ME | FM
Society of BC

Annual General Report 2024-2025

Message from the Executive Director

This year marked a fundamental transformation for the ME | FM Society of BC—we have evolved from a community support organization into the province's authoritative voice on ME/CFS, Fibromyalgia, and Long COVID policy and care.

Our priority was grounding advocacy in unassailable data. The community survey we launched represents the largest systematic assessment of ME/FM healthcare experiences in BC history. With **1,045 respondents** providing over **3,000 written comments**, it was documentation of a healthcare crisis affecting hundreds of thousands of British Columbians.

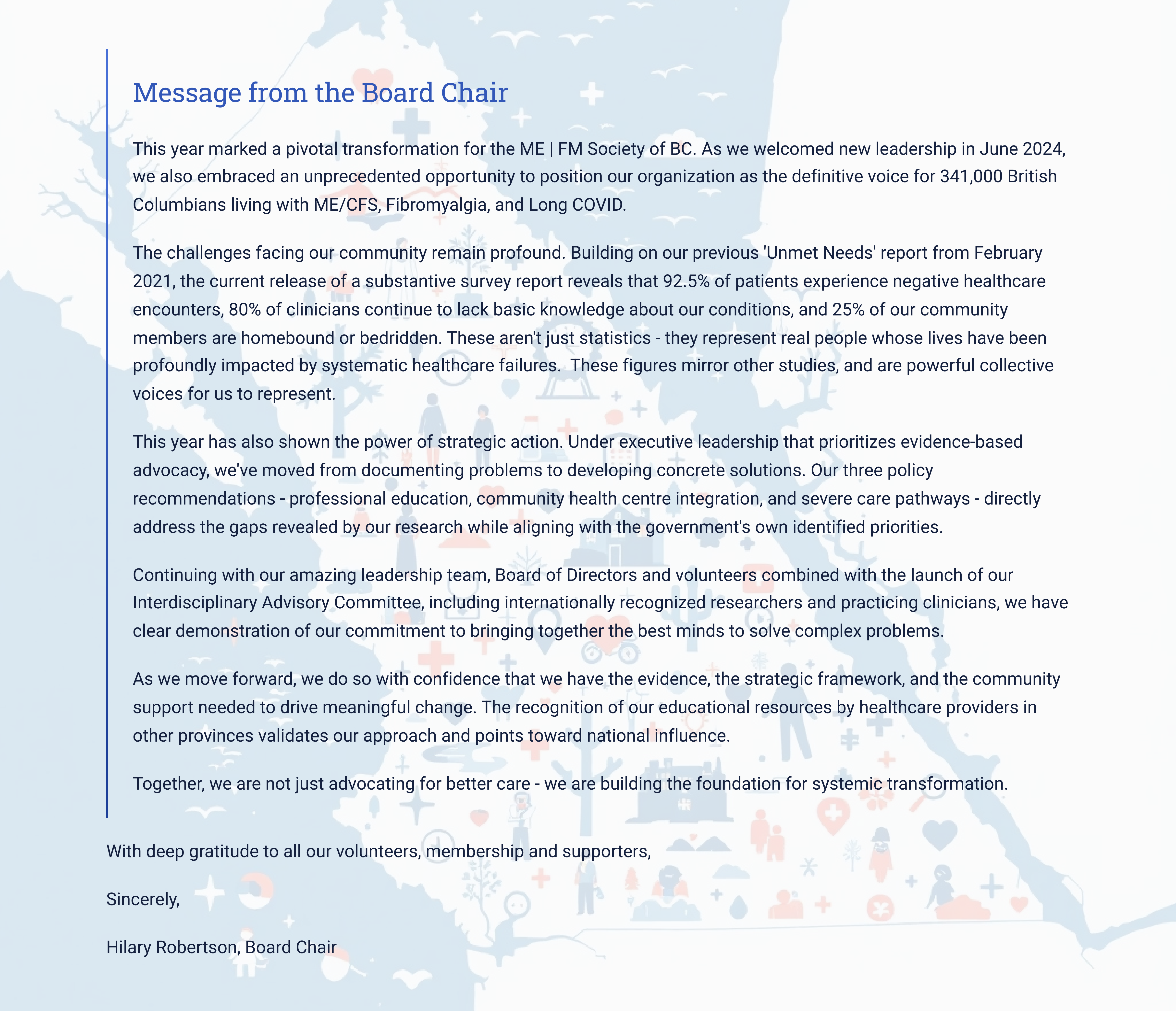
The stories that emerged were both heartbreaking and powerful. One community member, a computer science professor, wrote: *"I was forced to retire in 2016 at the age of 45. I now live on a small disability pension and rarely leave my home. Would it not be better to treat people with ME/CFS and invest in research so that we could be productive?"* His story, multiplied across our community, demonstrates the devastating human and economic cost of healthcare system failure.

Rather than making isolated requests, we used data to develop comprehensive policy solutions that position our recommendations within government's own identified priorities. This approach transforms us from supplicants asking for help to partners offering solutions to problems the government has already acknowledged.

The next six months will see the release of our white papers, comprehensive stakeholder engagement with healthcare professional organizations, and continued policy development. We have built the foundation for sustainable, evidence-based advocacy that positions British Columbia as a leader in addressing complex chronic illness.

In solidarity and service,

Talia R.C, Executive Director



Message from the Board Chair

This year marked a pivotal transformation for the ME | FM Society of BC. As we welcomed new leadership in June 2024, we also embraced an unprecedented opportunity to position our organization as the definitive voice for 341,000 British Columbians living with ME/CFS, Fibromyalgia, and Long COVID.

The challenges facing our community remain profound. Building on our previous 'Unmet Needs' report from February 2021, the current release of a substantive survey report reveals that 92.5% of patients experience negative healthcare encounters, 80% of clinicians continue to lack basic knowledge about our conditions, and 25% of our community members are homebound or bedridden. These aren't just statistics - they represent real people whose lives have been profoundly impacted by systematic healthcare failures. These figures mirror other studies, and are powerful collective voices for us to represent.

This year has also shown the power of strategic action. Under executive leadership that prioritizes evidence-based advocacy, we've moved from documenting problems to developing concrete solutions. Our three policy recommendations - professional education, community health centre integration, and severe care pathways - directly address the gaps revealed by our research while aligning with the government's own identified priorities.

Continuing with our amazing leadership team, Board of Directors and volunteers combined with the launch of our Interdisciplinary Advisory Committee, including internationally recognized researchers and practicing clinicians, we have clear demonstration of our commitment to bringing together the best minds to solve complex problems.

As we move forward, we do so with confidence that we have the evidence, the strategic framework, and the community support needed to drive meaningful change. The recognition of our educational resources by healthcare providers in other provinces validates our approach and points toward national influence.

Together, we are not just advocating for better care - we are building the foundation for systemic transformation.

With deep gratitude to all our volunteers, membership and supporters,

Sincerely,

Hilary Robertson, Board Chair

Our Mission and Vision

Our Mission

To improve the lives of British Columbians affected by Myalgic Encephalomyelitis (ME/CFS), Fibromyalgia, and Long COVID through education, awareness, support, advocacy, and research.

Our Vision

Healthy, supported, and empowered ME/FM communities across British Columbia where every person receives knowledgeable, compassionate healthcare and has access to the resources they need to live with dignity.

Education

Developing comprehensive resources and training programs to increase understanding of ME/CFS, Fibromyalgia, and Long COVID among healthcare providers and the community.

Awareness

Raising public consciousness about these complex chronic conditions and their impact on individuals, families, and communities across British Columbia.

Support

Providing resources, community connections, and practical assistance to help individuals navigate their healthcare journey and daily challenges.

Advocacy

Championing policy changes and healthcare system improvements through evidence-based recommendations and strategic engagement with government and healthcare organizations.

Research

Supporting and conducting research initiatives that advance understanding, diagnosis, and treatment options for ME/CFS, Fibromyalgia, and Long COVID.

The Community Survey: Documenting a Healthcare Crisis

Our community survey stands as a landmark achievement in Canadian ME/FM research. Completed in April 2025, this comprehensive assessment captured the healthcare experiences of **1,045 British Columbians** living with ME/CFS, Fibromyalgia, Long COVID, and Lyme Disease across all health authority regions.

1,045

Survey Respondents

Across all BC health authority regions

3,000+

Written Comments

Detailed healthcare experiences documented

347,000+

British Columbians Affected

Living with ME/CFS, Fibromyalgia, Long COVID and Lyme

Systematic Healthcare Failures Revealed

- **92.5%** reported negative healthcare encounters including dismissal and misdiagnosis
- **75%** of reported health care providers had no or inadequate knowledge of these conditions
- **98.5%** have no access to illness-focused care
- **92%** of emergency department encounters were negative
- **25%** of community members are homebound or bedridden

Economic Impact: Our analysis reveals an annual burden of **$18.7-43.4 billion** across BC, including direct healthcare costs of $1.2-3.1 billion, productivity losses of $14.9-36.4 billion, and social support costs of $2.6-3.9 billion.

> "When I was lucky enough to find a family doctor, she had no understanding of my condition. I had to scour the web and do my own research while dealing with my symptoms, eventually educating her on ME/CFS and asking whether she could medically diagnose me."
>
> — Community Survey Participant

Strategic Policy Development

Instead of making isolated funding requests, we developed a sophisticated policy framework that positions our recommendations as implementation strategies for the government's own identified priorities. Using our three strategic asks to the provincial budget committee as an anchor, we created comprehensive solutions addressing multiple government objectives simultaneously.

01

Professional Education and Clinical Guidelines

Respond to Budget Committee Recommendation 27 for "targeted investments in chronic disease treatment." Our comprehensive continuing medical education programs and clinical guidelines rapidly expand ME/FM care capacity across BC while addressing the documented 80% provider knowledge gap.

02

ME Pilot Integration into Community Health Centres

Delivers on Budget Committee Recommendations 31 & 36 for "community health centres" and "team-based care." Rather than requesting separate infrastructure, we propose designating ME/FM as priority conditions in pilot Community Health Centres.

03

Severe ME Care Gap Solutions

Advance Budget Committee Recommendations 29 & 32a for "home care services" and "digital health solutions." For the 85,000+ British Columbians who are homebound or bedridden, we propose specialized home-based medical services and telehealth supports.

1

October 2025

Release of first white paper with stakeholder engagement strategy

2

November 2025

Second white paper launch and healthcare professional organization outreach

3

December 2025

Final white paper release and comprehensive policy implementation roadmap

We are developing three interconnected white papers providing detailed implementation roadmaps. These will be released between October and December 2025, each accompanied by targeted stakeholder engagement to maximize policy impact.

Innovation and Community Impact

Our educational resources have gained national recognition beyond BC's borders. Our e-series and toolkit are now being used as education tools in another province, validating our evidence-based approach and positioning BC as a leader in ME/FM resource development.

Caregivers Toolkit

Comprehensive resource developed using community-driven design principles and incorporating member feedback to ensure practical applicability for families and support networks.

Summer in BC Toolkit

Practical guide helping community members navigate seasonal activities while managing their conditions, featuring accessible options across British Columbia.

Community Campaigns

Our structured campaign approach with **#SummerTogether** and **#MECommunityStrength** initiatives provided multiple participation levels to accommodate varying energy capacities within our community.

- Social media engagement campaigns
- Community story sharing initiatives
- Accessible participation options
- Energy-conscious activity design

Interdisciplinary Advisory Committee

Distinguished committee including Dr. Luis Nacul (internationally recognized ME/CFS researcher), Dr. Elizabeth Zubek (practicing Family Physician),Kathleen Dennis, RN, and Sarah Townsend bringing invaluable lived experience and clinical expertise.

Board Expansion

Welcomed three exceptional new board members, strengthening our organizational capacity and bringing diverse perspectives to our governance and strategic direction.

Opera Mariposa Fundraiser and Wickerson Family Gift.

Our incredible community allies organized a creative fundraising event, raising **$10,626.98** and demonstrating the power of grassroots support and artistic collaboration for our mission. Our steadfast support from the Wickerson Family continues to push our programming and reach further. We are very grateful.

Provincial Reach and Impact

The Society's work demonstrates impact across all BC regions, with survey respondents from every health authority area documenting similar patterns of healthcare system failure. This provincial scope validates our approach and demonstrates the need for system-wide solutions.

Fraser Health

Highest absolute numbers while revealing urban-specific challenges including long wait times and overcrowded healthcare facilities.

Northern Health

Greatest barriers to care access with vast distances and limited healthcare infrastructure in remote communities.

Vancouver Coastal

Similar knowledge gaps despite proximity to major medical centers and research institutions.

Interior Health

Additional barriers including travel requirements and limited specialist availability in rural communities.

Island Health

Ferry-dependent travel challenges creating significant barriers to accessing specialized care on the mainland.

Community Health Centre Integration

Building local capacity through specialized ME/FM care designation in pilot programs

Professional Education Programs

Training healthcare providers in each region to address the significant knowledge gap

Telehealth Solutions

Connecting remote patients with knowledgeable providers regardless of geographic barriers

Home-Based Care Models

Serving homebound patients across all regions with specialized medical services

Looking Forward: Strategic Priorities 2025-26

The next six months will see the culmination of this year's foundation-building work. We will release our three white papers between October and December 2025, each accompanied by targeted stakeholder engagement and media strategy to maximize policy impact.

White Paper Release Strategy

Three comprehensive policy documents providing detailed implementation roadmaps for healthcare system transformation, released strategically over three months.

Stakeholder Engagement

Targeted outreach to healthcare professional organizations, government officials, and policy makers to build support for our recommendations.

Media and Communications

Strategic communications campaign to raise public awareness and build momentum for policy changes across British Columbia.

Cross-Provincial Expansion

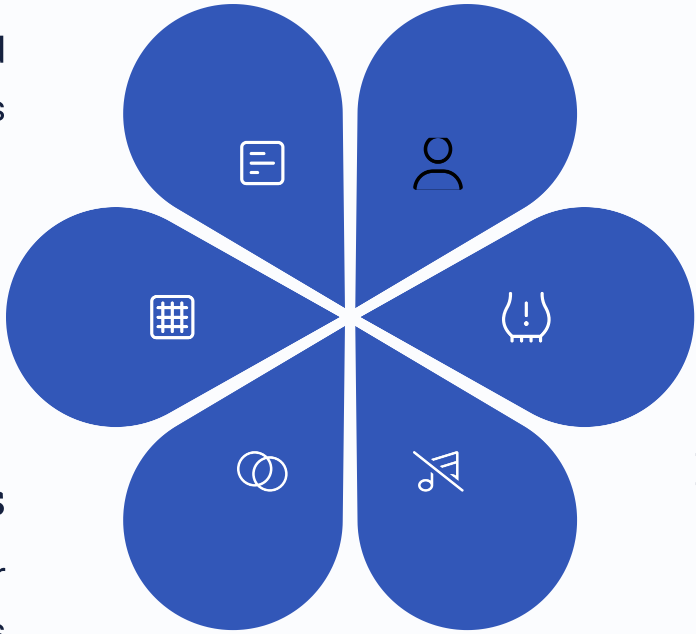
Building on recognition of our educational resources in other provinces, we will continue developing policy frameworks to amplify systemic change efforts nationally.

Key Milestones Ahead

- **October 2025:** First white paper launch with healthcare professional engagement
- **November 2025:** Second white paper and government stakeholder meetings
- **December 2025:** Final white paper and comprehensive policy presentation

Recognition and Gratitude

Our work is possible only through the dedication and courage of community members who shared their stories, participated in research, and advocated for change despite the challenges of chronic illness. We extend deep gratitude to our survey participants, advocacy campaign contributors, resource development contributors, and all community members who supported our mission.



Survey Participants

1,045 brave individuals who shared their healthcare experiences

Board Members

Current and new board members for their continued dedication

Cross-Provincial Partners

Organizations now using our educational resources

Advocacy Contributors

Community members who wrote to MLAs and participated in campaigns

Resource Development

Contributors who helped create toolkits and educational materials

Donors

Our donors who help us keep our programming running and our research work ongoing.

> ### Government and Policy Partners
>
> We acknowledge our government and policy partners, including the provincial Budget 2026 Committee whose findings align with our recommendations, and MLAs from across party lines who engaged with community member letters.

The strength of our community, despite facing significant health challenges, continues to inspire and drive our mission forward. Every contribution, whether through survey participation, advocacy efforts, or creative fundraising, has been essential to our transformation into BC's authoritative voice on ME/FM policy and care.

Conclusion: Leading Transformation

This year the ME | FM Society of BC has demonstrated that the ME/FM community, despite the challenges of chronic illness, can mobilize effectively for systemic change. From survey participation to MLA letter-writing to grassroots fundraising success, our community has shown remarkable strength and strategic sophistication.

1. **Leadership**
   BC leading transformation
2. **Partnership**
   Government collaboration
3. **Evidence**
   Data-driven solutions
4. **Community**
   347,000+ British Columbians

From Supplicants to Partners

By positioning our solutions within government's own identified priorities, we have moved from requesting help to offering partnership in solving acknowledged problems. Our evidence base, strategic framework, and professional partnerships provide the foundation needed to drive meaningful healthcare system change for hundreds of thousands of British Columbians.

Evidence-Based Foundation

Largest ME/FM healthcare survey in Canadian history with 1,045 respondents providing unassailable data for policy development

Strategic Framework

Comprehensive policy solutions aligned with government priorities, transforming advocacy approach from requests to partnerships

Professional Partnerships

Interdisciplinary Advisory Committee and healthcare professional engagement providing clinical credibility and implementation pathways

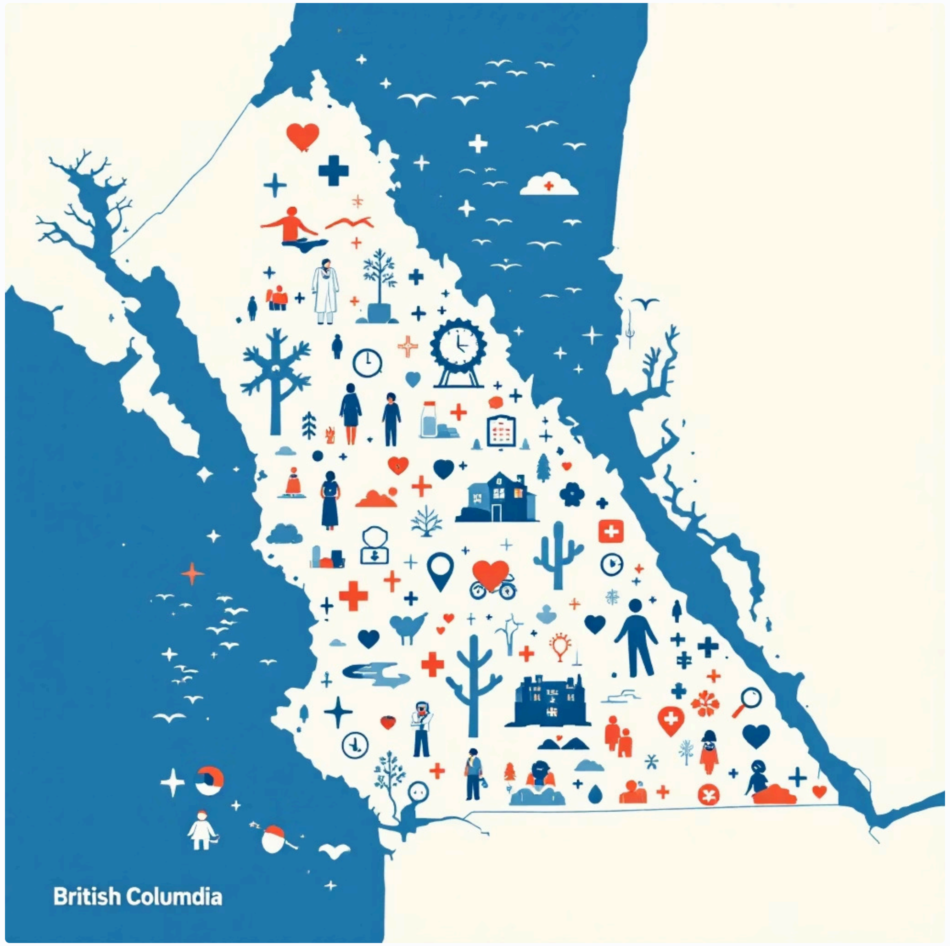
Leading Transformation

The ME | FM Society of BC is leading the transformation of chronic illness care in British Columbia and beyond. Our community's courage, combined with strategic advocacy and evidence-based solutions, is creating the foundation for systemic healthcare change that will benefit hundreds of thousands of British Columbians living with ME/CFS, Fibromyalgia, and Long COVID.

ME | FM Society of BC

www.mefm.bc.ca

Supporting 347,000+ British Columbians living with ME/CFS, Fibromyalgia, and Long COVID



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