



Andrea and Jakob, (see p.4)

Annual Report

2020-2021



Canadian
Immunodeficiencies
Patient
Organization

Table of Contents

1	Letter from the Chair & Message from the Executive Director
2	Patient Profile - Meet Jakob
3	Mission & Goals in 2020
4	Focus - COVID-19 Response
5	2020- By the Numbers
6	Volunteer Profile - Meet Deborah
7	Focus - New Programs
8	Donor Profile - Meet Peter
9	Donor Recognition
10	Board, Committees and Staff
11	Acknowledgements



Tara, patient and plasma product recipient

Letter from the Chair

This has been an unprecedented year of developments and progress in the Primary Immunodeficiency community in Canada. Although we are still experiencing the challenges of the COVID-19 pandemic, this year has brought us optimism with the procurement and distribution of vaccines. It has tested our resourcefulness and flexibility to follow and adjust to frequently changing guidelines for public safety, of which many of our PI community is quite familiar. It has tested our health care workers to maintain balance in our healthcare system while pressing individuals to remain determined in their efforts to protect themselves and keep each other safe. I'm proud to acknowledge the resilience of our PI community who continue to fight steadfastly with their chronic conditions in the face of today's climate.

It has been an eventful time at CIPO as well. We happily watched as provinces began to include testing for SCID in Newborn Screening programs, broadcasted webinars and COVID-19 updates to keep our members informed on the latest news in PI, as well as many other events to provide support, education and advocacy to immunodeficiency patients in Canada.



Looking ahead to the next year, as CIPO approaches its 25th anniversary, there is much planning of many new events and activities. We are following novel innovations in the development of plasma products and their delivery, and working towards creating new webinars and programs (both virtual and maybe even some old fashioned in person get togethers). As always, we anticipate yet another year of interesting and exciting things ahead to share with you.

Sincerely,

A handwritten signature in dark ink that reads "Christine Duncan". The signature is fluid and cursive, with the first name and last name clearly distinguishable.

Christine Duncan
Chair, Board of Directors
CIPO

Message from the Executive Director



2020 was a year to remember. For many across Canada it will be associated with terrible loss. For the majority of CIPO members, it will be associated with fear and anxiety. Many settled into a life of isolation immediately and are still living in it. Like most organizations, CIPO reimaged how we offer programs and offered all of our programs virtually. We knew that would not be enough to address the emotional and social needs of our population.

We added social events online, more meetup groups online and education webinars. We created our first podcast, "Slice of PI", aspects of lived experience of life with primary immunodeficiency. We offered financial support, including mental health support for our members.

2020 saw the beginning of new programs and services, of note, our Family Zone - programming geared specifically towards families, youth and children affected by PI. Within FZ we have lots of fun things happening - a dedicated quarterly newsletter, special events for kids and families, parent support groups, FZ webinars, Spotify playlists, and coming up in 2022, a summer camp retreat.

As vaccines were developed we worked with other patient organizations in Canada and around the globe to stay on top of research and technology. We advocated for our members, working with Canadian Blood Services

and Hema Quebec to create a product home delivery service to keep patients out of the blood banks. Although not all provinces picked up on this service, we felt it addressed a need at the beginning of the pandemic.

The past year proved that even in a global pandemic we need to fight for our voice to be heard. As the pandemic continues, the fight continues. We will continue to advocate for vaccine and antibody access for immunodeficiency patients across Canada. We continue monitoring plasma supply and our work to ensure that all patients have access, and will continue to have access going forward, to plasma products across Canada.

Our team is hard at work creating, running and maintaining programs that will continue to educate, advocate and support.

Thank you for your ongoing support,

A handwritten signature in black ink, reading "Whitney Goulstone". The signature is fluid and cursive.


Whitney Ayoub Goulstone
Executive Director
CIPO

Patient Profile

Meet Jakob

Jakob was born with ADA-SCID, a severe form of primary immunodeficiency.

"Without newborn screening, we would not have Jakob with us right now." - Andrea, Jakob's mom

A young boy with short brown hair, wearing a tan t-shirt, is smiling and looking upwards. He is standing in a park-like setting with trees and a path in the background.

Ten days after he was born, Andrea's son Jakob was diagnosed with severe combined immunodeficiency (SCID). The genetic condition affects his ability to fight infections, and his body can't keep him from getting sick. The family was told he likely only had a few months to live. "It was pretty tough, pretty awful," Andrea recalls. "We were so upset. We never imagined this would happen to us." But because of newborn screening, the condition was discovered early, and little Jakob quickly received treatments – treatments that will likely continue the rest of his life. Jakob is now 2 years old, receives antibiotics every day, and enzymes twice a week that help his lungs heal and stay healthy.

Our Mission & Goals in 2020

OUR VISION

We envision comprehensive care for Primary Immunodeficiency disorders for all patients in every province within increased visibility in the general population.

We envision greater physician support in identifying undiagnosed patients and maintaining an accurate national patient registry.

We work to ensure the provision of education programs for physicians and nurses and for the establishment of dedicated PID nurses.

OUR MISSION

To provide advocacy, education and support for all immunodeficient patients diagnosed and not yet diagnosed in Canada.



2020 GOALS

Due to the nature of 2020, the primary area of concern quickly became the health and safety of primary immunodeficiency patients across Canada during the pandemic. Our early goals of education and support were put on hold to focus on the immediate needs and to be able to respond quickly when needed.

As an organization, our internal goals were to strengthen our staff team with the addition of a social media coordinator and a new administrator.

"WE are most grateful for what YOU do at CIPO! Finding CIPO has been a huge source of support in caring for our daughter." - Glenda McGillivray, SK.

Focus - COVID-19

Response

Early on, global **research** confirmed that PI patients were at a higher risk to contract COVID-19 and that if contracted suffered **worse** outcomes. CIPO was committed to delivering its members up-to-date information, providing education throughout the pandemic and taking part in **global** research to better understand and benefit the PI community in Canada.

CIPO also **implemented** several support resources for members to remain connected and combat social isolation during the pandemic:

- Financial support for mental health
- Virtual patient meetup groups
- Monthly virtual social events

PROJECTS	DETAILS	OUTCOME
Updates	We sent out regular updates throughout the pandemic and continue to keep our website updated on the latest information regarding COVID-19	<ul style="list-style-type: none">• Members were able to stay informed regarding COVID and PI
Webinars	We held 3 COVID specific webinars (including 1 regarding COVID vaccines) targeted at the PI population	<ul style="list-style-type: none">• Members were able to ask questions to experts regarding COVID & PI• Members were able to stay informed
Research	We did a study of COVID vaccine hesitancy in the PI population in Canada and took part in a global patient study.	<ul style="list-style-type: none">• Over 490 members took part• Results will be public when study is published
Advocacy	We advocated across Canada for vaccine priority and more recently, access to third doses for PI patients.	<ul style="list-style-type: none">• This included member letter writing campaigns and media outreach.• Most provinces implemented vaccine priority for PI patients as well as third doses

2020- By the Numbers

6

Virtual theme
nights

15

Peer support
coaches

3

COVID-19
webinars

178

Total volunteer hours

4

Staff members

1213

Total downloads of "Slice of PI"
Season 1

14

Virtual
patient
"meetups"

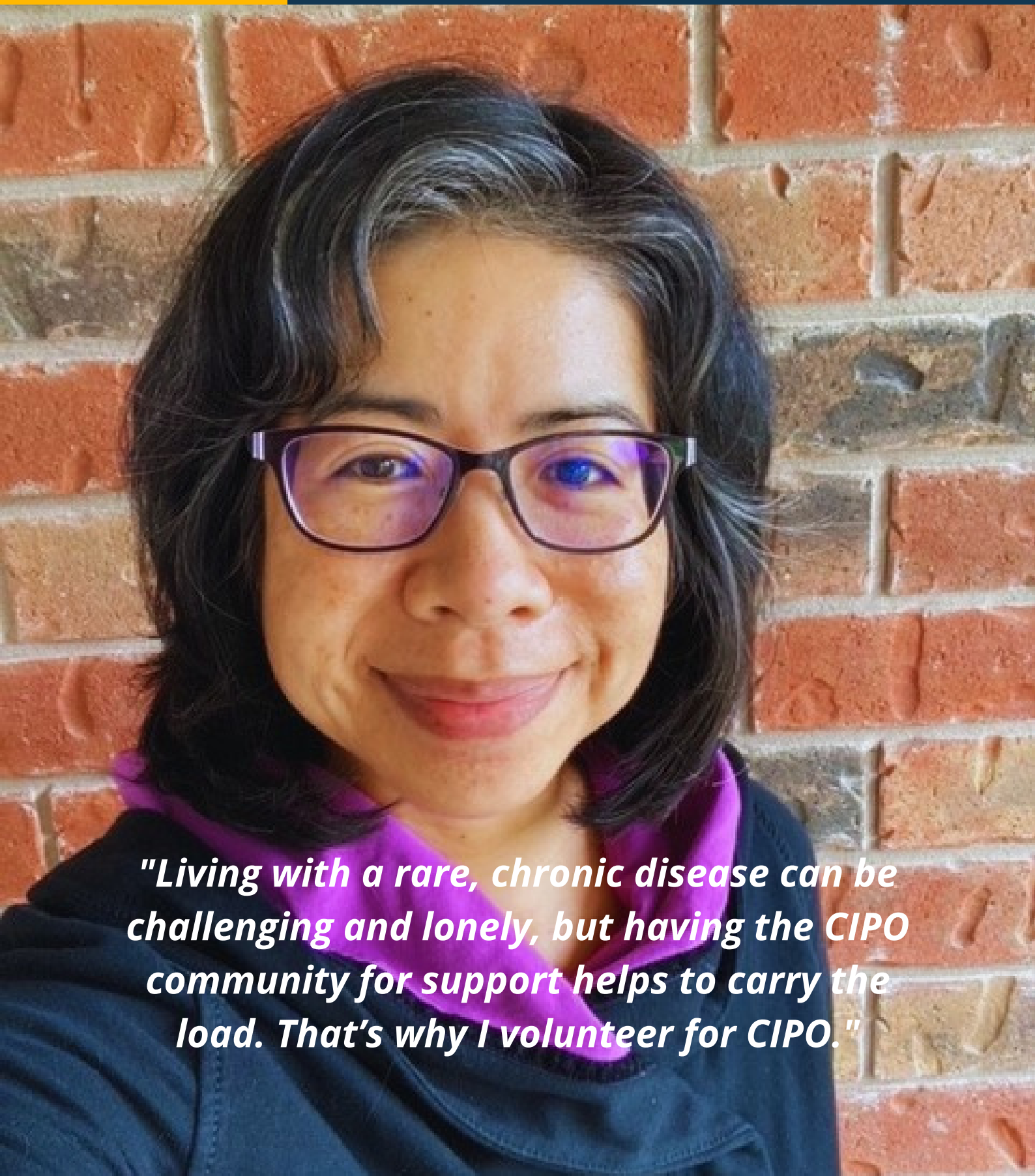
7

COVID-19
updates to
members

Volunteer Profile:

Meet Deb

Patient and volunteer. Deborah currently volunteers as a member of Ontario's Steering Committee. Deb was diagnosed with Common Variable Immune Deficiency.



"Living with a rare, chronic disease can be challenging and lonely, but having the CIPO community for support helps to carry the load. That's why I volunteer for CIPO."

Focus - New Projects

2020

In 2020, CIPO expanded our program offering. We also adapted our programs and services early in the year, due to COVID-19. CIPO's programs and services centre around our three pillars: Education, Support and Advocacy. **New** offerings were added to assist the PI community adjust to life during the pandemic, while many across Canada faced **isolation** for the majority of the year.

Our team knew that the COVID-19 pandemic meant that PI patients and their families were adjusting to a new way of living.

This meant that not only could CIPO no longer offer our in-person programs and services, but we would also need to implement supporting services for those facing hardship caused by the pandemic.

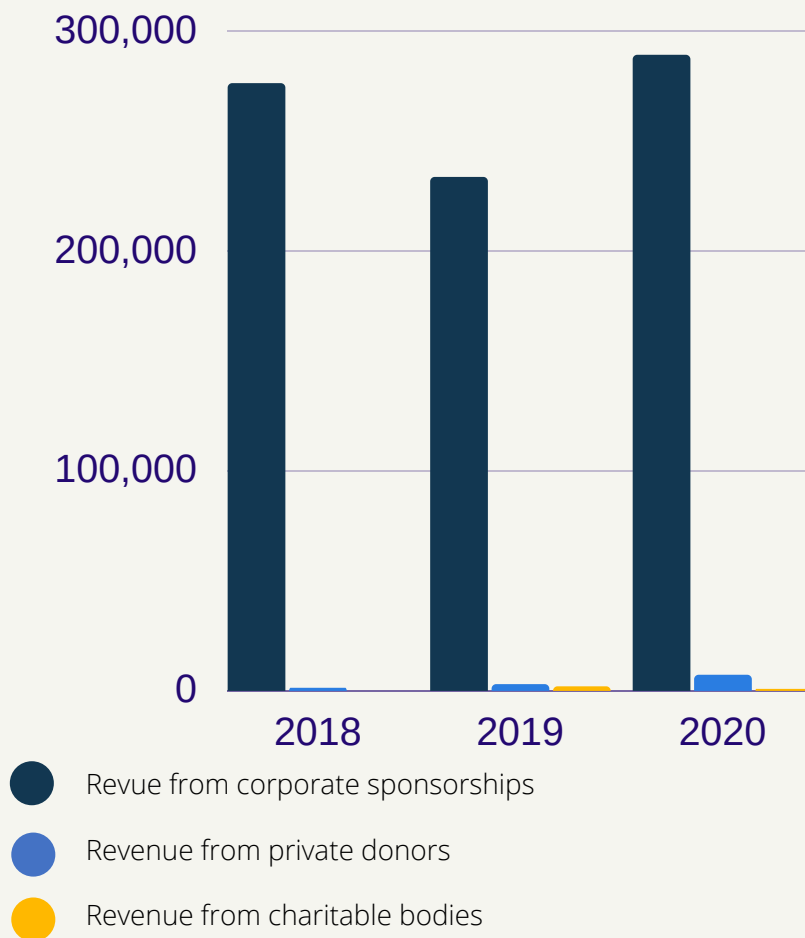
We attempted to continue to deliver the **quality** programming that our members expect when they would attend a support group or an education day in their chapter, but also supplement with services and programs to bring the community together.

PROJECTS	DETAILS	OUTCOME
Virtual Social Activities	We hosted a series of virtual social events for our members during COVID	<ul style="list-style-type: none">• Members were able to connect during the months of isolation and take part in a fun craft or activity• Over 80 members attended the events
"Slice of PI" Podcast	CIPO's first podcast - for patients by patients	<ul style="list-style-type: none">• 13 episode season• Season 2 starting December 2021• See Appendix A in Programs
Patient Meetups	Our support groups moved online - with bi-weekly informal "meetups"	<ul style="list-style-type: none">• Patients commented that these groups are more accessible• Started monthly, increased demand moved to bi-weekly.

In 2020, as CIPO expanded our services offerings, globally the not for profit sector saw a decrease in private donations and corporate sponsorships. CIPO is dedicated to the sustainability of the organization and the continued financial stability.

REVENUE 2020

A look at CIPO's donations and sponsorships in 2020



2%

Amount of CIPO's revenue in 2020 that was generated outside of corporate sponsorships and grants

\$7343

Total private donations CIPO received in 2020

CIPO has identified funding diversity as a high priority area of concern. In order to secure funding diversity, CIPO is taking the following measures:

- The appointment of a professional Fund Development Coordinator.
- The implementation of a Fund Development Plan.
- The implementation of a donor management system.
- Establishing a new "culture of giving" within our membership and organization, including paid events.
- We will continue to monitor and review as we move forward, making changes as necessary. We understand that the future of giving in Canada has been affected by the COVID-19 pandemic and we need to adapt in order to continue serving the PI community.

Donor Profile

Meet Peter

Peter Jaworski is a professor of ethics at Georgetown University's McDonough School of Business and CIPO donor.

I've been researching the ethics and economics of the plasma industry for many years, and as part of my research I had the opportunity to meet and speak with many patients... Listening to their stories inspired me to become a regular donor.

There is still so much more that needs to be done, and seeing how much CIPO does makes me feel proud to support this organization. I'm happy to do it, I hope it helps, and I hope many others join me

Our Donors & Supporters 2020

CIPO would like to thank the following corporations, individuals and foundations for their support in 2020.

Corporate Sponsors:

Takeda Canada
Grifols Canada
CSL Behring Canada
Octapharma Canada

Charitable Donations:

IPOPI
Seger Family Foundation



Private Donors:

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Tod Markelj
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Toni Quinn
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Adam Clarkson
Peter Jaworski
Margaret Jurocko
Elke Ruediger-Dooley
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Dave and Glenda McGillviray
Ingrid Brodie
Michelle DesHarnais
Delia Cooper
Genevieve Iori
John Boyle
Natalie Huizinga
Sergio Vulej
Doris Gates
Lee Strickland
Carol King
Marlene Lillico
Julie McIntosh

We thank you for your
continued support

Canadian Immunodeficiencies
Patient Organization
#206-645 Fort Street, Victoria,
BC, V8W 1G2
(250)381-7134
www.cipo.ca
info@cipo.ca

Our Board, Staff & Committees

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Acknowledgements

The Canadian Immunodeficiencies Patient Organization (CIPO) would like to acknowledge the following people:

- Our volunteers across the country
- Our Chapter Steering Committee members
- Our Board of Directors
- Our Medical and Science Advisory Committee
- Our Nurse Advisory Committee

Our **colleagues** from our Partner Organizations

Our staff who continued to work tirelessly to serve the immunodeficiency community across Canada.

All those who **contributed** to this report



Volunteer, Safira, Medicine Hat, AB.



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