

# 2022

## Annual Report

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# Letter from the Chair of the Board



Welcome Stakeholders of ImmUnity Canada to our 2022 Annual Report!

Entering my ninth year on the board of directors and fourth year as Chair of (now) ImmUnity Canada, I am so pleased to invite you - our members, stakeholders and supporters - to take a look at our highlights and insights from last year.

2022 was a milestone year for our organization. We were happy to be able to celebrate our 25th anniversary as an organization, supporting patients and families across Canada. Over my time with ImmUnity Canada, I have been lucky to watch the organization grow in numbers, visibility, credibility and financially. I believe our programs and services have never been better, yet they continue to develop, year over year.

Thank you to our partners, supporters and donors for making the past 25 years possible, and allowing us to achieve everything we have done. Thank you to our members and volunteers for being the backbone of the organization. Thank you to our tireless staff, who put into action what we envision.

Lastly, thank you to the patients and families across Canada who we serve and have served for the past 25 years and will continue to serve for another 25 and more. Patients are the why in healthcare, and ImmUnity Canada is here and will continue to be to support, educate, advocate and ensure patient-focused care in the standard for the immunodeficiency population in Canada.

Sincerely,

A handwritten signature in black ink that reads "Christine Duncan". The signature is written in a cursive, flowing style.

**Christine Duncan**  
Board Chair, ImmUnity Canada



# Letter from the Executive Director

2022 was a year of tremendous change, not only for our organization but also for the community we serve. Demand for our services, programs, expertise and leadership has never been higher. As Canada's only national organization supporting those whose lives are impacted by immunodeficiency, we understand the needs of that community and responded.

A new strategic plan was unveiled, setting strategic directives, goals and objectives for the next five years. This was closely followed by an organizational rebranding where the Canadian Immunodeficiencies Patient Organization became ImmUnity Canada. This brand change from CIPO to ImmUnity Canada was a long and thoughtful process, with engagement across our stakeholders.

We also undertook an organizational needs assessment to ensure that the programs and services we offer are relevant, evidence-based, and sustainable. This included a national membership survey, regional data gathering events and focused interviews.

While we worked internally to fortify the organization for success and sustainability, we continued to offer virtual programs and events. We held our first ever fundraising Walk for PI during World PI Week. Over 100 members joined and walked across Canada from their home. We also held our first virtual conference, a two-day event with over 250 registered participants.

New faces joined our forces with Fiona Coyle and Yaheli Serrano to oversee the volunteer program and administration, respectively.

On behalf of ImmUnity Canada I would like to commend all staff and volunteers for continuing to deliver core services and programs during the third year of the pandemic. I continue to be humbled by the passion and dedication of everyone involved and consider myself lucky to be able to lead them and this organization.

Sincerely,

A handwritten signature in black ink, appearing to read 'Whitney Goulstone'. The signature is fluid and cursive.

**Whitney Ayoub Goulstone** *(she/her)*  
Executive Director, ImmUnity Canada



# Rebranding

In the 1990s, a Canadian with primary immunodeficiency (PI) wanting to connect with other patients found that a national organization representing PI didn't exist. So they made one.

ImmUnity Canada was founded in 1997 with help from the International Patient Organization for Primary Immunodeficiency (IPOPI). Initially known as the Canadian Immunodeficiency Patient Organization (CIPO), we invited patients and caregivers across the country to join and connect with fellow patients.

Early on, CIPO joined the Network for Rare Blood Disorders Organization (NRBDO). This pan-Canadian coalition of patient organizations assists each other in governance and best practices. The NRBDO was vital in helping ImmUnity Canada establish by-laws and policies in our transition from non-profit to charitable status.

Throughout our first 15 years, a volunteer board of directors led CIPO with chapter volunteers overseeing regional work. As our organization's mandate grew, in 2014, we hired our first Executive Director, Whitney Goulstone.

In celebration of our 25th anniversary, our organization began a months-long process to update our strategic plan and brand. The results give us a clear path forward and help us better communicate with our members, healthcare professionals and the wider public.

In October 2022, the Canadian Immunodeficiency Patient Organization unveiled its new name:



**immunity** canada  
Primary Immunodeficiency Society

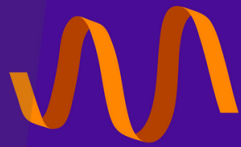
*“It is important to know there is an **active patient organization** working hard to keep patients informed and to provide advocacy.”*

— Member survey response (2022)

But while our name has changed, our purpose is still the same. Each day, we work to empower Canadians impacted by immunodeficiency disorders to live well through education, support, advocacy, community-building, and research.

ImmUnity Canada started modestly as a volunteer-run organization with patients and families nationwide giving their time to educate others and promote awareness of primary immunodeficiencies. Today, our volunteers and members continue to be the lifeblood of our organization and community. From the beginning, one message rings louder than the rest:

**You are not alone.**



**Introducing**  
**immunity canada**  
Primary Immunodeficiency Society

## **Mission**

We empower Canadians impacted by immunodeficiency disorders to live well through education, support, advocacy, community-building, and research.

## **Vision**

All Canadians with immunodeficiency disorders have access to the resources they need to thrive.

## **Values**

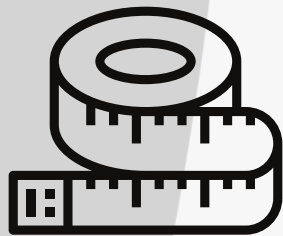


Community | Equity | Inclusiveness | Empowerment | Excellence | Innovation

# Strategic Plan

Over the last two years, ImmUnity Canada's leadership has made great strides reinvigorating the Board of Directors, professionalizing operations, and stepping up to the challenges of COVID-19. With the 2017 strategic plan expiring in February 2022, ImmUnity Canada began developing a new strategic plan for 2022-2027.

Following a review of current materials, meetings of the Executive Director, Chair, and Board of Directors, and a Strategic Planning Retreat, ImmUnity Canada identified four Strategic Goals for the next five year period:



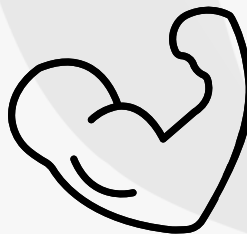
**Programs with  
Measurable Impact**

**A Growing,  
Inclusive Community**



**Equitable Access  
Through Advocacy**

**Operational Strength  
& Sustainability**



[Read the Full  
Strategic Plan](#)

These goals, alongside an analysis of ImmUnity Canada's Strengths, Weaknesses, Opportunities, and Threats were used to develop a framework of action items to continue to improve how we support our members and everyone living with PI in Canada.




# **Membership & Committees**

Meet

# Vennie Tu

*PI Patient*



Vennie was born with x linked agammaglobulinemia that was diagnosed around 1 year old.

He had infusions once a month at SickKids and then St. Michaels in Toronto, until he moved to subcutaneous treatment during the pandemic, which he self administers it once a week.

He has been very susceptible to severe infections his entire life. So he has to be extra vigilant about any little scrape or cut that could lead to severe infections that in the past have led to being on crutches, extended hospital stays, and, in one case, surgery.



# Membership

ImmUnity Canada's membership was more active than ever! In 2022 members attended a variety of events, both online and in person, and continued to advocate for all patients with immunodeficiency in Canada. In total, we ended the year with a **958 members**— increasing by nearly 100 members since 2021.

As mentioned in the 2022 Annual Report, a growing, sustainable community is a goal for us moving forward. One primary method for this is through social media, and as such we broadened our social media following this year; increasing to a total **1,400 followers** across all platforms (Facebook, Instagram, Twitter, and LinkedIn). Beyond our followers, our 838 posts reached **101,000 eyes**. Our most popular post was the announcement that British Columbia has adopted provincial infant screening for SCID.

*“[ImmUnity Canada has given me a] **better understanding** of how to protect myself while balancing the necessity of work, family, and community life”*

— Member survey response (2022)

IMAGE: Members gather for a photo outside of the Ontario Data Party



# The Board

The ImmUnity Canada board oversees the organizational strategic direction, and as such board members are tasked with ensuring that ImmUnity Canada's services and programs adhere to organizational mandate, mission and vision.

In 2022, this involved the approval of the: annual budget, finances, fundraising goals, and year end financial statements, as well as reviewing ImmUnity Canada's policies,

procedures, programs, events, and documents including the new 2022 - 2027 Strategic Plan and this annual report!

This year, the ImmUnity Canada board also oversaw the hiring of three new employees: Fiona Coyle, our Project and Volunteer Coordinator; Yaheli Serrano, our Administrative Assistant; and Lamia Bhuyian who joined us as a temporary event co-ordinator through the Canada Summer Jobs Program.



*IMAGE: [Left to Right] Lee Strickland, Paola Andrea Fernandez de Soto Abdul-Rahim, Christine Duncan-Wilson, Brent Leonard of the ImmUnity Canada Board*

## Members of the Board

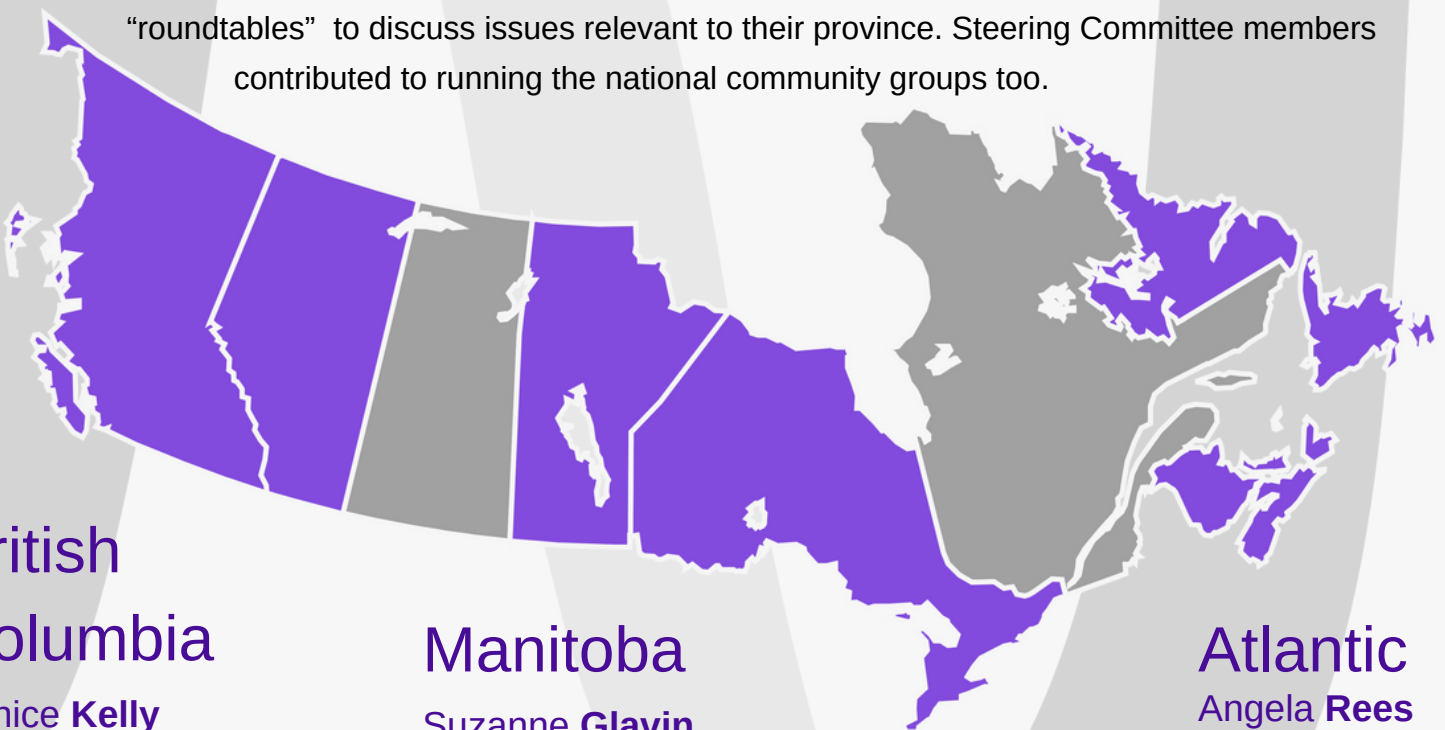
Chair	Christine <b>Duncan</b>
Vice Chair	Lee <b>Strickland</b>
Treasurer	Brent <b>Leonard</b>
Secretary	Thomas <b>Lee</b>
Director	Ingrid <b>Brodie</b>
Director	Kim <b>Hansen</b>
Director	Alyshah <b>Nurani</b>
Director	Paola Andrea <b>Fernandez de Soto Abdul-Rahim</b>

The team also supported the start of several new programs, including the Walk for Immunodeficiency in April, the cross-Canada Data Parties in the autumn and winter, and all of the webinars, community groups, and fundraisers ImmUnity Canada hosted throughout 2022.

# Steering Committees

Steering Committees continued to raise important issues of concern for the Primary Immunodeficiency communities across Canada to ImmUnity Canada. 18 chapter volunteers across Canada were involved in a review of the Steering Committee model, and made recommendations for national and provincial volunteering opportunities across Canada for 2023. The report was presented at the April 2023 national conference in Ottawa. Those based in British Columbia also contributed to the campaign to secure provincial newborn screening.

Steering Committee members met interested members at the virtual conference at “roundtables” to discuss issues relevant to their province. Steering Committee members contributed to running the national community groups too.



## British Columbia

Janice **Kelly**  
Adele **Poier**

## Alberta

Safira **Lachapelle**  
Tina **Hunter**

## Manitoba

Suzanne **Glavin**  
Khalie **Jackson-Davies**

## Ontario

Kristina **Skeries**  
Angela **DiMondo**  
Rosemary **Burnett**  
Meaghan **Mitchell**  
Deborah **Chang**

## Atlantic

Angela **Rees**  
Ashley **Hickey**  
Funda **Eyupoglyu**  
Amanda **Sawler**



# Medical Science & Nursing Advisory Committees

ImmUnity Canada is not a medical organization, but is affected by medical and scientific issues. We therefore rely on members from our medical community to assist us periodically. Our Medical Science Advisory Committee (MSAC) and Nurse Advisory Committee (NAC) members are valued for their expertise and guidance in many ways.

The purpose of the MSAC and NAC are to support the Executive Director, the Board of Directors and the Organization in the scientific and medical fields. This is accomplished through establishing good standards, supporting the organization and its direction, and fully engaging at the committee level. Our MSAC and NAC members will be expected to engage and actively participate in their respective committees. Occasionally, we will ask for members to take part in activities including: educational sessions,

media interviews,  
medical  
reviews,  
policy

consultations, policy submissions, government and policy meetings, and the development of educational and informational resources and research.

In 2022 the ImmUnity Canada Medical Science Advisory Committee engaged in the following initiatives on behalf of immunodeficiency patients and families:

- Took part in a medical submission appeal process for a Plasma Protein Products review process with CADTH for a new immunoglobulin (IG) product
- Took part in a Plasma Protein Products review process with Canadian Blood Services for a new IG product
- Inputted into the National IG Shortages Management Plan through the National Emergency Blood Management Committee and Health Canada
- Created the ImmUnity Canada Immunology Resident Research Grant

Some members of the committee also participated in the following:

- Canadian Blood Services RFP for Immunoglobulin products (5 year contracts)
- ImmUnity Canada virtual conference
- ImmUnity Canada publication of 2021 COVID-19 vaccine hesitancy study

## NAC Members

Becky Rock  
Florence Mackay  
Karen Chestney  
Noor Zhu

## MSAC Members

Dr. Stephen Betschel Co-Chair  
Dr. Bruce Ritchie Co-Chair  
Dr. Gina Lacuesta  
Dr. Beata Derfalvi  
Dr. Bruce Mazer  
Dr. Donald Vinh  
Dr. Hugo Chapedelaine  
Dr. Vy Kim  
Dr. Kyla Hildebrand



Meet  
**Khalie  
Jackson  
Davis**  
*PI Parent*

**Managing serious illness followed by a life-changing diagnosis of a PI has been challenging...**

Adding a pandemic into the mix and trying to navigate the world as a parent of an immunocompromised child is even more challenging. The support we have found through ImmUnity Canada has been our saving grace. As a family, the support, friendships and answers we have received through ImmUnity Canada have been a shining light on a sometimes dark and lonely path. Learning through podcasts, educational webinars, and connecting with others who have a primary immunodeficiency through bi-weekly support groups have all helped us figure out what it means to live with a PI.



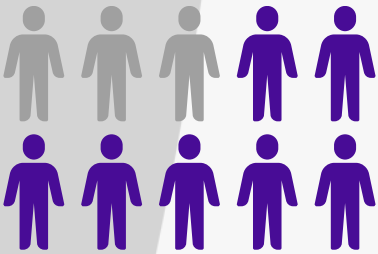
# Programs

# Membership Survey

In 2022, ImmUnity Canada kicked off its 25th year of existence by surveying its membership to understand more about their needs, how we could improve what we do for members, and understand more about the impact of our initiatives to date. 169 people responded, and comments helped inform the Strategic Plan 2022 - 2027 developed in April 2022.

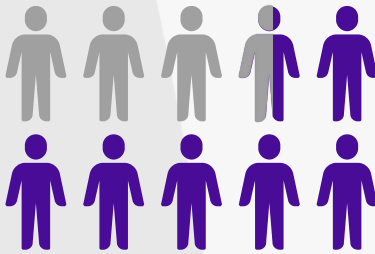
We found that, since becoming members:

69%



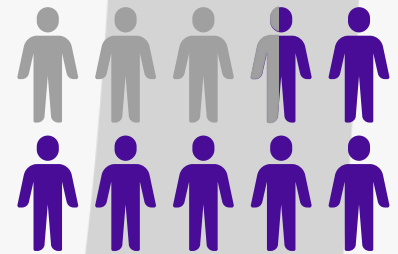
felt **more confident** managing their PI or caring for someone else with PI.

66%



felt **more confident** talking about their PI

64%



found they were **more engaged** in issues which impact the PI community

Over half of respondents said membership provided them a better support network than they had previously, and they they had begun advocating on behalf of the PI community. Another 41% said they started actively participating in activities with the purpose of improving the lives of others with PI.

Also in the survey, members mentioned that the most significant impact of joining ImmUnity Canada was feeling connected, increasing their knowledge and skills, and helping to improve the lives of others affected by PI.

**“Education.**  
*Good, solid, current, reliable education about what it means to live with a PI”*

— Member survey response (2022)



*“The toll of having a PI is more than just the disease.*

*It affects all aspects of life, including your social life and your income”*

— Member survey response (2022)

Throughout the year, members across Canada continued to provide each other with support, as well as connect socially through monthly online meetups and in-person meetings to learn from one another. Provincial and regional members continued to meet each month to discuss issues which impacted them through our Volunteer Steering Committees, which were integral to helping plan upcoming events in 2023.

In early 2022, the PI Educational Webinar series ended, and our first three-day virtual PI educational conference took place in September 2022 attended by 150 individuals. Patients and health care practitioners provided over 6 educational sessions. ImmUnity Canada continued to provide important updates to patients and their families with regards to COVID-19, and held our most popular online COVID-19 Q+A event with Dr. Bruce Ritchie.

From January to May 2022, our “**Slice of PI**” podcast- hosted by Paola Andrea Fernandez de Soto Abdul-Rahim- was listened to by hundreds of individuals. The podcast was considered a great way to explore the diverse experiences of people living with a PI through reflexive investigation of the social and emotional well-being of people living with these diseases.

Later in the year, feedback through over 80 interviews and focus group discussions led to

revisions in how members want to be connected socially and be supported by one another, and plans to improve the overall membership experience and volunteer experience as well as ensuring improvements were made to communications. ImmUnity Canada traveled to Vancouver, Toronto, Halifax and Edmonton and met with over 50 individuals, representing patients, families, health practitioners and industry to help plan to meet members immediate and longer-term needs.

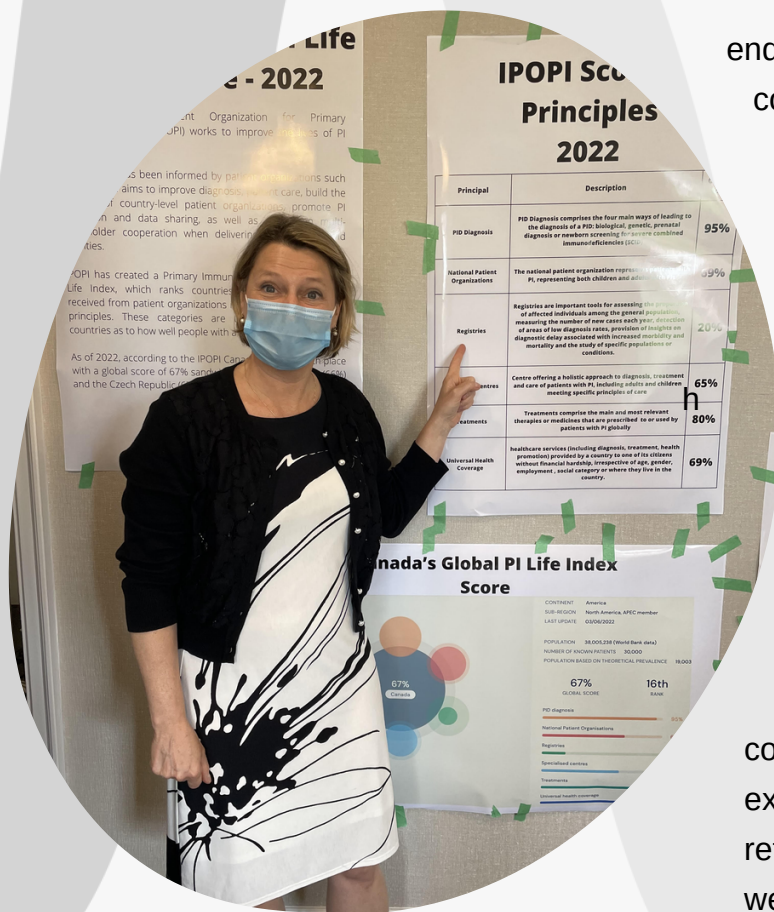


IMAGE: Medical Science Advisor Committee member, Dr. Beata Derfalvi attends our Halifax Data Party.



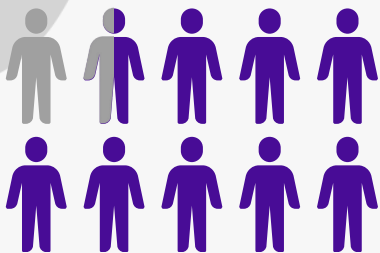
IMAGE: The participants of the Halifax Data Party

During PI Awareness Week 2022, ImmUnity Canada launched their first national awareness “Walk for Immunodeficiency” event, where over 103 individuals registered. Thanks to members walking in many parts of Canada to highlight the needs of living with an invisible disease, we were able to raise over \$10,000.

In addition, ImmUnity Canada hosted a special webinar looking at access to treatment globally, including how the Russia-Ukraine war affected PI patients in the conflict zone.

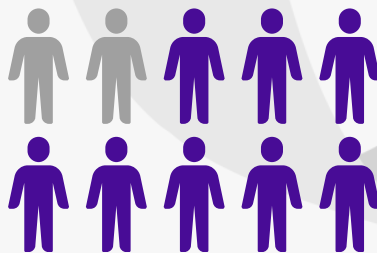
Our survey also found that, after members attended an Immunity Canada Event:

**85%**



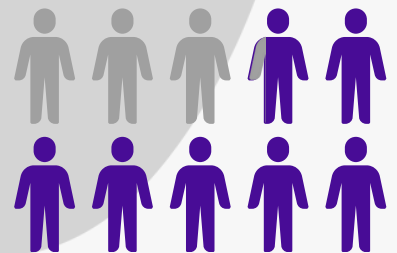
said that they had improved their knowledge about PI

**80%**



increased their interest in issues which affect our community

**58%**



said that they learned new skills to cope with issues impacting their lives

*“I feel normal when I meet up with other members, whether online or in person”*

— Member survey response (2022)



# Policy

ImmUnity Canada represented the PI patient population during different consultations, working groups and committees affecting the community in 2022, including:

- The Request for Proposal for Immunoglobulin Products with Canadian Blood Services.
- Health Canada's Drugs for Rare Disease Strategy
- National Emergency Blood Management Committee IG Shortage Plan
- Canadian Blood Services IG Patient Forum

In October 2022 Executive Director, Whitney Goulstone, and Programs Manager, David Josey, represented Canada at the Global Patient Meeting in Gotenburg, Sweden. At the meeting, Whitney was voted on to the International Patient Organization for Primary Immunodeficiencies (IPOPI) board and is pleased to represent Canada's PI population on the global level.

## Newborn Screening

After several years of continued advocacy work across the country to get Severe Combined Immune Deficiency (SCID) included on provincial newborn screening programs, much progress was made as British Columbia became the 9th province and the Yukon became the third territory to add SCID to their newborn screening panel.

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***As of September 2022, babies born in all provinces and territories except Newfoundland & Labrador are screened for SCID at birth.***

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*IMAGE: Dawn Shirley and daughter Quinn, born with SCID in BC. Dawn and family advocated for the addition of SCID to the newborn screening program in British Columbia and the Yukon.*

In December 2022, ImmUnity Canada launched a joint initiative with the Network for Rare Blood Disorders Organization (NRBDO) for the creation of a national newborn screening program. Working with Health Canada within the framework of the Federal Drugs for Rare Disease program, ImmUnity Canada continues to work with the NRBDO and other stakeholders towards this goal.

A portrait of Avery Hanson, a young person with long, wavy, light brown hair, looking directly at the camera with a slight smile. The background is a simple indoor setting with a white wall and a dark doorway. An orange circular graphic is overlaid on the top right corner, containing text.

Meet

# Avery Hanson

*Scholarship  
Recipient*

Since the start of the pandemic, I have been locked down and limited many engagements and interactions that prove particularly risky. One of the things I found limited were opportunities for work, and going into university, I found it difficult even to cover tuition without assistance. I am very grateful to receive the award in a time where I am under exceptional circumstances that make it especially difficult to fund my own education.




# Research & Development

In April, 2022 ImmUnity Canada (then CIPO) produced a study on “Understanding attitudes and obstacles to vaccination against COVID-19 in patients with primary immunodeficiency” which was published in *The Journal of Allergy and Immunology*.

Research | [Open access](#) | [Published: 09 May 2022](#)


## Understanding attitudes and obstacles to vaccination against COVID-19 in patients with primary immunodeficiency

[Babak Aberumand](#) , [Whitney Ayoub Goulstone](#) & [Stephen Betschel](#)

*Allergy, Asthma & Clinical Immunology* **18**, Article number: 38 (2022) | [Cite this article](#)

Also in 2022, ImmUnity Canada created new programs to contribute to the ongoing development of the PI community. These included the following awards:

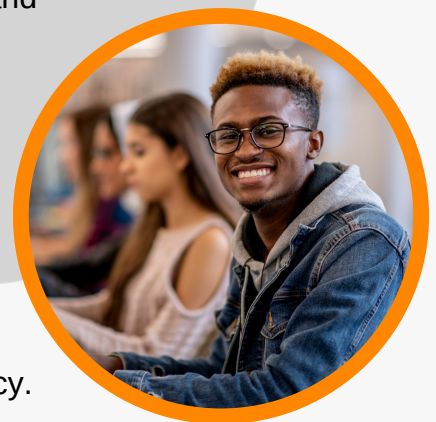
### The Immunology Resident Research Award



The Immunology Research Award is intended to support a resident enrolled in a Royal College of Physicians and Surgeons of Canada (RCPSC) Clinical Immunology and Allergy residency training program, who is pursuing qualitative or translational research project at the field of immunology, at an academic centre in Canada, and whose research aligns with one or more of ImmUnity Canada’s goals: improving patient care, patient education, patient support and advocacy. Candidates are expected to have a well-described research project that is feasible to complete within one year and with potential to improve the quality of life of patients living with immunodeficiencies.

### Youth Higher Education Scholarships

The Youth Higher Education Scholarships are intended to support youth (aged 17-25) currently enrolled in a recognized Canadian higher education program, and whose lives have been affected by immunodeficiency.



Meet

# Kevin Lee

*Research Grant Recipient*



Kevin Lee is a recent graduate from the Adult Clinical Immunology and Allergy program at the University of British Columbia. His clinical rotations with Dr. Biggs and Dr. Pourshahnazari at the Primary Immunodeficiency Transition Clinic furthered his appreciation for having a strong, patient-centered, transition-of-care clinic for individuals with complex conditions. As such, he is excited to have the opportunity to advocate for individuals with primary immunodeficiency through the project titled, *“Understanding the needs and barriers to care of adolescents and young adults with primary immunodeficiency (PID) in Canada”*.

The objective of the project is to describe the challenges faced by adolescents and young adults living with PID in accessing the adult healthcare system and how socioeconomic factors may influence this experience (e.g. social support, finances, food insecurity, housing insecurity). We also hope this will be an opportunity to generate innovative solutions to mitigate such barriers to care.

This will be completed through an online survey aimed at 18-35 year old individuals with PID living in Canada. The English version of the survey was launched as of Aug 2023 via REDCap\*, and we hope to launch a French version soon. The link was shared to ImmUnity Canada & Clinical Immunology Network-Canada (CINC) for dissemination. The grant is being used towards the REDCap survey, and to remunerate survey participants for their time (survey is estimated to take 30-45 minutes). Their team hopes to have some preliminary data by early Winter of 2023.

**Fill Out the Survey!**



<https://rc.med.ubc.ca/redcap/surveys/?s=ERA3MN9R7XFTJXY9>



# Volunteering



Meet

# Allie Smith

*ImmUnity Canada  
Volunteer*



**Where are you from?**

*Angus Ontario!*

**What do you do?**

*I am the General Manager for a custom home builder*

**Which three words would you use to explain your personality to a stranger?**

*Outgoing, lively, positive*

**Why do you like to host meet-up events?**

*I love to meet other people in the community and try support/encourage in any way I can!*

**Do you have any hobbies or interests?**

*I love to ski, read and spend time with my family and friends*

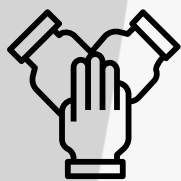
**What made you join ImmUnity Canada?**

*I love the organization and all that it stands for! Being part of a community of people going through similar life experiences.*

# Professionalising the Volunteer Experience

Towards the end of 2022, ImmUnity Canada brought on a new staff member, Fiona Coyle, as our Project and Volunteer Coordinator. Fiona joined the team help review and improve the volunteer experience and increase the ways volunteers can support and improve the lives of the PI community across Canada.

As part of this work, ImmUnity Canada has begun development on a number of volunteer guides, policies, and outreach strategies to ensure a consistent, supportive, and mutually beneficial environment for all volunteers. We also began defining a number of new and continuing volunteer roles in order to better clarify their structure and purpose. These roles included:



Board & Committee Members



CommUnity Outreach Leaders



Patient Advisory Committee



Patient Storytellers



CommUnity Connect Leaders



Event Volunteers



Plasma Awareness Leads



& more!

In total, ImmUnity Canada worked with **83 volunteers** in 2022, a number which we aim to continue to grow alongside our organization as we look forward to 2023.

*“**Connecting** with other PI patients. This **changed my life** and my whole outlook on being someone with a PI.”*

— Member survey response (2022)

## Thank You

to all of the wonderful volunteers who supported ImmUnity Canada and PI patients across Canada in 2022. We couldn't do what we do without you!

Meet

# Fiona Coyle

*Project & Volunteer  
Coordinator*



Fiona has a background in social science research, community engagement and working within the rare disorders community. She helps implement our strategic plan and works with volunteers to fulfil ImmUnity Canada's role for its members. Fiona enjoys hiking, five rhythms dancing, African drumming, learning the clarinet and solving cryptic crosswords.



# Finances





Meet

# Baden Klein

*Scholarship  
Recipient*

Hello, I'm Baden and I am studying Sport Management at Niagara College. I was so happy and proud to get the youth scholarship from [ImmUnity Canada] in 2022. The financial help really helped me in my first year of college so that I was able to focus on my studies. My first year went really well and I am excited to continue my studies and hopefully get a placement with a sporting organization at the end of next school year.

Thank you [ImmUnity Canada]!



# Finances

*“Thank you for the support you provide. I always look forward to the newsletter and updates”*

— Member survey response (2022)

2022 saw our first government funding, with a successful Canada Summer Jobs Grant, as well as an increase in donations from three private foundations: the Foster Hewitt Foundation, the Lohn Family Foundation and the Loyal Protestant Association.

We also held our first fundraising event, the Walk for PI, in 2022, which saw a marked increase in individual donations.

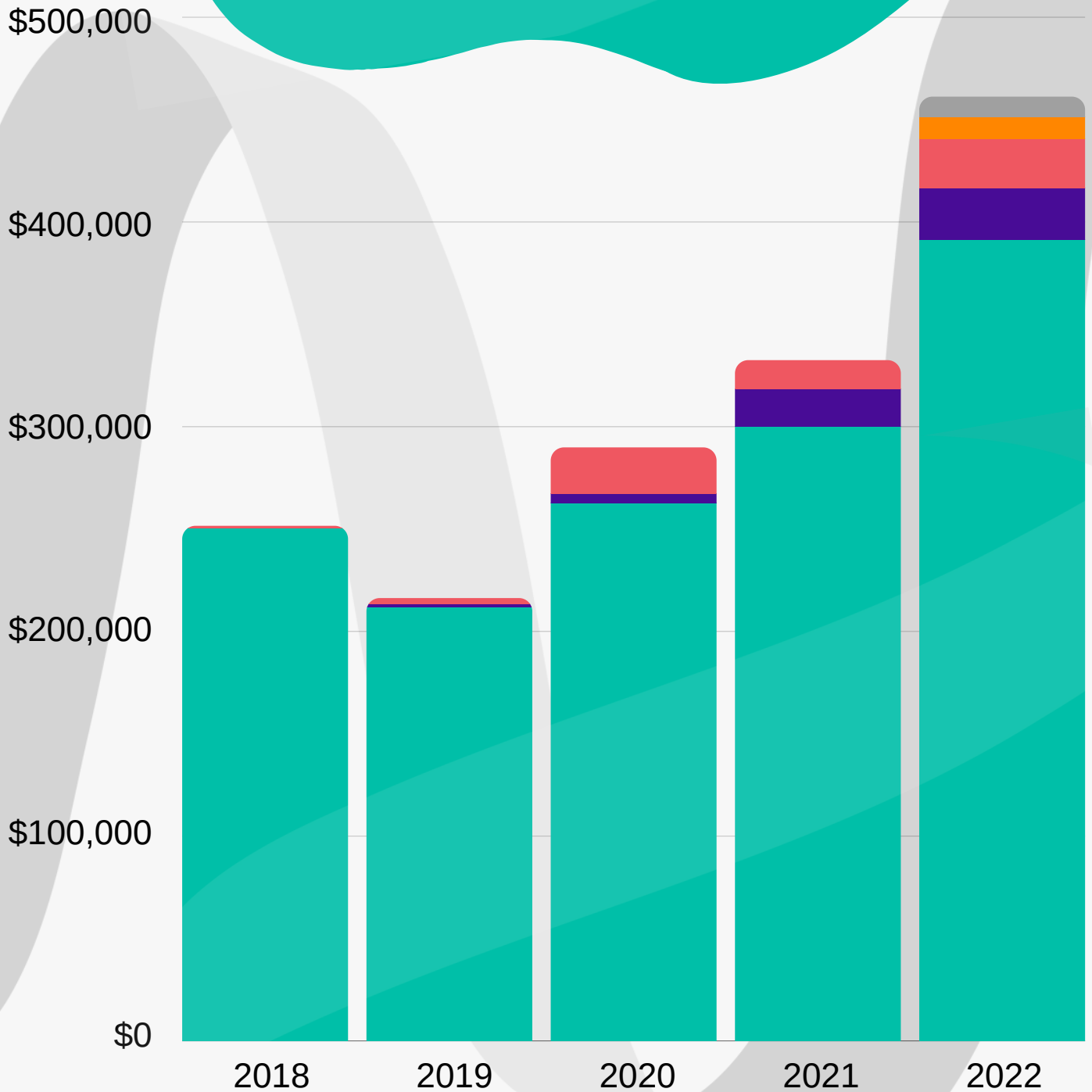
Our 2022 financial statements were audited by Welch LLP, with bookkeeping services by BDO.

In 2022, the organization was fortunate enough to substantially increase its revenue by 39% through purposeful fundraising. This was achieved primarily through building on the ongoing exceptional quality and consistency of services and programs provided by the organization, as well as the areas identified in the strategic plan. In the strategic plan, sustainability and funding were identified as priority areas to focus on going forward (2022-2027).



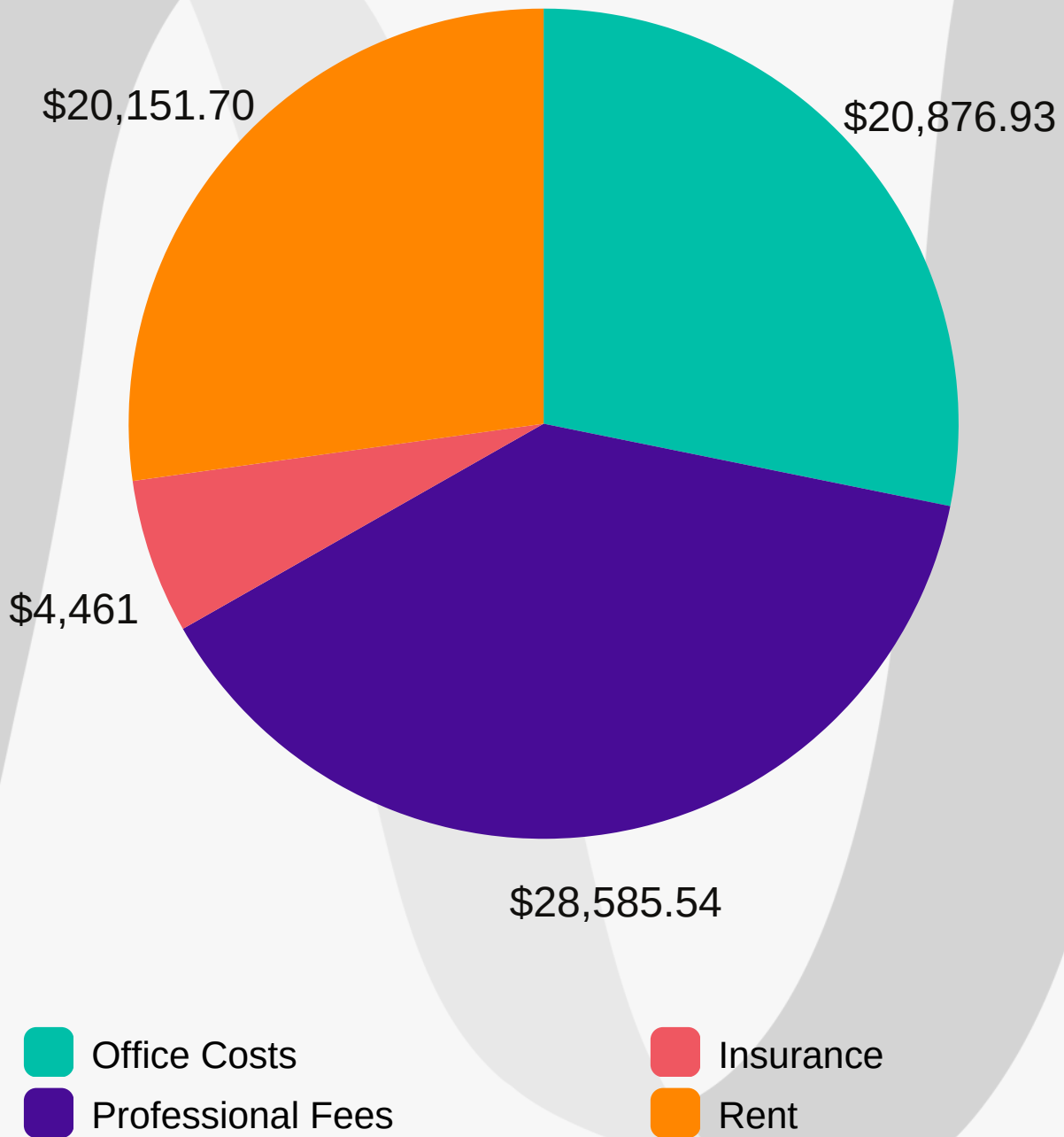
IMAGE: Immunity Canada member Beth Sasges' family take part in our first annual Walk for PI

# Revenue

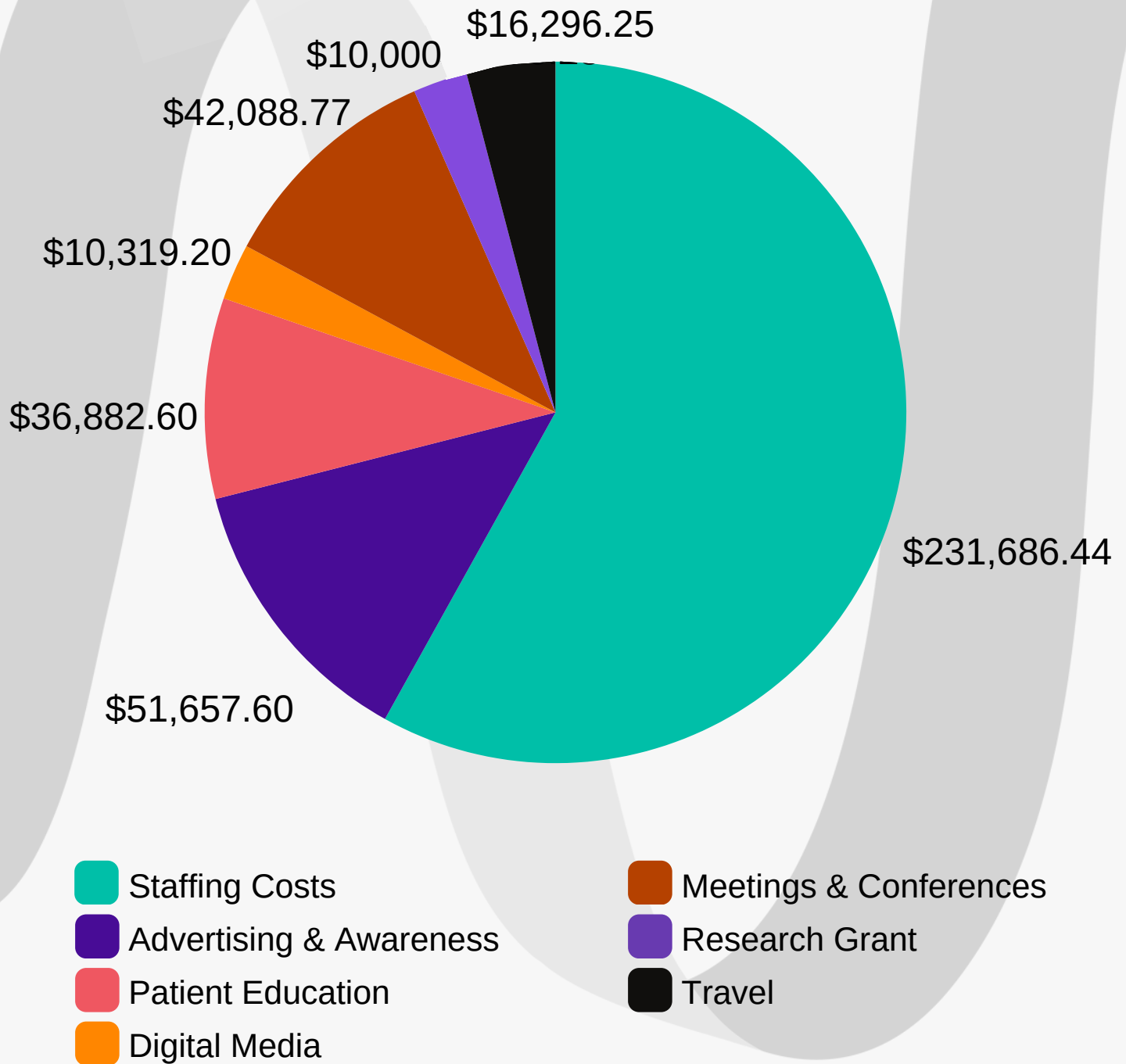


- Corporate Sponsorships & Donations
- Grants & Private Foundations
- Private Donations
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