan Inc
- Alzheimer Society of Simcoe County
- Alzheimer Society of Thunder Bay
- Alzheimer Society of Timmins-Porcupine District Inc.
- Alzheimer Society of Toronto
- Alzheimer Society of Windsor and Essex County
- Alzheimer Society of York Region
- Alzheimer Society Sudbury-Manitoulin North Bay & Société Alzheimer Sudbury-Manitoulin North Bay et Districts
- Alzheimer Society Waterloo Wellington
- Alzheimer / Society of Cornwall & District / Societe Alzheimer de Cornwall et Region
- Amberheart Cancer Foundation
- Amicale des Diabétiques du Chum
- Amyotrophic Lateral Sclerosis Society of BC
- Amyotrophic Lateral Sclerosis Society of Canada / Société Canadienne de la Sclérose Latérale Amyotrophique
- Amyotrophic Lateral Sclerosis Society of Essex County
- Amyotrophic Lateral Sclerosis Society of New Brunswick and Nova Scotia
- Angel Flight of British Columbia Society
- Angels & Friends Foundation Corporation
- Angioma Alliance Canada
- Ankors - AIDS Network Outreach and Support Society
- Anorexie et Boulimie Québec
- Aphasia Association of Nova Scotia
- Aphasia Centre of Ottawa Carleton
- Aphasia Institute
- Aphasie Rive-Sud
- Aplastic Anemia and Myelodysplasia Association of Canada / Association Canadienne de L'Anémie Aplasique et de la Myélodysplasie
- Armstrong Spallumcheen Medical Equipment Loan Cupboard Society
- Art for Cancer Foundation
- Asian Canadian Cancer Fellowship Association
- Asperger Manitoba Inc.
- Asperger's Society of Ontario
- Association Canadienne de Myelite Transverse / The Canadian Transverse Myelitis Association
- Association Canadienne des Ataxies Familiales
- Association D'anémie Falciforme du Québec
- Association de Fibromyalgie du Bas-Richelieu
- Association de Fibromyalgie et du Syndrome de Fatigue Chronique de Vaudreuil-Soulanges
- Association de Fibromyalgie Région de Quebec
- Association de la Fibromyalgie (Fibrosite) du Saguenay-Lac-St-Jean
- Association de la Fibromyalgie Arthabaska-Érable
- Association de la Fibromyalgie des Laurentides
- Association de la Fibromyalgie et de la Fatigue Chronique de Manicouagan et La Haute Cote-Nord Inc.
- Association de la Fibromyalgie Mauricie / Centre-Du-Quebec
- Association de la Fibromyalgie Region Chaudiere-Appalaches
- Association de la Fibromyalgie Région Ile-De-Montreal
- Association de la Fibromyalgie Région Montérégie
- Association de Spina Bifida et D'hydrocéphalie de L'estrie Inc.
- Association D'entraide D'arthrite de L'Ouest de L'ile de Montreal Inc.
- Association des Arthritiques du Saguenay Lac St-Jean
- Association des Implantés Cochléaires du Québec
- Association des Personnes Aphasiques de la Mauricie et du Centre-Du-Québec (APAMCQ)
- Association des Personnes Aphasiques du Richelieu-Yamaska
- Association des Personnes Aphasiques Granby-Région
- Association des Personnes Handicapees Visuelles du Bas St-Laurent
- Association des Personnes Intéressées à L'Aphasie et à L'Accident Vasculaire Cérébral (A.P.I.A.-A.V.C.)
- Association des Personnes Vivant Avec La Douleur Chronique
- Association des Personnes Vivant Avec Une Surdit   de Laval

- Association des Stomises de la Mauricie
- Association des Stomises de Richelieu-Yamaska
- Association des Stomises du Grang-Portage (A S G P)
- Association des Traumatismes Cranio-Cerebraux de la Mont.
- Association du Diabete du Quebec Inc
- Association du Diabète Laval, Laurentides Inc.
- Association du Quebec pour Enfants Avec Problemes Auditifs
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Abitibi-Temiscamingue (08) Inc
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Estrie (05) Inc
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Lac Saint-Jean (02 Est) Inc
- Association du Québec pour Enfants Avec Problèmes Auditifs (A.Q.E.P.A.) Montréal Régional (06-13-14-15-16) Inc.
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Bas St-Laurent (01) Inc.
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Quebec Metro (03-12) Inc.
- Association du Quebec pour Enfants Avec Problemes Auditifs (A.Q.E.P.A.) Saguenay (02 Ouest) Inc.
- Association du Québec pour Enfants Avec Problemes Auditifs Mauricie-Centre-Du-Québec Inc.
- Association du Syndrome de Sjogren Inc. / Sjogren's Syndrome Association Inc.
- Association du Syndrome de Usher du Québec
- Association Epilepsie-Estrie Inc
- Association Fibromyalgie de Duplessis
- Association Paralysie Cerebrale Reg Mauricie Centre Quebec
- Association Pulmonaire du Québec Québec Lung Association
- Association Quebecoise de la Dysphasie Region Saguenay Lac- Saint-Jean
- Association Québécoise de la Dysphasie, Région Montérégie
- Association Québécoise de la Maladie de Lyme
- Association Quebecoise de L'encephalomyelite Myalgique
- Association Quebecoise de L'epilepsie
- Association Québécoise de Sport pour Paralytiques Cérébraux
- Association Quebecoise des Personnes Aphasiques
- Association Quebecoise des Personnes Stomisees
- Association Québécoise du Lymphodème / Lymphedema Association of Québec
- Association Quebecoise du Syndrome de Rett
- Association Quebecoise pour Les Enfants Dyspraxiques (AQED)
- Association Régionale de la Fibromyalgie de Lanaudière
- Association Regionale pour Personnes Epileptiques (Region 02)
- Association Renaissance des Personnes Traumatisees
- Craniennes du Saguenay-Lac-St-Jean
- Association Sclérose en Plaques de Lanaudière
- Association Sportive des Sourds du Québec Inc.
- Asthma Canada / Asthme Canada
- Ataxia Telangiectasia Children's Project (Canada)
- Au Sein des Femmes Québec
- Autism Aspergers Friendship Society of Calgary
- Autism Community
- Autism Connections Fredericton Inc.
- Autism Dog Services Inc.
- Autism Home Base Durham Inc.
- Autism Resource Centre Inc.
- Autism Resource Centre Inc.
- Autism Resources Miramichi Inc.
- Autism Services of Saskatoon Inc.
- Autism Society Alberta
- Autism Society Canada / Société Canadienne de L'Autisme
- Autism Society Manitoba Inc.
- Autism Society Nova Scotia
- Autism Society of Edmonton Area
- Autism Society of Newfoundland and Labrador Inc.
- Autism Society Ontario
- Autism Society P.E.I. Inc.
- Autism Yukon
- Autisme - Centre du Québec
- Autisme de L'Est-du-Québec
- Autisme Montérégie

- Autisme Sans Limites / Autism Without Limits
- Avalon Dragon Boating Inc.
- AVC-Aphasie Laval
- Baluchon Alzheimer
- Barth Syndrome Foundation of Canada
- Battlefords Society for Autism, Inc.
- Bc Ataxia Society
- Believe in the Gold
- Benign Essential Blepharospasm Canadian Research Foundation Inc
- Bladder Cancer Canada
- Blind Beginnings Society
- Blind Sailing Association of Canada
- Braille Literacy Canada / Littérature Braille Canada
- Brain Injury Association (Sudbury & District)
- Brain Injury Association of Durham Region
- Brain Injury Association of London and Region
- Brain Injury Association of Niagara
- Brain Injury Association of North Bay and Area
- Brain Injury Association of Sault Ste-Marie and District
- Brain Injury Association of the Ottawa Valley / Association des Neurotraumatisés Crâniens de la Région D'Ottawa
- Brain Injury Association of Thunder Bay and Area
- Brain Injury Association of Windsor and Essex County
- Brain Injury Association of York Region Inc.
- Brain Injury Association Quinte District
- Brain Injury Association Sarnia-Lambton
- Brain Injury Association Waterloo-Wellington
- Brain Injury Canada / Lésion Cérébrale Canada
- Brain Injury Community Reentry (Niagara) Inc
- Brain Injury Services of Northern Ontario
- Brain Injury Services of Simcoe County Inc
- Brain Injury Society of Toronto Inc.
- Brain Tumour Foundation of Canada
- Brantford & District Ostomy Association
- Breast Cancer Action Kingston
- Breast Cancer Action Manitoba Inc
- Breast Cancer Action Sensibilisation au Cancer du Sein
- Breast Cancer Support Fund
- Breast Cancer Supportive Care Foundation
- Breast Friends Society of Edmonton
- Breast Quest Dragon Boat Society
- Breaststrokes
- Bridgepoint Center Inc.
- British Columbia Autism Foundation
- British Columbia Brain Injury Association
- British Columbia Epilepsy Society
- British Columbia Lung Association
- British Columbia Lymphedema Association
- British Columbia Transplant Society Branch
- Bulimia Anorexia Nervosa Association-Can-Am
- Bursary of Hope for Autism
- Calgary (Alberta) Neuropathy Association
- Calgary Cerebral Palsy Association
- Calgary Dolphins Swim Club
- Calgary Ostomy Society
- Callanish Healing Retreats Society
- Camp Circle O'Friends Inc.
- Camp Oki
- Canadian AIDS Society / La Société Canadienne du Sida
- Canadian Alopecia Areata Foundation
- Canadian Amyloidosis Support Network, Inc.
- Canadian Angelman Syndrome Society
- Canadian Association for Porphyria Inc. / Association Canadienne de Porphyrie Inc.
- Canadian Blind Hockey
- Canadian Breast Cancer Network
- Canadian Cancer Society / Société Canadienne du Cancer
- Canadian Cancer Survivor Network
- Canadian Celiac Association - Regina Chapter
- Canadian Celiac Association - Saint John Chapter
- Canadian Celiac Association - British Columbia
- Canadian Celiac Association - Edmonton Chapter
- Canadian Celiac Association - Kelowna Chapter
- Canadian Celiac Association - Nova Scotia Chapter
- Canadian Celiac Association - Toronto Chapter

- Canadian Celiac Association, L'Association Canadienne de la Maladie Coeliaque - Calgary Chapter
- Canadian Celiac Association - Thunder Bay Chapter
- Canadian Celiac Association / L'Association Canadienne de la Maladie Coeliaque
- Canadian Celiac Association - Victoria Chapter
- Canadian Chapter of Batten's Disease Support and Research Association
- Canadian Chiari Association
- Canadian Congenital Heart Alliance
- Canadian Continence Foundation
- Canadian Council of the Blind Alberta Division
- Canadian Council of the Blind B.C. - Yukon Division
- Canadian Deafblind Association - Alberta Chapter
- Canadian Deafblind Association
- Canadian Deafblind Association - BC Chapter (CDBA-BC)
- Canadian Deafblind Association - New Brunswick Inc.
- Canadian Deafblind Association - Saskatchewan Chapter Inc.
- Canadian Diabetes Association / Association Canadienne du Diabète
- Canadian Digestive Health Foundation / Fondation Canadienne pour La Promotion de la Santé Digestive
- Canadian Down Syndrome Society
- Canadian Dupuytren Society / Société Canadienne de Dupuytren
- Canadian Epilepsy Alliance / Alliance Canadienne de L'épilepsie
- Canadian Fanconi Anemia Research Fund /
- Canadian Federation of the Blind
- Canadian Foundation for Trauma Research and Education Inc. / Fondation Canadienne pour la Recherche et L'éducation sur le Traumatisme Inc.
- Canadian Friends of Larger Than Life
- Canadian Hard of Hearing Association
- Canadian Hard of Hearing Association - Calgary
- Canadian Hard of Hearing Association - Newfoundland and Labrador Inc.
- Canadian Hard of Hearing Association - Regina and District Branch Inc.
- Canadian Hard of Hearing Association - Sudbury Branch
- Canadian Hard of Hearing Association - Manitoba Chapter
- Canadian Hard of Hearing Association - National Capital Region
- Canadian Hard of Hearing Association New Brunswick Chapter
- Canadian Hard of Hearing Association Yellowknife Branch
- Canadian Hard of Hearing Association, Hamilton Branch
- Canadian Hard of Hearing Association- Edmonton Branch
- Canadian Hard of Hearing Association - North Shore Branch
- Canadian Hemochromatosis Society / Societe Canadienne de L'Hemochromatose
- Canadian Hemophilia Society - Societe Canadienne de L'Hemophilie
- Canadian Hemophilia Society, Manitoba Chapter Inc.
- Canadian Hemophilia Society, B.C. Chapter
- Canadian Immunodeficiencies Patient Organization / Organisation Canadienne des Personnes Imminodeficientes
- Canadian League Against Epilepsy
- Canadian Liver Foundation
- Canadian Lung Association - Association Pulmonaire du Canada
- Canadian Lyme Disease Foundation
- Canadian Lymphedema Framework
- Canadian National Autism Foundation
- Canadian Organization for Rare Disorders (CORD)
- Canadian Osteogenesis Imperfecta Society
- Canadian Pbc Society
- Canadian Pulmonary Fibrosis Foundation
- Canadian Retinoblastoma Society / La Societe Canadienne du Retinoblasotme
- Canadian Skin Cancer Foundation
- Canadian Spinal Research Organization
- Canadian Transplant Society
- Canadian Vhl Alliance
- Cancer Assistance Program City of Hamilton & District
- Cancer Assistance Services of Halton Hills
- Cancer Driveline Society
- Cancer Fermont

- Cancer Kids Entertainment Inc.
- Cancer Patient Services Corporation
- Candlelighters Childhood Cancer Support Group
- Candlelighters Simcoe-Parents of Children with Cancer
- Canucks Autism Network Society
- Cape Breastoners (Dragon Boat) Team Society
- Cape Breton Down Syndrome Society
- Carcinoid-Neuroendocrine Tumour Society-Canada
- Cardiac Health Foundation of Canada
- Care for Kidneys Foundation
- Carion Fenn Foundation
- Cassie and Friends: A Society for Children with Juvenile Arthritis and Other Rheumatic Diseases
- CCB Nova Scotia Division
- Central Alberta Brain Injury Society
- Central Okanagan Association for Cardiac Health
- Central Plains Cancer Care Services Inc
- Centre Associatif Polyvalent D'aide Hepatite C (Capahc)
- Centre Familial Chaleur de L'Autisme et Asperger Inc. / Chaleur Family Center for Autism and Asperger Inc.
- Cerebral Palsy Association in Alberta
- Cerebral Palsy Association of British Columbia
- Cerebral Palsy Association of Manitoba Inc.
- Cerebral Palsy Association of NI Inc.
- Cerebral Palsy Foundation (Saint John) Incorporated
- Cerebral Palsy Parent Council of Toronto
- CH.I.L.D. Foundation
- Charlotte County Cancer Society Inc.
- Chatham Kent Down Syndrome Association
- Chemo Savvy Inc
- Chha Moncton
- Childcan the Childhood Cancer Research Association
- Childhood Cancer Canada Foundation / Fondation Canadienne du Cancer Chez L'Enfant
- Childhood Cancer Family Support Society
- Childhood Obesity Foundation (COF)
- Children's Heart Network of BC Society
- Children's Heart Society
- Children's Organ Transplant Society of BC
- Chinese Community Health Society
- Chris Knox Foundation Inc.
- Chris Stoikos Memorial Foundation
- Chronic Cerebral Spinal Venous Insufficiency (CCSV1) Society of Grande Prairie and District
- Colchester Stroke Club
- Colorectal Cancer Canada / Cancer Colorectal Canada
- Comfort & Smile for Children & Families Affected with Sickle Cell Anemia Disease
- Community Cancer Care
- Community-Based Research Centre Society
- Comox Valley Dragon Boat Society
- Comox Valley Head Injury Society
- Concussion Legacy Foundation (Canada) Inc.
- Connaigre Peninsula Cancer Benefit / Support Group Inc
- Cottage Dreams Recovery Initiative Inc.
- Craig's Cause Pancreatic Cancer Society
- Crohn's and Colitis Canada / Crohn et Colite Canada
- Crps Hope & Awareness Foundation
- Cure Sma Canada Society
- Cystic Fibrosis Canada / Fibrose Kystique Canada
- D.s.r.f. Down Syndrome Resource Foundation
- Dancing with Parkinson's Inc.
- Deafblind and Sensory Support Network of Canada
- Deaf-Blind Association of Toronto Inc.
- Delta Stroke Recovery Society
- Desmoid Tumour Foundation of Canada
- Diabete Amiante Inc.
- Diabete Bois-Francis
- Diabète Brome-Missisquoi (DBM)
- Diabete Charlevoix
- Diabete Drummond Inc.
- Diabète Estrie
- Diabete Iles-de-la-Madeleine Inc.
- Diabete Mauricie-Becancour-Nicolet
- Diabete Mont-Laurier
- Diabete Outaouais Inc.
- Diabete Rive Nord
- Diabete Rouyn-Noranda
- Diabete Saguenay

- Diabète Saint-Hyacinthe Inc.
- Diabète Suroît
- Diabète Val-D'Or Inc.
- Diabetes Association (Brooks & District)
- Diabetes Canada
- Diabetes Research and Treatment Centre Winnipeg Inc
- Diabétiques de Lanaudière Inc.
- Diabetiques Haut St-Laurent / Diabetics Haut St-Laurent
- DIL Walk Foundation
- Donna Schmidt Lung Cancer Prevention Society
- Down Syndrome Association - National Capital Region
- Down Syndrome Association of Brantford and District
- Down Syndrome Association of Kingston
- Down Syndrome Association of Lambton County
- Down Syndrome Association of Ontario
- Down Syndrome Association of Toronto
- Down Syndrome Association of Peterborough
- Dr. E. Murakami Centre for Lyme Research, Education & Assistance Society
- Dravet.ca
- Durham Down's Syndrome Association
- Dysphasie Laurentides (DI)
- Dysphasie Québec
- Dystonia Medical Research Foundation Canada
- Dystrophic Epidermolysis Bullosa Research Association of Canada (Debra Canada)
- Eastern Canada Association of the Deaf Incorporated
- Eating Disorder Council of New Brunswick Inc.
- Eating Disorder Foundation of NI Inc.
- Eating Disorder Support Network of Alberta Society
- Eating Disorders Association of London Inc.
- Eating Disorders Foundation of Canada
- Eating Disorders Nova Scotia Association
- Eating Disorders of York Region
- Eczema Society of Canada / Société Canadienne de L'eczéma
- Edmonton Cerebral Palsy Association
- Elizabeth Lue Bone Marrow Foundation
- ELS for Autism Canada
- Empwr Foundation
- Endometriosis Association (Canada), Incorporated
- Environmental Health Association of Alberta
- Environmental Health Association of Nova Scotia
- Epilepsie Gaspésie Sud
- Epilepsie Granby et Region Inc
- Epilepsie Mauricie Centre du Quebec
- Epilepsie Outaouais Inc
- Epilepsie Section de Quebec
- Epilepsy (Ontario) Ottawa-Carleton
- Epilepsy (Ontario) Simcoe County Inc.
- Epilepsy and Seizure Association of Manitoba Inc
- Epilepsy Association of Calgary
- Epilepsy Association of the Maritimes
- Epilepsy Canada
- Epilepsy Durham Region
- Epilepsy London & Area
- Epilepsy Newfoundland and Labrador Inc.
- Epilepsy Niagara
- Epilepsy Ontario
- Epilepsy Peterborough and Area
- Epilepsy Saskatoon Inc.
- Epilepsy South Central Ontario
- Epilepsy Toronto
- Epilepsy York Region
- Essex County Chapter of New Voices
- Essilor Vision Foundation Canada
- Ezras Cholim Organization
- Families of Alberta for Conductive Education (F A C E)
- Fertile Future
- Fibromyalgia Support Group of Winnipeg Inc.
- Fibromyalgia Well Spring Foundation
- Fondation Coeur Invincible Invincible Heard Foundation
- Fondation des Maladies de L'Oeil - Eye Disease Foundation
- Fondation Donespoir Cancer
- Fondation du Cancer de Gaspé / Gaspé Cancer Foundation
- Fondation du Cancer Héritaire du Sein et des Ovaies / Hereditary Breast and Ovarian Cancer Foundation
- Fondation du Lymphoedème Mauricie Centre du Québec
- Fondation du Syndrome D'angelman
- Fondation HTAPQ (Hypertension Artérielle Pulmonaire - Québec)



- Fondation Linda Lemore-Brown / Linda Lemore-Brown Foundation
- Fondation Marie-Ève Saulnier
- Fondation Melissa et Ses Ami(E)S Inc
- Fondation Néz pour Vivre
- Fondation Pain et Espoir
- Fondation Québécoise de la Maladie Coeliaque / Quebec Celiacfoundation
- Fondation Québécoise de la Maladie D'alzheimer et des Maladies Apparentées
- Fondation Quebecoise du Cancer Inc.
- Fondation Virage pour le Soutien Au Cancer
- Food Allergy Canada / Allergies Alimentaires Canada
- Foundation for Prader-Willi Research Canada
- Four Counties Brain Injury Association
- Fraser Valley Autism Society
- Fredericton Chapter, Canadian Celiac Association
- G. Magnotta Foundation for Vector-Borne Diseases
- Gaby Davis Foundation
- Gdb International
- Genetic Aortic Disorders Association Canada / L'Association Canadienne des Maladies Genetiques de L'Aorte
- Georgian Bay Cancer Support Centre
- Gérer le Cancer Au Masculin
- GI (Gastrointestinal) Society / Société GI (Gastro-Intestinale)
- Gilda's Club Greater Toronto
- Gilda's Club Simcoe Muskoka
- Gilles Boudreau & Friends Cancer Help Fund Association
- Gio's Cares
- Gist Sarcoma Life Raft Group, Canada
- Goodhearts Transplant Foundation
- Gordie Howe Center for Alzheimer's Research and Education Society
- Greater Moncton Down Syndrome Society Inc. / Societe du Syndrome de Down du Grand Moncton Inc.
- Greater Vancouver Association of the Deaf
- Greater Vancouver Chinese Parkinson's Society
- Greater Victoria Down Syndrome Society
- Groupe D'entraide Cancer et Vie
- Groupe D'entraide de la Fibromyalgie et des Douleurs Chroniques des Îles
- Guts & Roses Inc.
- Halifax Regional Cerebral Palsy Association
- Halifax Stroke Club
- Halton Down Syndrome Association
- Hamilton and District Ostomy Association
- Head Injury Rehabilitation Ontario
- Heart and Stroke Foundation Canadian Partnership for Stroke Recovery
- Heart and Stroke Foundation of B.c and Yukon
- Heart and Stroke Foundation of Canada / Fondation des Maladies du Coeur et de L'AVC du Canada
- Heart and Stroke Foundation of Nova Scotia
- Heart and Stroke Foundation of Ontario
- Heart and Stroke Foundation of PEI Inc
- Heart Transplant Home Society
- Hearth Place Cancer Support Centre
- Heartlife Foundation
- Helping Acquired Brain Injury Treatment (H.A.B.I.T.)
- Hemophilia Ontario
- Hemophilia Saskatchewan
- Hepatitis Ressources
- Hepatitis Outreach Society of Nova Scotia
- Hepcbc Hepatitis C Education and Prevention Society
- Hereditary Breast Ovarian Cancer Society of Alberta
- Hhtcanadathh
- Highway to Healing Support Society
- Histiocytosis Association of Canada
- Hope Air
- Hope Cancer Help Centre Inc.
- Hopewell Eating Disorder Support Centre of Ottawa
- Hpv Awareness Corporation
- Humboldt Emergency Relief Organization Inc.
- Huntington Society of Canada
- Hydrocephalus Canada
- Hypertension Canada
- I Challenge Diabetes
- IBD Foundation
- Immunodeficiency Canada / Immunodéficience Canada
- Integrated Services for Autism and Neurodevelopmental Disorders
- Intergroupe O.A. Français de Montréal
- International Association for Individuals with Autistic Spectrum Disorders / Association Internationale pour

Individus Avec Troubles de Spectre Autistique	• La Societe Alzheimer de L'Estrie	• Living Positive Resource Centre, Okanagan
• International KSS Foundation	• La Societe Alzheimer de Quebec	• Lloydminster & Area Brain Injury Society Inc
• Island Deaf and Hard of Hearing Centre Association	• La Société Alzheimer des Laurentides	• Local Cancer Benefit Group
• Island Kids Cancer Association	• L'Association Canadienne de la Maladie Coeliaque, Chapitre Quebecois / Canadian Celiac Association, Quebec Chapter	• Loeys-Dietz Syndrome Foundation Canada / Fondation du Syndrome Loeys-Dietz Canada
• Jennifer A. Cutler Foundation Inc.	• L'Association de Paralysie Cérébrale du Québec Inc.	• London Club of the Deaf, Inc.
• Jivana Organ Donation Society	• L'Association de Spina Bifida et Hydrocephalie du Québec / Quebec Spina Bifida & Hydrocephalus Association	• Looking Glass Foundation for Eating Disorders
• Juvenile Diabetes Research Foundation Canada / Fondation de la Recherche sur le Diabete Juvenile Canada	• L'Association des Personnes Stomisees de L'estrie	• Love, Betty Cancer Foundation
• Kabuki Syndrome Network Inc	• L'Association du Cancer de L'est du Quebec	• Lumi-Vie
• Kamloops Brain Injury Association	• L'Association du Syndrome de Turner du Quebec	• Lung Association of Nova Scotia
• Karen Lynn Macdonald Allergy Awareness Society	• L'Association, Epilepsie Cote-Nord, Inc.	• Lung Cancer Canada Cancer Pulmonaire Canada
• Katelyn Bedard Bone Marrow Association	• Laurentian Region Cancer Support Group Inc. / Groupe de Soutien du Cancer de la Region des Laurentides Inc.	• Lung Disease Support Group Inc.
• Kawartha Lakes Autism Support	• Le Groupe D'entraide de la Sclérose en Plaques de la Banlieue Ouest / West Island Multiple Sclerosis Self-Help Group	• Lupus Canada
• Kawasaki Disease Canada	• Le Parkinson en Mouvement	• Lupus Newfoundland and Labrador Inc
• Kc's Cancer Cushion Fund Trust	• Les Diabetiques de Baie Comeau Inc.	• Lupus Ontario
• Kelowna Cardiac Exercise Society	• Les Diabetiques de la Baie des Chaleurs	• Lupus Sk Society Inc.
• Kidney Cancer Canada Association	• Les Diabétiques de la Haute-Yamaska Inc.	• Lupus Society of Alberta
• Kids Autism Network	• Les Diabetiques de Quebec	• Luxor Temple Shrine Hospital Patient Transportation Fund
• Kids Kicking Cancer Canada Corp.	• Les Diabetiques Sorel-Tracy Inc	• Lyme Ontario
• Kingston Chapter of the Canadian Celiac Association	• Les Diabetiques-Amis du K R T B	• Lymehope
• Knight's Cabin Medical Retreat	• Letsstopaids	• Lymphedema Association of Manitoba Inc.
• Kootenay Brain Injury Association	• Lindsey Villages	• Lymphedema Association of Saskatchewan Inc.
• Korean Canadian Alzheimer's Society		• Lymphoma Foundation Canada
• La Fondation Cardio-Vasculaire de Valleyfield et du Suroit Inc.		• M.E. Society of Edmonton (Chronic Fatigue Syndrome)
• La Societe Alzheimer Chaudiere-Appalaches		• M.e. Victoria Association
• La Societe Alzheimer de Lanaudiere Inc		• Maison Alois Alzheimer des Laurentides
		• Manitoba Blind Sports Association Inc.
		• Manitoba Brain Injury Association Inc.



- Manitoba Cerebral Palsy Sport Association Inc.
- Manitoba Down Syndrome Society Inc
- Manitoba Families for Effective Autism Treatment, Inc.
- Manitoba Neurofibromatosis Support Group Corp.
- Manitoba Rett Syndrome Association
- Mastocytosis Society Canada / Societe Canadienne de la Mastocytose
- Mefm Myalgic Encephalomyelitis and Fibromyalgia Society of BC
- Mélanie's Way
- Melanoma Network of Canada
- Meningitis Relief Canada (MRC)
- Mid Island Kidney Association
- Mikey's Place for Autism
- Mitocanada Foundation
- Moses-Mueller Compassionate Patient Support Foundation
- Mouvement D'aide Paralyisie Cerebrale Estrie
- Movember Canada
- Multiple Myeloma Canada / Myelome Multiple Canada
- Multiple Sclerosis Society of Canada / Société Canadienne de la Sclérose en Plaques
- Muscular Dystrophy Canada / Dystrophie Musculaire Canada
- Myasthenia Gravis Manitoba Inc.
- Myasthenia Gravis Society of Canada
- Myeloma Alberta Support Society
- Myositis Canada / Myosite Canada
- Nanny Angel Network Inc.
- National Capital Skin-Disease Foundation
- National Gaucher Foundation of Canada
- National Indigenous Diabetes Association Inc.
- National ME / FM Action Network
- National Trauma and Tragedy Resource Group Incorporated
- Neurofibromatosis Society of Ontario
- New Beginnings, Abi and Stroke Recovery Association
- New Brunswick Breast and Women's Cancer Partnership Inc. / Le Partenariat du Cancer du Sein et des Cancers Féminins du Nouveau-Brunswick Inc.
- New Brunswick Breast Cancer Network Inc.- Réseau Neo-Brunswickois du Cancer du Sein Inc.
- New Brunswick Chapter of the Canadian Hemophilia Society Inc
- New Brunswick Lung Association Inc. / Association Pulmonaire du Nouveau Brunswick Inc.
- New Brunswick Lyme Disease Association Inc.
- Newfoundland & Labrador Brain Injury Assoc. Inc.
- Newfoundland and Labrador Down Syndrome Society Incorporated
- Newfoundland and Labrador Prostate Cancer Support Groups Advisory Board Inc.
- Newfoundland and Labrador Psoriasis Society Inc
- Newfoundland and Labrador Stuttering Association Inc.
- Noah's Clubhouse Charitable Organization
- North American Intestinal Disease Education and Awareness Society
- North Island Dragon Boat Society
- North Okanagan / Shuswap Brain Injury Society
- North Shore Dragon Busters Society
- Northern Brain Injury Association
- Northwest Pain Foundation
- Nova Scotia Hemophilia Society
- Nwt Breast Health / Breast Cancer Action Group
- Obesity Canada / Obésité Canada
- Obsessive Compulsive Disorder Canada
- Oceanside Stroke Recovery Society
- Ontario Aboriginal HIV / AIDS Strategy
- Ontario Association of the Deaf
- Ontario Brain Injury Association
- Ontario Cerebral Palsy Sports Association
- Ontario Deaf Foundation
- Ontario Deaf Sports Association
- Ontario Federation for Cerebral Palsy
- Ontario Lung Association
- Ontario Parents Advocating for Children with Cancer
- Ontario Prader-Willi Syndrome Association
- Ontario Society for Crippled Children
- Ontario Visually Impaired Golfers Corporation
- Organisation Québécoise des Personnes Atteintes du Cancer (1984) Inc.
- Organisme Voué Aux Personnes Atteintes de Cancer (Ovpac)

- Osteoporosis Canada / Osteoporose Canada
- Ostomy Canada Society Inc. - Société Canadienne des Personnes Stomisées Inc.
- Ostomy Halifax Society
- Ostomy Toronto Corporation
- Ottawa Ostomy Support Group
- Ottawa Regional Cancer Foundation / Fondation du Cancer de la Région D'Ottawa
- Ovarian Cancer Canada / Cancer de L'Ovaire Canada
- P E I Lung Association (Ltd )
- Pain BC Society
- Pancreatic Cancer Canada Foundation
- Parkinson Association of Alberta
- Parkinson Canada Inc.
- Parkinson Centre-Du-Québec. Mauricie Inc.
- Parkinson Montréal-Laval
- Parkinson Outaouais
- Parkinson Québec
- Parkinson Saguenay-Lac-Saint-Jean
- Parkinson Society British Columbia
- Parkinson Society Newfoundland and Labrador Inc. / Société Parkinson Terre Neuve & Labrador Inc.
- Parkinson Society Southwestern Ontario
- Parkinson Wellness Project
- Parkinson's Resource Centre
- Pawsitive Independence Autism Service Dogs of Saskatchewan Inc.
- Peace By Piece-Autism Development and Sensory Centre
- Pediatric Cancers Survivorship Society of BC
- Pediatric Glaucoma & Cataract Family Association
- Pediatric Oncology Group of Ontario
- People in Pain Network Society
- Phelan-Mcdermid Syndrome Foundation Canada
- Physical Lifestyles for Autistic Youth Corporation
- Pictou County Heart and Stroke Support Group
- Pictou County Prostate Cancer Support Association
- Pink Pearl Foundation
- PKD Foundation of Canada / Fondation Canadienne de la MPR
- Polio Regina Inc
- Portail VIH / SIDA du Québec Inc. / Quebec HIV / AIDS Portal Inc.
- Post Traumatic Stress Disorder Association
- Post-Polio Network (Manitoba) Inc.
- Powell River Brain Injury Society
- Praxis Spinal Cord Institute
- Premier Jour After Breast Cancer
- Prince Edward Island Cerebral Palsy Association
- Prince Edward Island Chapter of the Canadian Hard of Hearing Association
- Prince Edward Island Chapter of the Canadian Hemophilia Society
- Prince George Brain Injured Group Society
- Project 321 Peel Down Syndrome Association
- Promoting Awareness of Reflex Sympathetic Dystrophy Syndrome / Complex Regional Pain Syndrome in Canada
- Prostate Cancer Canada
- Prostate Cancer Canada Network - Regina Inc.
- Prostate Cancer Canada Network - Thunder Bay
- Prostate Cancer Canada Network Calgary Society
- Prostate Cancer Canada Network Ottawa
- Prostate Cancer Foundation BC
- Psoriasis Society of Canada
- Pulmonary Hypertension Association of Canada
- Pythian Cerebral Palsy Committee
- Rare Disease Foundation
- Regional HIV / AIDS Connection
- Regroupement des Stomisés Québec-Lévis Inc.
- Regroupement Québécois des Maladies Orphelines
- Réseau Cancer de la Prostate Canada de L'Ouest de L'île de Montréal / Prostate Cancer Canada Network - Montréal West Island
- Réseau D'Action en Santé Cardiovasculaire / Cardiovascular Health Action Association
- Rethink Breast Cancer Canada
- Richmond Stroke Recovery Centre
- River Valley Cancer Support Group Inc.
- Robbie's Rainbow
- Rowbust Breast Cancer Survivor Dragon Boat Racing Society Inc
- Saanich Peninsula Stroke Recovery Association
- Sarcoma Cancer Foundation of Canada
- Saskatchewan ALS Foundation Inc.

- Saskatchewan Association for the Rehabilitation of the Braininjured
- Saskatchewan Cerebral Palsy Association Inc.
- Saskatchewan Deaf and Hard of Hearing Services Inc.
- Saskatchewan Down Syndrome Society Inc.
- Saskatchewan Epilepsy Inc.
- Saskatchewan Preservation of Vision in Distress Or Economic Hardship Inc.
- Saskatchewan Rett Syndrome Association
- Saskatoon Ostomy Association
- Saskatoon Stroke Recovery Association
- Sault Ste. Marie Down Syndrome Society
- Save Your Skin Foundation
- Scleroderma Association of B.C.
- Scleroderma Canada
- Scleroderma Manitoba Inc.
- Scleroderma Society of Ontario
- Sclerose en Plaques du Grand Charlevoix
- Sclerose en Plaques Haute-Yamaska-Richelieu
- Sclerose en Plaques St-Hyacinthe-Acton
- Screen Colons Canada
- Seaway M.E. / FM Self Help Group
- Seizure & Brain Injury Centre
- Sequoia Breast Cancer Association of Ontario
- SHBC: Speech and Hearing BC Association
- Shine On Chantelle Foundation Inc.
- Shine Through the Rain Foundation
- Shwachman Diamond Syndrome Canada
- Sickle Cell Association of BC
- Sickle Cell Association of Ontario
- Sickle Cell Awareness Group of Ontario Inc.
- Sickle Cell Disease Association of Canada / Association D'anemie Falciforme du Canada
- Sidalys
- Sistership Dragon Boat Association
- Sjogren's Society of Canada
- Skin Cancer Canada
- Sleeping Giant Ostomy Group
- Société Alzheimer Abitibi Témiscamingue
- Société Alzheimer de Granby et Région Inc.
- Societe Alzheimer de la Sagamie
- Societe Alzheimer de la Vallee de L'Or Inc
- Société Alzheimer de Montréal Inc. / Alzheimer Society of Montreal Inc.
- Société Alzheimer du Haut-Richelieu
- Societe Alzheimer du Suroit
- Société Alzheimer Outaouais / Alzheimer Society Outaouais
- Société Alzheimer Rive-Sud
- Société Canadienne de la Sclérose en Plaques (Division du Québec)
- Societe Canadienne de la Sclerose en Plaques Region de Quebec
- Societe Canadienne de la Sclerose en Plaques Section Abitibi-Témiscamingue
- Societe Canadienne de L'Hemophilie Section du Quebec
- Societe de la Sclerose Laterale Amyotrophique du Quebec
- Societe de L'Autisme et des Autres Troubles de L'Abitibi Témiscamingue
- Societe de L'Autisme et des TED (Laval)
- Société de L'Autisme S.A.R. Laurentides
- Société de Sclérose Systémique (Sclerodermie) du Québec Inc.
- Societe Franco-Ontarienne de L'Autisme
- Société Québécoise de la Fibromyalgie
- Societe Quebecoise de la Trisomie-21
- Societe Quebecoise du Syndrome D'angelman
- Society for the Treatment of Autism
- Soft Bones Canada
- Solaris Autism Services Inc.
- Sooke Region Women's Cancer Support Society
- Sotos Syndrome Support Association of Canada / Association Canadienne D'entraide du Syndrome de Sotos.
- South Asian Autism Awareness Centre
- South Central Cancer Resource Inc.
- South Okanagan / Similkameen Brain Injury Society
- Southern Alberta Brain Injury Society
- Southwestern Ontario Optimist Conductive Ed Trust Fund
- Spina Bifida & Hydrocephalus Association of P.E.I.
- Spina Bifida and Hydrocephalus Association of Canada

- Spina Bifida and Hydrocephalus Association of Manitoba
- Spina Bifida and Hydrocephalus Association of Northern Alberta
- Spina Bifida and Hydrocephalus Association of Nova Scotia
- Spina Bifida and Hydrocephalus Association of South Saskatchewan Inc.
- Spinal Cord Injury Association Alberta
- Spinal Cord Injury Canada
- Spinal Cord Injury Manitoba Inc.
- Spinal Cord Injury Ontario
- Spinal Cord Injury P.E.I. Inc.
- Spinal Cord Injury Saskatchewan Inc.
- Spirit Abreast Dragon Boat Society
- Starlight Children's Foundation Canada / Fondation pour L'enfance Starlight
- Stevens Johnson Syndrome Canada
- Strathcona Chinese Stroke Club Society
- Stroke Recovery Association Cambridge & District Chapter
- Stroke Recovery Association of British Columbia
- Stroke Recovery Association of Calgary
- Stroke Recovery Association-Richmond Hill Chapter
- Students' Alzheimer's Alliance at the University of Toronto (SAAUT)
- Sudep Aware
- Summit Foundation for Cystic Fibrosis
- Supa Surf's Up for Autism Society
- Support for Memory Loss Foundation
- Survivors Abreast of Peterborough Inc.
- Survivorship Dragon Boat Team Society
- Survivor-Thrivers-Breast Cancer Survivors Society
- Team Finn Foundation
- Team Shan Breast Cancer Awareness for Young Women
- Testicular Cancer Canada
- Thalassemia Foundation of Canada
- The AIDS Committee of Cambridge, Kitchener, Waterloo
- The AIDS Committee of Ottawa / Le Comité du Sida D'Ottawa
- The Alberta Chapter of the Canadian Hemophilia Society
- The Allergy Wellness Awareness Research and Education Foundation
- The Alzheimer Society of Sault Ste. Marie & Algoma District
- The Anti-Nmda Receptor Encephalitis Foundation, Inc.
- The Arthritis Research Centre Society of Canada / Arthrite-Recherche Canada
- The Arthritis Society / La Société D'arthrite
- The Association for the Rehabilitation of the Brain Injured
- The Autism Centre of Canada
- The Beyond Multiple Sclerosis Association of Canada
- The Brain Aneurysm Foundation of Canada
- The Brain Injury Coalition of Prince Edward Island Inc.
- The British Columbia Prader-Willi Syndrome Association
- The Bulkley Valley Brain Injury Association
- The Campbell McLaurin Foundation for Hearing
- The Canadian Addison Society / La Société Canadienne D'addison
- The Canadian Association for Williams Syndrome
- The Canadian Association of the Deaf
- The Canadian Celiac Association
- The Canadian Celiac Association - Prince Edward Island Chapter
- The Canadian Celiac Association (Manitoba Chapter) Inc.
- The Canadian Celiac Association Kitchener Waterloo chapter
- The Canadian Celiac Association Ottawa Chapter
- The Canadian Council of the Blind
- The Canadian Council of the Blind-Ontario Division
- The Canadian Hard of Hearing Association / British Columbia Chapter
- The Canadian National Institute for the Blind / L'institut National Canadien pour Les Aveugles
- The Canadian National Society of the Deaf-Blind
- The Canadian Orthopaedic Foundation / Fondation Canadienne D'Orthopédie
- The Canadian Paraplegic Association (Nova Scotia)
- The Canadian Society for Mucopolysaccharide & Related Diseases
- The Canadian Society of Intestinal Research
- The Canadian Sudden Arrhythmia Death Syndromes (SADS) Foundation

- The Candlelighters Association of Newfoundland and Labrador
- The Capital Region Prostate Centre
- The Carlo Rossini Memorial Diabetes Foundation
- The Casey Foundation for Autism Support Inc.
- The Center for Epilepsy and Seizure Education British Columbia
- The Charles H. best Diabetes Centre
- The Chronic Pain Association of Canada - Alberta
- The Cryptic Rite Charitable Foundation Inc.
- The David Cornfield Melanoma Fund
- The Dementia Society of Ottawa and Renfrew County / La Société de la Démence D'Ottawa et du Comté de Renfrew
- The Down Syndrome Association of York Region
- The Edmonton Epilepsy Association
- The Edmonton Ostomy Association
- The Endometriosis Network Canada
- The Epilepsy and Seizure Disorder Resource Centre of South Eastern Ontario Inc.
- The Experiential Diabetes Education Group
- The Fabrys Charity Association
- The Firefighters' Burn Fund Inc.
- The First Open Heart Society of British Columbia
- The Foundation Fighting Blindness
- The Friends of Gilda's Society Nova Scotia
- The Greater Victoria Cardio-Pulmonary Resuscitation Society
- The Happy Liver Society
- The Hearing Foundation of Canada / La Fondation Canadienne de L'Ouïe
- The Heart and Stroke Foundation, New Brunswick
- The Heart of Richmond AIDS Society
- The ILC Charitable Foundation
- The Isaac Foundation for Mps Treatment and Research
- The Kelly Shires Breast Cancer Snow Run for Fun Trust
- The Kidney Foundation of Canada / La Fondation Canadienne du Rein
- The Lending Cupboard Society of Alberta
- The Leukemia & Lymphoma Society of Canada / Societe de Leucemie & Lymphome du Canada
- The Lung Association of Saskatchewan Inc.
- The Lymphovenous Association of Ontario
- The Mikey Network
- The Montreal Chapter of Dysautonomia Foundation
- The Multiple Sclerosis Scientific Research Foundation
- The Myalgic Encephalomyelitis Association of Ontario
- The Nipissing Respiratory Organization
- The Oakville Stokers
- The Pediatric Liver Foundation
- The Prader-Willi Syndrome Association
- The Rosalin Nickerson "Care" Fund Society
- The Sanatorium Board of Manitoba
- The Sanfilippo Children's Research Foundation
- The Sarnia Organ Donor's Awareness Group
- The Saskatchewan Brain Injury Association Inc.
- The Scoliosis Association of British Columbia Chapter 100
- The Seeing Eye Organization
- The Sickle Cell Foundation of Alberta
- The Stephen Russell Memorial Fund
- The Steven Young Trust
- The Stroke Recovery Association of Manitoba Inc.
- The Stroke Recovery Association, Barrie & District Chapter
- The Sturge-Weber Foundation (Canada) Inc
- The Thalidomide Victims Association of Canada / L'Association Canadienne des Victimes de la Thalidomide
- The Vancouver Thalassemia Society of B C
- The Victoria Stroke Recovery Association
- The Walnut Foundation
- The Waterloo Regional Down Syndrome Society
- The Winnipeg Ostomy Association Inc.
- The Yukon Lung Association / Yukon Tyberculosis & Health
- Thrombosis Canada  
Thrombose Canada
- Thyroid Cancer Canada / Cancer de la Thyroïde Canada
- Thyroid Foundation of Canada / La Fondation Canadienne de la Thyroïde
- Together Helping Women
- Toronto Lung Transplant Civitan Club Inc.

- Tourette Syndrome Association of Ontario
- Tourette Syndrome Foundation of Canada / La Fondation Canadienne du Syndrome de la Tourette
- Transforming Faces
- Transplant Advocate Association
- Trillium Childhood Cancer Support Centre / Centre Trillium D'entraide des Enfants Atteints du Cancer
- Tuberous Sclerosis Canada Sclerosis Tubereux
- Tumour Foundation of BC
- United Ostomy Assoc Inc Vancouver British Columbia Chapter
- United Ostomy Association Inc Stratford and District Chapter
- United Ostomy Association of Canada N.I. Chapter # 604
- United Ostomy Association of Canada-Moncton Chapter
- Ups and Downs - Calgary Down Syndrome Association
- U-Turn Parkinson's Inc.
- Valley Cardiac Rehab Society
- Vancouver AIDS Society
- Vancouver Brain Injury Association
- Vancouver Island Autistic Homes Society
- Vancouver Island Multiple Myeloma Support Group Society
- Vancouver Island Persons Living with HIV / AIDS Society
- Vernon Friends of Ms Society
- VHL Canada
- Victoria Brain Injury Society
- Victoria Cardiac Rehabilitation Society
- Victoria Epilepsy and Parkinson's Centre Society
- Victoria Society for Children with Autism
- Ville Marie Oncology Foundation / Fondation D'Oncologie Ville Marie
- Vision Impaired Resource Network (VIRN) Inc.
- Visual Process Society
- Volunteer Cancer Drivers Society
- Waldenstrom's Macroglobulinemia Foundation of Canada
- Warriors of Hope Breast Cancer Survivors Dragon Boat Racing Team
- Waves of Changes for Autism
- We Rage, We Weep Alzheimer Foundation
- Wee Braveheart Foundation
- Wehaveaface.org Canada
- Wellspring Calgary
- Wellspring Chinguacousy Foundation
- Wellspring Edmonton
- Wellspring Niagara Cancer Support Foundation
- West Island Cancer Wellness Centre / Centre de Bien-Être de L'Ouest-De-L'île pour Personnes Atteintes de Cancer
- Western Institute for the Deaf and Hard of Hearing
- Westman Aphasia Inc.
- Westman Prostate Cancer Support Group
- Wigs for Kids
- Wildrose Polio Support Society
- Windsor Celiac Foundation
- Wonderbroads Charitable Dragon Boat Racing Organization
- World Parkinson's Program
- Wounds Canada Foundation
- Yael's Indaba Charitable Initiative Society
- Young Adult Cancer Canada Inc.





# References

# REFERENCES

- 1 CanadaHelps. 2020. *TheGivingReport 2020*. Toronto: CanadaHelps.org <https://www.canadahelps.org/en/the-giving-report/>
- 2 Lasby, D. 2020. *Sector Monitor: Charities & the COVID-19 Pandemic*. Toronto: Imagine Canada [https://imaginecanada.ca/sites/default/files/COVID-19%20Sector%20Monitor%20Report%20ENGLISH\\_0.pdf](https://imaginecanada.ca/sites/default/files/COVID-19%20Sector%20Monitor%20Report%20ENGLISH_0.pdf)
- 3 The Senate Special Committee on the Charitable Sector. 2019. *Catalyst for Change: A Roadmap to a Stronger Charitable Sector*. Ottawa: Senate Printing Service [https://sencanada.ca/content/sen/committee/421/CSSB/Reports/CSSB\\_Report\\_Final\\_e.pdf](https://sencanada.ca/content/sen/committee/421/CSSB/Reports/CSSB_Report_Final_e.pdf)
- 4 Lasby, D. & Barr, C. 2018. *30 Years of Giving in Canada The Giving Behaviour of Canadians*. Toronto/Ottawa: Rideau Hall Foundation and Imagine Canada [https://live-imagine-canada.pantheonsite.io/sites/default/files/2019-05/30years\\_report\\_en.pdf](https://live-imagine-canada.pantheonsite.io/sites/default/files/2019-05/30years_report_en.pdf)
- 5 Ontario Nonprofit Network. 2019. *Sector 360° Survey: Taking the pulse of Ontario's Nonprofit Sector*. Toronto. [https://theonnn.ca/wp-content/uploads/2019/11/Report\\_ONN-Sector-360-Survey.FINAL\\_November-2019.pdf](https://theonnn.ca/wp-content/uploads/2019/11/Report_ONN-Sector-360-Survey.FINAL_November-2019.pdf)
- 6 CanadaHelps. 2020. *TheGivingReport 2020*. Toronto: CanadaHelps.org <https://www.canadahelps.org/en/the-giving-report/>
- 7 Canada Revenue Agency. 2019. *T1 Final Statistics 2019 edition (for the 2017 tax year)*. <https://www.canada.ca/en/revenue-agency/programs/about-canada-revenue-agency-cra/income-statistics-gst-hst-statistics/t1-final-statistics/2017-tax-year.html>
- 8 Philanthropic Foundations Canada. 2019. *Canadian Foundation Facts*. <https://pfc.ca/resources/canadian-foundation-facts/>
- 9 Carter, T.S. & Man, T.L.M. 2016. *When Is A Gift Not A Gift? And What To Do When Gifts Go Bad?* Toronto/Ottawa. Carters Professional Corporation <http://www.carters.ca/pub/seminar/charity/2016/Handout-When-is-a-Gift-Not-a-Gift.pdf>
- 10 Imagine Canada. *Sector Source, Basics of Tax Receipting for Donations*. <http://sectorsource.ca/managing-organization/gifts-and-receipting/receipting>
- 11 Canada Revenue Agency. 2012. *Fundraising by registered charities CG-013*. <https://www.canada.ca/en/revenue-agency/services/charities-giving/charities/policies-guidance/fundraising-registered-charities-guidance.html>
- 12 Hagggar-Guenette, Cynthia, Yu, Mingyu. 2009. *Satellite Account of Nonprofit Institutions and Volunteering : 2007*, (Catalogue no. 13-015-X, ISSN 1710-9264). Ottawa. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/13-015-x/13-015-x2009000-eng.pdf>
- 13 Canada Revenue Agency. 2012. *Fundraising by registered charities CG-013*. <https://www.canada.ca/en/revenue-agency/services/charities-giving/charities/policies-guidance/fundraising-registered-charities-guidance.html>
- 14 CBC News. September 22 2010. *Charities paid \$762M to private fundraisers*. <https://www.cbc.ca/news/canada/charities-paid-762m-to-private-fundraisers-1.916829>
- 15 Association of Medical Research Charities (AMRC). 2017. *Making a difference: Impact report 2017*. <https://www.amrc.org.uk/making-a-difference>
- 16 Van de Bovenkamp HM, Trappenburg MJ. *Government influence on patient organizations*. Health Care Anal. 2011;19(4):329-351. doi:10.1007/s10728-010-0155-7
- 17 Souliotis K, Agapidaki E, Peppou LE, et al. *Assessing patient organization participation in health policy: a comparative study in France and Italy*. Int J Health Policy Manag. 2018;7(1):48–58. doi:10.15171/ijhpm.2017.44
- 18 Dorota Sienkiewicz, D., Van Lingen, C. 2017. *The Added Value of Patient Organisations*, Brussels. European Patients Forum [https://www.eu-patient.eu/globalassets/library/publications/epf\\_added\\_value\\_report\\_final.pdf](https://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report_final.pdf)
- 19 Berglas, S., Jutai, L., MacKean, G. et al. *Patients' perspectives can be integrated in health technology assessments: an exploratory analysis of CADTH Common Drug Review*. Res Involv Engagem 2, 21 (2016). <https://doi.org/10.1186/s40900-016-0036-9>
- 20 Canada Revenue Agency. 2019. *Public policy dialogue and development activities by charities CG-027*. <https://www.canada.ca/en/revenue-agency/services/charities-giving/charities/policies-guidance/public-policy-dialogue-development-activities.html#toc4>



- 21 Broder, P. 2019. *Charities' Political Activities Question Quietened, If Not Fully Resolved*. LawNow. <https://www.lawnow.org/charities-political-activities-question-quieted-if-not-fully-resolved/>
- 22 HealthPartners. 2020. *The Impact of COVID-19 on Our Most Vulnerable Canadians*. Ottawa. <https://healthpartners.ca/sites/default/files/COVID-19-Impact-Report-En-20200507.pdf>
- 23 CAF America. 2020. *The Voice of Charities Facing COVID-19 Worldwide*. [https://www.cafamerica.org/wp-content/uploads/3\\_CV19\\_Report\\_6\\_10.pdf](https://www.cafamerica.org/wp-content/uploads/3_CV19_Report_6_10.pdf)
- 24 Health Charities Coalition of Canada. 2020. *Emergency Funding to Support Life-Changing Health Research*. Ottawa. [http://www.healthcharities.ca/news-and-events/emergency-funding-to-support-life-changing-health-research-\(1\).aspx](http://www.healthcharities.ca/news-and-events/emergency-funding-to-support-life-changing-health-research-(1).aspx)
- 25 Jensen, E. 2020. *Sector Stories: Revenue Loss Threatens Survival of Charities And Nonprofits*. Toronto: Imagine Canada <https://imaginecanada.ca/en/360/sector-stories-1>
- 26 Health Charities Coalition of Canada. 2020. *With revenue cut in half and staff layoffs, health charities concerned about patient care*. Ottawa. <http://www.healthcharities.ca/news-and-events/with-revenue-cut-in-half-and-staff-layoffs,-health-charities-concerned-about-patient-care.aspx>
- 27 Lasby, D. 2020. *Sector Monitor: Charities & the COVID-19 Pandemic*. Toronto: Imagine Canada [https://imaginecanada.ca/sites/default/files/COVID-19%20Sector%20Monitor%20Report%20ENGLISH\\_0.pdf](https://imaginecanada.ca/sites/default/files/COVID-19%20Sector%20Monitor%20Report%20ENGLISH_0.pdf)
- 28 CBC News. July 16, 2020. *Health charities in Canada hit with historic loss in revenue during COVID-19*. <https://www.cbc.ca/news/health/health-charities-1.5651328?vfz=medium%3Dsharebar>
- 29 Canada Revenue Agency. *What is the difference between a registered charity and a non-profit organization?* <https://www.canada.ca/en/revenue-agency/services/charities-giving/giving-charity-information-donors/about-registered-charities/what-difference-between-a-registered-charity-a-non-profit-organization.html>
- 30 Canada Revenue Agency. *Program areas and field codes*. <https://www.canada.ca/en/revenue-agency/services/charities-giving/charities/operating-a-registered-charity/program-areas-field-codes.html>



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