



Inflamed Brain Alliance 2026 Strategic Priorities



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Introduction

Over the past five years, the Inflamed Brain Alliance has achieved remarkable early successes, validating its vision and demonstrating the strength of a connected, committed community. From hosting Canada's first medically accredited national PANS/PANDAS conference in May 2025 to engaging patients, families, and health professionals, and launching major awareness initiatives such as the global Light Up Campaign and the national Steppin' Out Walk, IBA has become a trusted voice and compassionate hub for those affected by PANS and PANDAS.

These efforts have strengthened partnerships, elevated national visibility, and laid the foundation for the Canadian PANS Registry—launched in May 2025—which will support research, advocacy, and evidence-based care as it continues to grow. Building on this momentum, IBA is now transitioning beyond its start-up phase to strengthen internal capacity, reduce reliance on a small group of leaders, and ensure long-term sustainability. These next steps will help ensure that patients, families, educators, and health professionals across Canada have the advocacy, education, and support they need.

Priority 1: Strengthen Financial Sustainability

Rationale: Stable, diversified funding ensures long-term growth and credibility.

Actions:

- 1.1 **Strategic Fundraising** | Develop a comprehensive fundraising plan with targets, timelines, and accountability.
- 1.2 **Key Revenue Sources** | Expand major donor and corporate sponsorship streams.
- 1.3 **Monthly Giving** | Grow monthly donor programs through events, storytelling, and social media.
- 1.4 **Financial Management** | Hire a bookkeeper/financial manager with charity experience to strengthen budgeting and reporting.

Priority 2: Invest in People and Leadership Capacity

Rationale: Expanding governance, staffing, and volunteer infrastructure reduces reliance on a few leaders and supports sustainable growth.

Actions:

- 2.1 **Board Leadership** | Recruit & develop board members with expertise in key areas.
- 2.2 **Executive Leadership** | Hire a part-time Executive Director to oversee operations and organizational development.
- 2.3 **Volunteer Leadership** | Re-establish a volunteer coordinator role to manage recruitment, training, recognition, engagement, and administrative oversight.
- 2.4 **Volunteer Plan** | Implement a volunteer plan with training, role clarity, recognition, and succession strategies.

Priority 3: Expand Programs and Evidence-Based Impact

Rationale: IBA's credibility rests on its registry, education, and community programs. Expanding CME, clinician and research partnerships, and caregiver supports will deepen impact and position IBA as a national leader in PANS/PANDAS advocacy and education.

Actions:

- 3.1 **Clinicians' Network** | Launch IBA's Clinicians' Network to connect health professionals across Canada.
- 3.2 **Research** | Launch the Canadian PANS Registry Steering Committee to guide a national research strategy, prioritize evidence-based studies, and foster collaborations with clinicians and researchers.
- 3.3 **Health Canada Statement** | Advocate for a national screening statement recommending physician evaluation for PANS/PANDAS in acute-onset neuropsychiatric cases.
- 3.4 **Education** | Grow CME offerings, including grand rounds, conferences, and modular education.
- 3.5 **Family Supports** | Expand leadership and the national peer support network through IBA's Hope Companions program, providing young adults and caregivers with meaningful, topic-focused sessions for support, connection, and practical guidance.
- 3.6 **Psychoeducation Programs** | Launch programs addressing patient and caregiver trauma and disease stigma.

Priority 4: Elevate Profile and Storytelling

Rationale: Awareness and credibility depend on compelling stories and national visibility, attracting donors, volunteers, and medical allies while supporting families.

Actions:

- 4.1 **Communications & Media** | Invest in communications and social media strategies, including reels, campaigns, a monthly newsletter, and storytelling.
- 4.2 **Signature Events** | Expand signature awareness events: Light Up Campaign, Steppin' Out Walk, World Awareness Day.
- 4.3 **Brand Positioning** | Position IBA as a trusted national voice through media engagement and thought leadership.
- 4.4 **Storytelling & Advocacy** | Share family and patient stories to humanize the cause and strengthen advocacy.
- 4.5 **Ambassadors for Awareness** | Launch an Ambassador Program to empower families, clinicians, and allies with tools, training, and messaging to drive grassroots awareness.