

A REPORT FOR:



## 2022-2027 Strategic Plan Report



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# Introduction

For 25 years, the Canadian Immunodeficiencies Patient Organization (CIPO) has served as a critical resource for individuals and families impacted by primary immunodeficiency (PI) and related conditions. CIPO has helped thousands of Canadians cope with complex and sometimes life-threatening disorders by providing educational and supportive programming; advocating for awareness, treatment access and dedicated care; and participating in global research.

Over the last two years, CIPO'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, the organization is at an exciting junction where a new strategic plan is imperative for growth and success.

In February 2022, CIPO engaged Offord Group (now Marts&Lundy) to facilitate a strategic planning exercise. Key inputs in the process included:

- Introductory meetings with the Executive Director and Chair, Board of Directors
- Materials review
- Board of Directors strategic planning retreat held March 19-20, 2022 (see [Appendix A](#) for a listing of participants)
- Review of a draft report by the Executive Director and Board of Directors

This report captures the work undertaken and provides the organization with a framework for the next three to five years.

Marts&Lundy would like to thank all participants, as this project benefitted significantly from their involvement, encouragement, and perspectives. We hope this serves as a platform for impact and success.

## 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 GOALS

Programs with Measurable Impact	Equitable Access through Advocacy	A Growing, Inclusive Community	Operational Strength and Sustainability
<ul style="list-style-type: none"> <li>• Further CIPO’s evidence-based, person-centred approach to education and support.</li> <li>• Continue pursuing high-impact research partnerships.</li> </ul>	<ul style="list-style-type: none"> <li>• Increase awareness of immunodeficiency disorders and CIPO in the medical community.</li> <li>• Champion equitable access to primary immunodeficiency (PI) treatment for patients.</li> <li>• Continue advocacy for a national PI patient registry.</li> </ul>	<ul style="list-style-type: none"> <li>• Redefine CIPO membership to emphasize community, inclusiveness and mutual support.</li> <li>• Enhance CIPO’s brand and communications to increase engagement and expand reach.</li> <li>• Revitalize the Chapter Steering Committees to increase awareness and community-building in all Canadian regions.</li> <li>• Take a strategic approach to raising awareness about PI among priority groups, including Canadians 19-35.</li> </ul>	<ul style="list-style-type: none"> <li>• Increase funding through diversified funding streams.</li> <li>• Ensure that organizational capacity is commensurate with goals.</li> <li>• Continue efforts to optimize Board governance and engagement.</li> </ul>

# Mission, Vision and Values

## Proposed Mission

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

## Proposed Vision

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

## Proposed Values

**Community:** We are dedicated to facilitating connections and collaborating to reach shared goals with our entire community – beneficiaries, partners and funders, volunteers, staff, and ultimately, all Canadians with immunodeficiency disorders.

**Equity:** We are committed to proactively seeking fairness in access to treatment, information, resources and care.

**Inclusiveness:** We believe in fostering an environment where all individuals and groups feel safe, respected, engaged and valued for who they are, their perspectives and their contributions.

**Empowerment:** We recognize our community's strengths and resilience, and bolster individual capacities to self-advocate.

**Excellence:** We are ambitious in our pursuit to support the immunodeficiency population and create meaningful and sustainable impact.

**Innovation:** We embrace change and opportunity; we strive to be courageous, progressive and creative.

# CIPO Today: SWOT Analysis

Through the consultation process, key topics of consideration for the strategic plan surfaced. These are summarized here in a Strengths/Weaknesses/Opportunities/Threats analysis.

## Strengths

- Revitalized, diverse and engaged Board of Directors
- Dedicated staff with strong skillsets
- Engaged membership and well attended programs
- Good connections, especially to the medical community
- Experience and longevity
- Credible subject matter expertise
- Distinct value as the only PI patient organization in Canada
- Track record of being proactive, progressive and adaptable
- Good community-builder

## Weaknesses

- Scope of geographic reach in Canada
- Chapter Steering Committees structure, engagement and vitality
- Membership definition
- Challenges identifying CIPO's population to increase support
- Brand and brand awareness
- Fund diversity
- Staff capacity
- Operational – financial transparency and reporting, by-laws, Board and staff role clarity

## Opportunities (in addition to addressing weaknesses)

- National patient registry
- Leveraging recent survey data
- Research
- Partnerships
- New website
- 25th anniversary (2022)
- Greater focus on diversity, equity and inclusion (DEI)
- Major gifts and endowment
- In-person programs and outreach
- Leveraging increased understanding of immunodeficiency through COVID
- Greater social media presence

## Threats

- Lingering effects of COVID on those with PI
- Competition/overlap with other organizations
- Low number of specialists and understanding within medical community
- Volunteer and membership recruitment
- Ageing membership
- Staff retention
- Global/political/economic realities

# Goals, Strategies & Tactics

The following goals, strategies and tactics are proposed for CIPO for 2022-2027. Some tactics will require further refinement during implementation and annual operations planning.

## 1. Programs with Measurable Impact

### 1.1 Further CIPO's evidence-based, person-centred approach to education and support.

- A) Complete the standardized program framework and integrate measurement, evaluation and learning planning.
- B) Use the 2022 survey as well as other data sources to inform the program framework.
- C) Assess programming through a diversity, equity and inclusion (DEI) lens, pursuing representation and inclusion of the full diversity of the immunodeficiency population in programming.
- D) Revitalize the peer-to-peer support program to ensure that it is meeting the expectations of volunteers and participants, especially in the COVID/post-COVID landscape.
- E) Explore the need for additional programming – online and in-person, including education and support around navigating the lasting COVID-19 environment.
- F) Develop and implement a volunteer management plan that recruits, empowers and retains program volunteers effectively.

### 1.2 Continue pursuing high-impact research partnerships.

- A) Mobilize the Medical, Science and Nurse Advisory Committees to identify and advise on research partnership opportunities that align with CIPO's capacities.
- B) Increase awareness about existing research and study participation opportunities through the website and other communication channels.
- C) Establish a nurse accreditation program in immunodeficiency, and subsequently explore the opportunity to establish a similar medical resident accreditation.
- D) Pilot a scholarship program for immunology residents and explore opportunities to grow it.

## 2. Equitable Access through Advocacy

### 2.1 Increase awareness of immunodeficiency disorders and CIPO in the medical community.

- A) Identify immunodeficient individuals' entry points into the healthcare system and pinpoint where in the process—and how— referrals to CIPO can be made.
- B) Actively raise CIPO's profile in the general practitioner community to educate physicians on PI and CIPO's services (through conferences, journals, and immunologist networks).
- C) Implement a process for quarterly check-ins with immunologists in CIPO's network of clinics to facilitate information sharing and mutual support.
- D) Build awareness with medical and nursing students and residents by connecting to university interest groups.

### 2.2 Champion equitable access to PI treatment for patients.

- A) Leverage strategic collaborations with health organizations (including NRBDO and CINC) to advocate for availability and access to treatment such as plasma therapy.
- B) Continue efforts to advocate to the government about priority access to diagnosis, treatment, testing, prevention therapy and vaccines for PI patients; build awareness around the increased access.
- C) Continue efforts to allow immunodeficient patients across Canada access to private clinics when alternatives are not possible or adequate.

### 2.3 Continue advocacy for a national PI patient registry.

- A) Actively participate in the Canadian Immunology Network – Canada initiative to create a patient registry.
- B) Collaborate with the Network on funding opportunities.
- C) Once launched, promote participation in the registry to patients and clinics.

## 3. A Growing, Inclusive Community

### 3.1 Redefine CIPO membership to emphasize community, inclusiveness and mutual support.

- A) Update by-laws to redefine the membership structure to include only board members as voting members, while reframing the definition around non-voting membership to emphasize a sense of community around CIPO's mission, learning and support.
- B) Determine what (if any) criteria must be met to qualify as a non-voting member and how this connects to CIPO's goals; consider renaming the group; articulate any associated levels and benefits through an engagement lens.



- C) Evaluate and adapt programming, communication, and other strategies to align with the new definition of membership.

### **3.2 Enhance CIPO's brand and communications to increase engagement and expand reach.**

- A) Engage a professional partner to lead a rebranding exercise and develop a rollout plan.
- B) Develop a communication plan aimed at effectively and consistently delivering important messages to the CIPO community. Content should include a mix of education, promotion of programming, fundraising and stewardship of partners/volunteers/beneficiaries/donors.
- C) Develop and monitor measures of engagement success.
- D) Use the new website launch as an opportunity to drive traffic to the website and increase email subscriptions.
- E) Ensure individual information, especially email addresses, is captured at all appropriate junctions.

### **3.3 Revitalize the Chapter Steering Committees to increase awareness and community-building in all Canadian regions.**

- A) Revisit the structure and mandate of the Chapter Steering Committees to augment their roles as advocates, promoters, and community-builders in their respective regions.
- B) Determine whether a regional structure can be more efficient and effective than a provincial one.
- C) Revise and simplify the terms of reference.
- D) Build in a mechanism for transparency, connection and collaboration between the committees and the Board of Directors.
- E) Implement a recruitment plan for committee volunteers.

### **3.4 Take a strategic approach to raising awareness about PI among priority groups, including Canadians 19-35.**

- A) Annually, identify a limited number of priority groups who are currently under engaged using the survey data and through a DEI lens. The 19-35 year old cohort should be an early priority.
- B) Assess the outreach and engagement tools and opportunities within CIPO's disposal (programs, marketing/communications and social media, events, partnerships and networks, etc.) and design and incorporate specific strategies.
- C) Develop and monitor measures of engagement success.

## 4. Operational Strength and Sustainability

### 4.1 Increase funding through diversified funding streams.

- A) Revisit the fund development plan so that it outlines goal-oriented strategies for individuals (annual giving and events, major gifts), corporations/pharmaceutical funders, and grants.
- B) Continue focus on growing unrestricted funds through individual giving that incorporates online appeals, calls for 100% board and chapter committee participation, and events with high ROI (including third-party events).
- C) Evaluate whether existing staffing and expertise are adequate for growing fundraising and consider re-adding capacity to the fund development function.

### 4.2 Ensure that organizational capacity is commensurate with goals.

- A) Assess CIPO's capacity to deliver on its goals and identify resource gaps and plans to address them.
- B) Review HR practices, including compensation and growth opportunities, to ensure they support recruitment and retention standards.
- C) Initiate succession planning for key leadership positions.

### 4.3 Continue efforts to optimize Board governance and engagement.

- A) Update job descriptions for Board and staff to ensure there is clarity around roles and expectations.
- B) Increase opportunities for Board enrichment and active involvement.
- C) Review the Board evaluation and recruitment tools to ensure they are still relevant and align with organizational values.
- D) Consider increasing the Board size to fill growing needs for skills and expertise, and diversity.
- E) Upgrade financial reporting to strengthen transparency and strategy.

## Next Steps

### Implementation and Annual Planning

The strategic plan will guide the development of an implementation plan and annual operating plans. The Executive Director will lead implementation planning, working with staff and the Board to lay out timelines, assign responsibilities and develop performance indicators. This work should take place over the next quarter. A template for implementation planning is provided in [Appendix B](#).

### Evaluating Strategic Plan Progress

The strategic plan should be used as a framework to guide decision-making and to keep staff and the Board accountable to shared goals. **Evaluating progress on the plan should be done quarterly**, at minimum, with a more thorough review annually.

**Given the ever-changing climate, it is recommended that the plan be fully assessed after three years.** At that point, CIPO may wish to keep and update it for another year or two if outstanding goals are still relevant, or it may choose to develop a new strategic plan.

*Thank you for partnering with Offord Group/Marts&Lundy on this important work. We believe that CIPO is in a strong position to put this strategic plan in motion to make a positive difference in the lives of Canadians with immunodeficiency.*

## Appendix A: List of Consultation Participants

- Whitney Goulstone, Executive Director
- David Josey, Programs Manager
- Lauren House, Administrator
- Christine Duncan, Chair, Board of Directors
- Lee Strickland, Vice Chair
- Brent Leonard, Treasurer
- Ingrid Brodie, Director
- Kim Hanson, Director
- Mario LeClerc, Director
- Thomas Lee, Director
- Alyshah Nurani, Director

# Appendix B: Implementation Planning Template

Available in Excel upon request.

	FY 2022				FY 2023				FY 2024				Outcome/Performance Indicator	Team Lead
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4		
<b>Goal 1</b>														
<b>1.1 Strategy</b>														
A. Tactic														
B. Tactic														
C. Tactic														
<b>1.2 Strategy</b>														
A. Tactic														
B. Tactic														
C. Tactic														
<b>1.3 Strategy</b>														
A. Tactic														
B. Tactic														
C. Tactic														
<b>Goal 2</b>														
<b>2.1 Strategy</b>														
A. Tactic														
B. Tactic														
C. Tactic														
<b>2.2 Strategy</b>														
A. Tactic														
B. Tactic														
C. Tactic														

