



**A National Organisation
to Serve Canada's
Fibromyalgia
and
Chronic Fatigue Syndrome/
Myalgic Encephalomyelitis
Community**

**Presented to:
The Honourable Dr. Carolyn Bennett, P.C., M.D.
Minister of State
Public Health**

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FM-CFS Canada Plan

Planning Overview

This document serves to describe the objectives, resources, and development plans that could form a national organisation capable of improving outcomes for the Fibromyalgia and Chronic Fatigue Syndrome/Myalgic Encephalomyelitis community.

A more detailed set of policies will be required, including finance, human resources, IT, legal, service and management practices.

The needs addressed in this plan were identified through consultations with patient groups, through patient data directly collected by FM-CFS Canada, and through discussions with knowledgeable health practitioners and researchers.

The planning process was aided by consultations with executives (CEOs, CFOs, Directors, etc.) at several well-known national health charities over the past three years. They shared materials, research, policies, and discussed how they address a wide range of organisational challenges.

FM-CFS Canada Plan

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Executive Summary

For a broader description of the community's and the health system's needs, this document should be considered in tandem with the April 20th, 2005, Federal Government Submission drafted by FM-CFS Canada.

This document provides a business case approach to the presentation of the community's need, presented here in organisational and financial terms. The Year 1 emphasis is on education, with Year 2 given more to research funding.

This planning document considers the needs of stakeholders, less fully than the April 20th submission, but within the context of a proposed organisation.

Essentially, the health care system needs a properly-resourced patient organisation devoted to FM & CFS/M.E.. to change the operating environment for all health practitioners and patients.

On a related note, a prepared patient organisation will work to compete successfully against the other well-established health charities for research funding. But it is in the public interest to see Government initiate and aide this effort, sooner than later.

In this plan, FM-CFS Canada presents basic services and functions that are common to all major health charities. To aide the development of the plan, over the past three years FM-CFS Canada has consulted other major health charities on their strategies, structures, policies, and programs.

The \$10 million plan provides for a pre-national roll-out development period, to set the necessary operating systems, policies and practices in place, described in greater detail in the Product and Services Development Section.

The FM-CFS Canada request is for \$25 million in funding over three years, to ensure this organisation has the development time to succeed against heavily entrenched practices and cultures in a competitive environment.

Funding of \$10 million per year for two years, with fund-raising in the first two, should prepare the organisation to meet year 3 with sufficient resources. We seek to build patient support for a self-sustaining organisation, recognising that all health charities find this a challenging task, even with strong brands and traditions in their favour. The final \$5 million is a buffer.

FM-CFS Canada has remade itself, from a group founded by intelligent and determined patients, to torch-bearers that have the relevant experience and broad support to build the organisation the community needs.

In conclusion, the economics of the current Federal expenditure, measured in the billions annually, suggest the Federal Government should invest in a patient group and invest more in research, in an effort to lower their current and future costs, to help the health system, and to inspire hope.

The Business Case

MORAL IMPERATIVES

There are frequent reports of suicides by patients who have given up hope, in a situation where reasons for hope are not apparent. There are also early intervention opportunities being missed by the untrained medical profession. Finally, there are new patients becoming ill every year at an alarming rate, requiring action to protect the still-healthy members of society.

SYSTEMIC OPPORTUNITIES

A properly-resourced patient organisation is missing in this field. Earlier investments by Government into the development of charitable health organisations has precedence; the Diabetes Association, Arthritis, and Cancer Societies are examples. Such non-profit health groups provide a valuable function.

ECONOMIC OPPORTUNITIES

Given the lost income and GST taxes and the Disability and Old-Age Assistance liabilities associated with these chronic illnesses, corrective action is merited and financially prudent.

GRATITUDE

An unusual item to include in a business case. Given that a Federal Minister could stand up for these patients in a significant manner and change their lives, these patients will accord greater recognition and appreciation to the first-to-market leader.

AT STAKE?

Consider that the solution, a resourced organisation, would cost about \$10 million annually - about the cost to the Federal Government in a day. Then ask, why the on-going and needless human cost? Why the systemic inefficiencies due to the lack of a properly resourced patient organisation? And the financial cost, all more than the cost of a properly resourced patient organisation. If it lowered Government's annual cost by more than 1%, it would save the Government more than \$30 million dollars annually.

WHO BENEFITS?

Federal, Provincial, and Municipal Governments and insurance companies bear direct costs due to the illnesses, primarily in the form of financial assistance payments and lost taxes.

Other economic costs, from employer losses to societal resources moved to the support of patients (Food Banks, etc), mean everyone is involved. Decreased returns on education and other investments are negative forces on the economy. Most of all, the patients, their families, and their communities benefit.

WHY US?

Founded by patients, FM-CFS Canada has added a team of recognised business leaders with experience in advising fast-growing companies and good management. This team, over the past three years, has become more knowledgeable about the illnesses, the situation, and patient needs. FM-CFS Canada has healthy people able to commit to long-term success. FM-CFS Canada is consulting widely and involving experts, having developed a clear vision of a future for the community.

FM-CFS Canada has also built relations with patient groups across Canada, developing a consensus on community needs and solutions, working towards common goals. The Executive Director of the other national FM & CFS organisation has been on our Advisory Board since 2002. FM-CFS Canada has also involved medical associations, experts, researchers, and the corporate community to rally resources.

FM-CFS Canada cares equally about both illnesses. One of our guiding principles is to provide free access to help for low-income patients.

The Need: Market Demand

Problem Identification, Needs Analysis:

FM-CFS Canada, over the course of years, has identified the needs of the community through research and consultation with patients and patient groups, with physicians, and researchers. Through consultation with other major health charities, FM-CFS Canada has studied the common responses to the needs.

Stakeholders

Patients - 1 million - 1.5 million
Families - 1 million - 4.5 million
Health Practitioners - 100,000 (family doctors, nurses, surgeons, physiotherapists, etc)
Government - Federal/Provincial/Municipal
Researchers - all disciplines
Business
Community Organisations
Public & Donors
Media

Stakeholder Demand

1. General Characteristics of Market Demand

Many of the stakeholders are not actively seeking the products or services a national patient organisation could provide.

There are specific reasons for a low Actual-versus-Potential demand:

1. Misdiagnosis, some patients and their families believe they have another condition. Nearly all have been initially misdiagnosed. Possibly half or more are still misdiagnosed.
2. The lack of proper formal education means some physicians and institutional representatives believe they know all they need to know about the illnesses, yet possess incorrect information.
3. Few researchers are involved, relative to the size of the patient community. There is little demand for funding. This is in part due to the competition system for funding and the attraction of other well-funded illnesses. The corollary is that the research community has not been stimulated by the awareness and funding support expected from the patient community.
4. The public is not generally aware that two chronic and potentially disabling illnesses are so widely prevalent, and not yet alarmed.
5. The business community suffers individually when employees leave, and hasn't realised its situation thoroughly. But through a recent court rulings, are more collectively learning about their risk. They can experience lost return on investments, the loss of mission-critical people, disruptions in business, higher health insurance premiums. A recent court ruling in Ontario under Employment Law awarded record damages for mistreatment of a CFS patient. This news is certain to circulate.

The Need: Market Demand

Stakeholder Demand

2. Market Demand of Each Segment

2 A) Patient Segment: 1 million - 1.5 million Patients

Needs:

1. Education of all stakeholders to change the environment serving them.
2. Research to treat or cure the illnesses.
3. Local organisers who can facilitate education and research.

Segments:

There are two broad and large patient segments: diagnosed and undiagnosed patients.

a) The diagnosed patients, like those with other illnesses, seek support, education, and research. These realise the need for a properly resourced patient organisation.

b) More medically urgent, but less easy to reach, are those who are misdiagnosed and do not realise their specific need, who may not readily heed a public message about the illnesses.

Other subsets of patients:

c) those who present early intervention opportunities, those who do not. Given the demonstrated potential for improved long-term outcomes, the early intervention population can yield high returns.

d) Low-income patients who can not afford the range of recommended therapies, and those who can. Not being able to afford a treatment strategy limits the return on explaining it to patients.

e) There are many more segments, indeed, the individual variation in the expression of the illnesses means that there are a wide range of situations: some requiring hands-on 24 hour care, some who live alone, some are children.

2 B) Family Segment: 1 - 3 million Family Members in Immediate Proximity

Numbers

It is known that some patients live on their own, but most seem to live in families, as is the Canadian norm. It may be this community experiences a higher degree of family break up than the norm, but also that the illness requires patients to have the support of a family.

The family math in Canada includes nearly 8 million families, with an average of three people per family living together. Such an average, for the population range estimated for FM & CFS patients, would suggest the number of family members involved could range from as low as 1 million if most patients live alone, to the average family unit, including more than 3 million people in the daily fight.

4.5 Million Canadians face FM or CFS/M.E. Every Day

Combine the patient population of 1 - 1.5 million patients with 1 - 3 million family members, and the number of people living face-to-face with the illnesses is from 2 - 4.5 million Canadians.

Possibly more than 10% of Canadians.

Needs:

- 1) Education
- 2) Supportive environment
- 3) Research. Is there an infectious risk?

THE NEED: MARKET DEMAND

Stakeholder Demand

2. Market Demand of Each Segment

2 C) Health Practitioner Segment:

Practitioner Needs:

1. Tools and materials to aid client service, to provide to patients.
2. To move part of patient education and care to a patient organisation.
3. To have complementary practitioners trained and available.

Health System Needs:

1. Education to improve diagnosis and treatment, reduce wasted consultations, improve outcomes.
2. Treatment testing to validate the international consensus to improve and add new treatments.
3. An easy lab test for the illnesses.
4. Currently, each health professional is dealing directly with patients without consultation with each other, for a partial view of the patient. A properly-resourced patient organisation can develop this consultation process through the education of all parties and the building of relations between parties, for better patient management.

2 D) Governments: the Primary Economic Beneficiaries

Federal

The Federal Government bears the greatest financial cost, with lost income and GST taxes, Disability Insurance liabilities turning into Old-Age Assistance, and other general economic losses.

The Federal Government, for 20% of the lower estimate of 1 million patients, would experience a financial cost of \$2 billion for Disability Insurance and another \$1.4 billion in lost taxes from patients; per day, nearly \$10 million. \$10 million is enough for a properly resourced patient organisation.

Reducing the \$3.4 billion annual cost by even 1% would achieve a saving of \$34 million. Since this amount is more than the \$10 million required to develop a patient organisation, there is at least a financial motive for the Government of Canada to invest. A properly resourced patient group should be able to reduce Government costs by more than 1%, and lower the future growth rate through increased early intervention. The Federal Government has the country's greatest impetus for action.

Provincial

The Provinces face health system costs and financial assistance costs, along with the general economic costs imposed by losing people from the workforce and creating greater social needs. The cost per Province varies by size, but the patient community is conservatively estimated to consume more than \$1 billion in medications alone. The cost of physicians seems more than \$1 billion. Where applicable, the disability payments and Provincial income taxes add further long-term costs.

The benefit to the Provinces of having a properly resourced patient organisation is that the task of educating health practitioners, patients, and the public, would be addressed, improving their efficiencies. Local team members in a national organisation would support local practitioners, aiding them to help patients. Having a strong patient group advocating for fundamental research might also result in a prevention measure or cure, thereby reducing Provincial costs.

Municipal

Municipal governments in some cases are responsible for welfare, which is a last resort commonly used by FM & CFS/M.E. patients as they seek stable financial assistance. Local governments also devote taxes to a variety of social services upon which some patients will depend for support.

THE NEED: MARKET DEMAND

Stakeholder Demand

2. Market Demand of Each Segment

2 E) Researcher Segment:

Society's need from researchers is to prevent, cure, and improve treatment. But there are not many FM or CFS/M.E. researchers in Canada, nor have they been supported by easy access to funding or patients.

Clearly, given the limited research and the scale of the problem, where the equivalent of a small city's population becomes ill every year, the FM & CFS/M.E. community needs to develop an institutional capacity dedicated to supporting researchers in competing for research resources.

To encourage more researchers to enter the field and accomplish a societal goal, researchers need stimulation, funding, and support. For example, easier access to funding for the pilot studies that support larger requests. A Research Chair to help network the community, build a centre of expertise. A large registry of patients that researchers can freely call upon. A properly resourced national patient organisation would be able to fund raise and arrange patients for researchers.

The magnitude, the chronic nature, and the severity of the illnesses, should be considered a public health crisis.

2 F) Business as Stakeholder

The business effects are not hard to identify, but more difficult to quantify without greater research. Business would benefit from greater resources being available to help patients remain at work in better health, by improving early intervention measures, research advances, and education.

Health insurance premiums will rise to account for the growing recognition of the illnesses and their long-term impact. On a related note, insurance companies are increasingly being prevented by courts from dismissing FM & CFS/M.E. claims, and settle many legal challenges out of court.

Business loses on its investment in human capital every time a trained employee leaves due to illness. Sometimes the people lost are mission critical, as all people in all walks of life are affected.

Business is now living in a legal environment where large damage claims can be successful for the wrongful treatment of FM & CFS/M.E. patients.

These illnesses are an increasingly visible to business, affecting their bottom line, their taxes. A patient organisation, while not yet a perceived demand by business, is in their interest, broadly.

2 G) Communities as Stakeholders

These chronic illnesses can be a root cause of other social problems. A reduction in the chronicity and severity of the illnesses limits this result.

Parental attention and resources can be diverted to the care of a patient, whether parent or child.

Parental income can be affected, possibly forcing a significant change in living circumstances, opportunities, support mechanisms.

Local social support resources, such as Food Banks, Shelters, etc., will experience a greater demand.



Product & Services

Product & Services

Product & Services of a National Patient Organisation: 'The Missing Catalyst'

Section 2:

Product & Services Overview	
Detail: The Local Representative + Local Resources	
Detail: Educational Materials	
Product & Service Development	
Marketing	

Planning Overview:

The organisation described in the following pages, is:

- a) with no capital costs for buildings,
- b) with inventory limited largely to computers and educational materials,
- c) a plan to hire 90 local healthy team members, to work from home offices, to serve locally.
(As done by the Arthritis Society. Local groups may be able to arrange offices.)
- d) includes initial costs to develop policies/procedures in the preparation of a national roll-out:
(\$250,000 budget for advisors, \$50,000 for hiring. Aided by Board & Advisors, others.)
- e) seeking two (2) years of \$10 million funding to achieve sustainability, and,
- f) seeking an additional financial reserve of \$5 million beyond the \$20 million investment
to help the organisation begin with greater financial safety, to help it attract Canada's leaders.

Product & Service Development

Two Year Start-up Plan

This overview looks at a two-year implementation plan, front-end loaded with education, with more for research in Year Two. In Year Three the goal is to encourage sufficient numbers of small contributions from patients and their families to end the need for Federal funding.

Consultations, Process & Procedure Development

Consultations with groups will guide the policy development, structure, and allocations.

Budget Overview: What can \$10,000,000 do?

- \$5 million** A team of 90 healthy people, all taxes/benefits/training included, at \$50,000 apiece. They provide local support for groups, physicians, patients; they run local patient education programs, raise awareness and funds for research. Five advisors work temporarily on start-up projects, five others to work long term on national projects for the community, ie. info line, children, law, etc.
- \$900,000** \$10,000 each for the 90 regions, to buy equipment as necessary, some items in bulk: computer, Internet access, telephone budget, banner, public event display, cards, etc.
- \$1 million** Education Campaign: \$1 million of national ad space bought by a charity, bulk, will generally achieve a buy of more than \$2 million of TV, radio, print. Educating the public, patients, medical practitioners, researchers, business, schools,...
- \$1 million** Physician education: profession-specific, patients guides, plus CD. Delivered.
- \$500,000** Patient education materials in various forms, bilingual.
- \$150,000** Education for the public, friends, family: video, brochures, etc.
- \$200,000** Two national conferences: the first one as soon as possible, the other to close the year. Patient group leaders, researchers, medical leaders, Federal/Provincial Governments, media. (incl. food/travel/lodging)
- \$250,000** Help local patient groups ensure legalities and audits are up-to-date.
- \$400,000** National executive: President, Research, Operations, Fund-Raising, CFO
- \$150,000** Overhead: rent, utilities, supplies, computers, postage, transportation, audits, legal, etc.
- \$100,000** Contingency fund.
- \$100,000** FM & CFS Research funding in Year 1, plus ads. Year 2 presents more than \$1 million.
- \$250,000** Unallocated: Minister's suggestion? (i.e. Suicide crisis line)

PRODUCT & SERVICES OVERVIEW

Product & Services meet needs

**Each capability strengthens the other,
the sum of the whole is greater than the sum of the parts.
Local patient groups will finally have resources, all getting the same.**

1) Local Organisation

Team of 90 healthy people, spread across Canada to work with local groups to:

- a) To organise sessions with local health practitioners to educate patients, families, practitioners
- b) To organise local fund-raising for research, encourage patient volunteers for research
- c) To educate local media, local advertising

2) Education Services:

- a) Educate the public, work to correct misperceptions, build empathy
- b) Educate health practitioners, practicing and new, in various manners
- c) Educate patients, their families, employers
- d) Provide focal point for interaction of experts with patients

3) Research Services:

- a) Recruitment of patients to help researchers
- b) Provision of information services to researchers
- c) A central hub to help network researchers
- d) Building traditions of giving for research
- e) Liaison between research news and patients
- f) The development of research goals

4) National Advancement, Administration

a) Start-up : pre-national roll-out stage, aided by FM-CFS Canada's advisors, special team.

Policies to evolve or develop include:

- ✦ Governance structures, goals, evaluation, reporting, patient group relations
 - ✦ Human Resource policies & practices, nationwide team management
 - ✦ Financial processes, giving processes, payments, receipts, foundation, insurance
 - ✦ Government relations, Federal, and Provincially - where applicable, Provincial groups lead
 - ✦ Direct national media/advertising campaign, common messaging with local groups
 - ✦ Information services: web site, telecom, management and fulfillment processes
 - ✦ Relations with more organisations, health care institutions
 - ✦ National research effort, fund-raising, research volunteers
- b) Effectively grow and operate national organisation

Local Services

Local Representation, Local Action

Detail: The Local Representative Package

Several parts of the overall \$10 million budget combine to provide local resources:

- \$5 million in healthy staff
- \$1 million in resources for local staff
- \$300,000 in advertising
- \$250,000 in legal and accounting costs
- \$1.65 million in educational materials for patients, physicians, and the public

These resources are supplemented by a national campaign.

Local Resource Package Breakdown

1) Personnel Budget: \$50,000

Fifty thousand dollars include taxes, health plan, travel and accommodation for two training sessions. Training sessions will take place nationally and regionally.

Objectives:

To work with local FM & CFS/M.E. patient groups to further develop regular, patient education sessions with experts in different fields. Work to develop local resources for patients. Support physicians by developing resources and structures for patients. Build media and community awareness. Aide research through patient recruitment and fund-raising.

2) Local Resource Package: \$10,000 Year 1 purchase example:

Bought in bulk, with some customization:

- \$3,000 - computer, software
- \$2,500 - indoor display, outdoor banner
- \$1,000 - IT support
- \$1,000 - office supplies, locking file cabinet
- \$1,200 - internet, telephone
- \$ 500 - business cards, letterhead
- \$ 800 - travel, food

3) Advertising Budget: \$3,000 (\$300,000 overall)

A \$3,000 advertising budget will be administered locally by the representative to support awareness of local events, education seminars, etc., under the direction of the local representative within guidelines.

4) Educational Materials, Promotional Materials

In both print and electronic form, educational materials will be available in large quantities for patient groups, health practitioners, patients and families, the media, and the public.

5) Legal and Accounting Budget: \$250,000 overall

This budget is set to help resolve national-local legal and accounting needs in the national infrastructure.

Note: Some regions have (no) groups, some groups wish to cease, others to gain legal status.

National Products

Detail: Educational Materials

A more complete and free Patient Guide is to be prepared after the various physician guides are completed, with a wide range of experts contributing.

Guides developed for the various health practitioners will be distributed through medical associations, local patient groups and the local representatives.

\$1,500,000 is allocated for educational material design, translation, reproduction and delivery.

Health Practitioner Educational Materials: \$1 million

\$425,000 for printing

\$25,000 allocated to content development (all volunteered so far)

\$50,000 for educational videos

\$100,000 for 90,000 educational CDs

\$400,000 for delivery (physician's kit includes patient materials, local representative's contact info.)

Professional	Total Cost	Quantity	Quantity	Quantity	Quantity
		FM - ENG	CFS - ENG	FM - FR	CFS - FR
Family Doctors	\$67,000	90,000	90,000	60,000	60,000
Psychologists	\$30,000	30,000	30,000	15,000	15,000
Psychiatrists	\$30,000	30,000	30,000	15,000	15,000
Rheumatologists	\$20,000	15,000	15,000	5,000	5,000
Anaesthesiologists	\$20,000	15,000	15,000	5,000	5,000
Emergency Med Teams	\$20,000	15,000	15,000	5,000	5,000
Nurses	\$50,000	90,000	90,000	25,000	25,000
Physiotherapists	\$25,000	20,000	15,000	5,000	5,000
Chiropractors	\$25,000	20,000	15,000	5,000	5,000
Massage Therapists	\$22,000	15,000	15,000	5,000	5,000
Naturopathic Drs.	\$22,000	15,000	15,000	5,000	5,000
Dietitians	\$22,000	15,000	15,000	5,000	5,000
Pharmacists	\$42,000	50,000	40,000	5,000	5,000
	\$395,000	420,000	400,000	60,000	60,000
Printing	\$395,000	+ GST =	\$425,000		

Patient Education Materials: \$500,000

\$130,000 available for distribution costs, most through local representatives.

Some patient materials to be distributed using the \$400,000 Health Practitioner mailing budget.

	Total Cost	FM - ENG Quantity /Cost	CFS - ENG Quantity /Cost	FM - FR Quantity /Cost	CFS-FR Quantity /Cost
Patients	\$370,000	1 million/ \$182,000	250,000/ \$47,000	500,000/ \$92,000	100,000/ \$21,000

Product & Service Development

First Steps: Policy & Procedure Development

Resourcing the Start-Up Team

The experts for these necessary projects will be expensed in the first year, to assist in the preparation of systems before implementation. In the second year their resources can be applied elsewhere. \$250,000 is allocated to the pre-launch preparatory period for policy and process development, and is not part of the Administration team's standard annual budget envelope.

- 1. Human Resources policy designer**
- 2. Legal advisor, executor**
- 3. CFO, financial systems design**
- 4. IT designer**
- 5. Governance advisor, policies, processes**

1. Human Resources

- a) Develop principles, processes, record and archive systems, data security.
- b) Policies and practice of: hiring; training; evaluations; termination; benefits; transitions; conflict resolution processes; safety practices; legal requirements; etc.
- c) Selection of national team leader to administer distributed team.
- d) Requirements for local interviews, candidate selection, local representation.
- e) \$50,000 advertising budget for hiring

2. Legal Advisors

- a) Acquisition of nexus status to operate in all Provinces.
- b) Resolution of local group legal requirements. Possible mergers.
- c) Training of local representatives, Board, in charity requirements, common pitfalls, etc.

3. Chief Financial Officer

- a) Financial systems for donations, personnel, foundation management, goal-setting, and reporting,
- b) Fund-raising: tax credit use by local representatives, solicitation rules, donation tools, processes

4. Marketing

- a) Further development of national advertising and public relations campaign,
- b) Bulk purchases at charity rate, a wide range of media.

5. Governance

- a) Build Board as necessary to respond to new opportunity,
- b) Build more formal oversight processes, reporting, etc.

6. Information Technology/Information Management

Planning, hardware, software, security, practices, archiving, local support

Product & Service Development

First Steps: Policy & Procedure Development

Educational Material development

With the support of a budget, educational materials can be developed for each relevant medical profession, for patients, their families, and the public, and translated into French.

Materials can be reproduced in appropriate formats, distributed nationwide through medical associations, through patient groups, and eventually, through the network of local representatives. A CD will be assembled to hold a larger collection for patients with computers but no Internet connection, with resources for groups, physicians.

This work can begin at a new pace, building on previous volunteer efforts, and based on the international consensus presented in the Diagnosis and Treatment Guidelines released in 2003 and 2004, developed under terms of reference set by and a panel of experts selected by Health Canada.

Negotiation of Bulk Purchases

Some media, local equipment resources, printing, fulfillment service contracts.

The National-Local Relation: a Starting Model

For efficiency and consistency, the model proposes having local patient groups interview candidates, with the salary paid nationally and certain standards and objectives met nationally. The local representative would fund-raise, conduct education, support patients, and organise volunteers, with the input of local groups. It seems all groups want the same advancements, the same services.

A package of resources would support each patient group through the representative. Local resources would include educational materials, a computer and telephone with access, an advertising budget and promotional materials. Bulk purchasing with some customisation will maximise returns.

Individual groups could become centres of excellence for various parts of the overall mission of advancement of patient and public interests. The **Provincial** groups would provide input to, or lead Provincial negotiations, with policy monitoring, media reporting, etc.

Of note: There are areas where there are no groups; and groups that wish to cease legal operation.

National Conference for patients, groups, government, researchers, practitioners, media:

One of the first steps will be to invite patient group leaders to a conference to develop an enduring national structure.

Product & Service Development

Marketing

Community Needs

The FM & CFS/M.E. community needs to connect with and build relations with its stakeholders. The community must work to change misperceptions held by various parties.

Organisational Needs - Marketing's Ultimate Objective

The community needs to develop a tradition of giving, so that in Year 3 the organisation is sustainable. Larger endowments, pro-active giving, and local campaigns, need to be encouraged.

Combined and Synergistic Needs

In delivering many of the messages needed by the community, the organisation can ensure that the message of giving is included. By delivering the range of messages, potential contributors will become more informed, more empathetically connected, and more disposed to donating.

Campaign Design Opportunity

It may be possible to interest a top-quality advertising agency to design a campaign for free, knowing that we have a budget to express it, and an open slate in the public's mind. Adding to the marketing messages already prepared, the many misconceptions identified, and current press tools.

\$1 million Advertising Budget Proposal*

- \$300,000 National advertising (TV, radio, print)
- \$300,000 Local advertising (100 areas x \$3,000)
- \$100,000 Medical journals of various health practitioners
- \$50,000 K-12 + University education program: school nurses, students
- \$50,000 Research
- \$50,000 Legal community advertising
- \$50,000 Reserve: special issue promotion
- \$50,000 Hiring
- \$50,000 Print promotional materials (posters, bookmarks, etc.)

*** Supported by budgets for educational materials for patients, physicians, the public.
Supported by press (versus advertising) campaigns at national & local levels.
Supported by resource package for each local representative with displays, banners, etc.,
for use in local events, mall presentations, seminars, etc.**

Press Campaign

Working nationally to set priorities, synchronize messages, achieve common objectives.

Campaign includes reaching out to a wide range of media formats, from community newspapers to radio to magazines, serial television shows, and public gatherings.

Supported by other promotional materials, such as posters, bookmarks, display at events. Presenting the illnesses to the public in a variety of forums, with synchronized national events.



Administration & Finance

Administration

Administration Overview

1) Executive : \$400,000 (includes taxes, benefits) (\$250,000 allocated to develop start-up)

Executive Director

Planning, Government & Public Relations, Marketing, Group Relations, Reporting

Fund-Raising Director

Develops Giving means/rules for team/local volunteers, solicits funds, promotes Giving

Research Director + \$100,000 research budget

Promotes research & funding, develops Patient Registry use, research volunteers

National Team & Human Resources Director

Works with local representatives, develops, promotes & synchronizes national activities

Chief Financial Officer

Sets financial policies, oversees daily accounting, reports

2) Central Services : \$250,000 (drawn from budget line for the 100 team members)

a) Book-keeper, membership/donation processing assistant, reports to CFO

b) Information telephone line receptionist, reports to National Team Director

c) Coordinator, assistant to Executive, marketing focus

d) K-12 + Universities education coordinator - reports to ED, may have outside input

e) Legal defense coordinator - reports to ED, may have outside input

* Insurance, taxes, benefits, on 5 member team included in their \$50,000 budgets.

3) Administration Overhead : \$150,000

Rent - \$30,000

Insurance on Office, General Liability - \$30,000

Office Equipment - \$40,000

Office Supplies - \$10,000

Postage - \$10,000

Transportation- \$10,000

Audits - \$10,000

Utilities - \$10,000

* Economies of scale in bulk purchasing of 100 computer/software with 90 local representatives

* Group health insurance plan separated in budget, bought with insurance for local teams

* Savings may be achieved in various categories, adds to the contingency fund.

4) Contingency Budget : \$100,000

Contingencies determined by the Board of Directors.

5) Legal & Accounting Budget : Local Operations : \$250,000

For reconciling relationships with local groups: audits, legal requirements.

6) Two (2) National Conferences : \$200,000

For: Patients & patient group leaders, Government, Researchers, Health Practitioners, Media

Costing predicated on travel/accommodation for ~100 group leaders

Based on \$1,000 average for transportation, accommodation

Sponsorship to be sought for amenities, food.

7) Research Budget : \$100,000

For prevalence studies?

8) Unallocated : \$250,000

Crisis line? To be determined by Minister?

Possibly a contribution to an existing Crisis Line with training for FM & CFS?

Administration

Executive's Perspective of Resources: Overview

1) \$250,000 allocated to start-up process for systems & policy development.

2) Management Team & Resources : \$400,000 (includes taxes, benefits)

Executive Director

Planning, Government & Public Relations, Marketing, Group Relations, Reporting

Staff: Legal defense coordinator - reports to ED, input from Ntl ME/FM Action Network.

Fund-Raising Director

Develops Giving means/rules for team/local volunteers, solicits funds, promotes Giving

\$300,000 National Advertising budget

Video & printed matter, mailing budget

Access to Patient Registry to encourage volunteers to be Members, donors.

Training session with 90 local representatives at national meeting, follow-on with team.

Range of Giving tools enabled by CFO (bequeaths, security donations, payroll, etc.)

Research Director

Promotes research & funding, develops Patient Registry use, research volunteers

Patient Registry database, with local teams, ads, press helping to recruit volunteers

\$50,000 per year advertising budget

Research studies : \$100,000 in Year 1, \$1,000,000 in Year 2

If Year 1 fund-raising successful, additional \$840,000 for Year 2 research funding

National Team / Human Resources Director

Works with local representatives, develops, promotes & synchronizes national activities

Staff: Information telephone line receptionist

Staff: K-12 + Universities education coordinator - input from Ntl ME/FM Action Network.

National & Regional Training session budgets built in to staff budget envelope.

\$300,000 local advertising budget

Physician, patient, and public educational information, promotional materials

Press campaign coordination, resource sharing.

Chief Financial Officer

Sets financial policies, oversees daily accounting, reports

Start with common system, open mandate to develop useful financial instruments, giving tools.

Staff: Book-keeper, membership/donation processing assistant

Staff: Coordinator, assistant to Executive team, marketing focus

3) Legal & Accounting Budget : Local Operations : \$250,000

For reconciling relationships with local groups: audits, legal requirements.

4) Two (2) National Conferences : \$200,000

For: Patients & patient group leaders, Government, Researchers, Health Practitioners, Media Sponsorship to be sought for amenities, food.

FM-CFS Canada Administration

Directors

- * Chair: Graham Mayes, SVP, Guardian Capital Advisors
- * Treasurer: Donna MacGregor, C.G.A
- * Howard Alper, Vice Rector, University of Ottawa
- * Paul Grof, M.D., Ph.D., F.R.C.P.(C)
- * Ed Napke, M.D., D Ph

Advisory Board Members

- * John Ernst, Executive Director, FM-CFS Canada
- * Dr. Patrick Faloon, Ottawa Physical Health Centre
- * Coralie Lalonde, CEO, Katsura Investments
- * David Mann, fmr. Chairman, Ottawa Centre for Research & Innovation
- * Lydia Neilson, Executive Director, National ME/FM Action Network
- * Janet Ruddock, Author, books on Fibromyalgia
- * Milan Topolovec, CEO, The TK Group
- * Shirley Westeinde, SVP, Westeinde Construction

The Medical Advisory Committee

- * Dr. Paul Grof, Chairman
Director of the Affective Disorders Service and Director of Research, Mood Disorders Program at the Royal Ottawa Hospital. Ottawa, Ontario
- * Dr. Harold Merskey
Professor Emeritus of Psychiatry University of Western Ontario, London, Ontario
- * Dr. Francisco Diaz-Mitoma
Chief, Virology, Children's Hospital of Eastern Ontario Ottawa, Ontario
- * Janet Raboud, PhD.
Biostatistician, Department of Public Health Sciences, University of Toronto and the University Health Network Ottawa
- * Dr. Sean O'Sullivan
Family medicine practitioner, specialises in CFS/M.E., Tillsonburg, Ontario
- * Dr. Ellen Thompson, MB BS, FRCPC
Anaesthesiologist, (Anaesthesia and Chronic Pain Management), Clinical Assistant Professor, University of Ottawa, Ottawa, Ontario Member: Canadian Pain Society, the American Pain Society, the International Association for the Study of Pain

Management Notes:

Certain members of the Board and Advisory Board were recruited for their expertise in guiding companies and organisations as they grow, namely David Mann, Coralie Lalonde, and Shirley Westeinde, all well-recognised business leaders. Donna McGregor and Graham Mayes' knowledge of foundations and financial instruments provides a wealth of knowledge to the organisation.

Outside counsel to the charity is also currently provided by a range of experts. Medical experts, patient groups, and through on-going consultations over the past three years with other major health charities on operational matters, structure, governance. Business experts help as well.

Consultations with Patient Groups:

FM-CFS Canada has developed a coalition of patient groups, developed a consensus on community needs, and continues in a practice of collaboration and consultation with them. A national conference can help the groups determine a structure between them.

Finances

Question: Financing

In the nearly 20 years since the last formal presentation to the Federal Government, there has yet to be a capable organisation arise to do what the community needs, evidently demonstrating a lost opportunity on their part perhaps, but a loss to everyone else as well.

A Speculation - Sustainability?

If it is built and demonstrates value, patients and their friends will have a clear place to put their support, and at an average costs of \$10 per patient spread over 1 million patients, this is probably a sustainable budget. This sustainability is arguably a speculative outcome, but without help, it seems apparent that such an organisation will not arise, and we'll all miss an opportunity.

A 2 year Request for Financial Assistance

The request for assistance covers at least two years to help the operation find all the patients, encourage giving, build its base, and suggests a Federal research funding commitment to stimulate the research effort, supported by volunteer patients.

A Bank Account

To help the organisation through the early transition period, wherein the \$10 million budget will be fully applied, add a cushion as a reserve, possibly \$5 million in trust.

Year 1 Budget: \$10 million

What could \$10,000, 0000 do? It would transform Canada.

\$5 million A team of 90 healthy people, all taxes/benefits/training included, at \$50,000 apiece. Team members to provide local support for physicians' patients, run local patient education programs, raise awareness and funds for research. Five more will work on special national projects for the community, ie. info line, K-12 education, etc.

\$1 million \$10,000 each for the 100 teams, buying some items in bulk: computer, Internet access, telephone budget, local banner, public event display, cards.

\$1 million Public Education Campaign

\$1 million Physician education: profession-specific, patients guides, CD, delivered.

\$500,000 Patient education materials in various forms, bilingual.

\$100,000 Education for the public, friends, family: video, brochures, etc. .

\$250,000 Unallocated: Minister's suggestion? (ie. Suicide crisis line)

\$200,000 2 national conferences: the first one as soon as possible, the other to close the year. Patient group leaders, researchers, medical leaders, Federal/Provincial Governments, media. (incl. food/travel/lodging)

\$250,000 Help ensure patient groups' legalities and audits up-to-date.

\$400,000 National executive : President/Communications, Research, Operations, Fund-Raising, plus 5 national service staff noted above.

\$100,000 Overhead: rent, utilities, supplies, computers, transportation, audits, legal, etc.

\$100,000 Contingency fund.

\$100,000 FM & CFS studies. Is the rate rising?

Year 2 Budget: \$10 Million

Budget Change

The second year would move some funds from physician education & advertising to research, and some first year costs would cease, namely local legal and accounting expenses and the first year start-up team.

\$10 million budget

\$5 million

A team of 90 healthy people, all taxes/benefits/training included, at \$50,000 apiece. Team members to provide local support for physicians' patients, run local patient education programs, raise awareness and funds for research. Plus 5 others long term on national projects for the community, ie. info line, K-12 education, etc.

\$900,000

\$10,000 each for the 90 regions, buying equipment as necessary, some items in bulk: computer, Internet access, telephone budget, banner, public event display, cards, etc.

\$500,000

Public Education Campaign: Advertising

Educating the public, patients, medical practitioners, researchers, business, schools,...

\$500,000

Physician education: profession-specific, patients guides, CD, delivered.

\$1 million

Research campaign, to solicit larger funding requests

\$500,000 Patient education materials in various forms, bilingual.

\$150,000 Education for the public, friends, family: video, brochures, etc. .

\$250,000 Minister's suggestion? (ie. Suicide crisis line)

\$100,000 1 national conference

\$400,000 National executive: President, Research, Operations, Fund-Raising, CFO

\$200,000 Overhead: rent, utilities, supplies, computers, postage, transportation, audits, legal, etc.

\$500,000 Contingency fund.

Year 3 Budget: \$7 Million Minimum Target

Minimal Financial Requirements

Year 1 and 2 provide an opportunity to educate patients, physicians, and the public with an extended campaign, and to accumulate educational resources. If needed, Year 3 financial requirements can focus mainly on personnel and their infrastructure, with membership and sponsorship sought to add resources.

\$5 million	100 team members, includes 5 personnel to support national services.
\$500,000	\$5,000 each for the 100 team members: Internet access, telephone budget, cards, etc.
\$500,000	Public Education Campaign: Advertising
\$250,000	Unallocated: Minister's suggestion? (ie. Suicide crisis line)
\$100,000	1 national conference
\$400,000	National executive: President, Research, Operations, Fund-Raising, CFO
\$150,000	Overhead: rent, utilities, supplies, computers, postage, transportation, audits, legal, etc.
\$100,000	Contingency fund.



FM-CFS Canada 3.25 year Budget

Year 1 starts when organisational preparation complete

Operating Revenue Lines	Preparation	Year 1	Year 2	Year 3
	Period			
Number of Individuals @ \$20		90,000	200,000	400,000
Donations online from Individuals		\$1,800,000.00	\$ 4,000,000.00	\$ 8,000,000.00
Research Fund-Raising				
90 Local Fund Raising Events		\$270,000.00	\$270,000.00	\$270,000.00
90 Local Corporate Sponsorship		\$270,000.00	\$270,000.00	\$270,000.00
National Sponsorship		\$150,000.00	\$1,000,000.00	\$1,000,000.00
			<i>Research Funding</i>	<i>Research Chair</i>
National Foundation Applications		\$100,000.00	\$200,000.00	\$300,000.00
Local Foundation Apps 30 x \$25,000			\$750,000.00	\$750,000.00
Other forms of Giving		\$50,000.00	\$150,000.00	\$400,000.00
Research Fund Subtotals				
Refunds of GST			\$ 291,683.00	\$ 206,143.00
	Total	\$2,640,000.00	\$6,931,683.00	\$ 11,196,143.00

Expenses	Preparation	Year 1	Year 2	Year 3
	Period			
90 Local Salaries: \$41,715 Year 2: 95 salaries		\$3,754,350.00	\$3,962,925.00	\$3,962,925.00
EI (\$1064 per person)		\$95,760.00	\$101,080.00	\$101,080.00
CPP (\$1801 per person)		\$162,090.00	\$171,095.00	\$171,095.00
Health Plan (\$3,000 per person)		\$270,000.00	\$285,000.00	\$285,000.00
Workers Comp: varies by Prov	ON : 0.33%	\$12,389.40	\$13,077.70	\$13,077.70
Training 2 x \$1000 : Travel/Accomm		\$167,610.60	\$176,922.30	\$176,922.30
Insurance - home office portion		\$37,800.00	\$39,900.00	\$39,900.00
Subtotal		\$4,500,000.00	\$4,750,000.00	\$4,750,000.00
5 Central Services Salaries : \$42,191		\$210,955.00	\$210,955.00	\$210,955.00
Coordinator/Book-keeper/Info Line/Education/Legal				
EI		\$5,040.00	\$5,040.00	\$5,040.00
CPP		\$9,005.00	\$9,005.00	\$9,005.00
Health Plan (\$3,000 per person)		\$15,000.00	\$15,000.00	\$15,000.00
Workers Comp: varies by Prov	ON : 0.33%	\$688.30	\$688.30	\$688.30
Training 2 x \$1000 : Travel/Accomm		\$9,311.70	\$9,311.70	\$9,311.70
Subtotal		\$250,000.00	\$250,000.00	\$250,000.00
Contract Consultants				
Hiring Advertising (from ad budget)	\$50,000.00	0	0	
Year 1 systems & policy development	\$250,000.00	0	0	
Legal & Accounting Budget	\$250,000.00	0	0	
Subtotal	\$550,000.00	0	0	

Expenses	Preparation Period	Year 1	Year 2	Year 3
5 Management Salaries \$73,967.59		\$369,837.95	\$369,837.95	\$369,837.95
EI		\$5,040.00	\$5,040.00	\$5,040.00
CPP		\$9,005.00	\$9,005.00	\$9,005.00
Health Plan (\$3,000 per person)		\$15,000.00	\$15,000.00	\$15,000.00
Workers Comp: varies by Prov	ON : 0.33%	\$1,117.05	\$1,117.05	\$1,117.05
Subtotal		\$400,000.00	\$400,000.00	\$400,000.00
Local Team Overhead (bulk purchases)				
Computers Year 1=90, Year 2 adds 5	\$270,000.00		\$200,000.00	\$50,000.00
Indoor display, outdoor banner	\$192,600.00		\$120,000.00	\$15,000.00
Business cards, letterhead	\$45,000.00		\$50,000.00	\$47,000.00
Furniture - locking file cabinet		\$9,000.00	\$5,000.00	\$1,000.00
IT support		\$90,000.00	\$90,000.00	\$90,000.00
Office Supplies		\$81,000.00	\$95,000.00	\$81,000.00
Internet (\$70 x 12 x 90 = \$75600) Tel. (\$64,800)		\$140,400.00	\$150,000.00	\$150,000.00
Travel, food		\$72,000.00	\$190,000.00	\$66,000.00
Subtotal	\$507,600.00	\$392,400.00	\$900,000.00	\$500,000.00
Prep period & Year 1 Overhead		\$900,000.00		
National Operations Centre				
Insurance on Office, General Liability		\$30,000.00	\$35,000.00	\$40,000.00
Office Equipment		\$40,000.00	\$40,000.00	\$10,000.00
Internet Hosting, e-comm functions		\$1,000.00	\$2,000.00	\$2,500.00
Telephone : 1-877 #		\$1,000.00	\$6,000.00	\$3,000.00
Telephone (10 lines)		\$6,000.00	\$6,000.00	\$6,500.00
Internet Costs		\$1,500.00	1,500.00	1,500.00
Hydro		\$1,200.00	\$1,500.00	\$1,500.00
Office rent		\$30,000.00	\$33,000.00	\$35,000.00
Postage		\$9,300.00	\$20,000.00	\$10,000.00
Consumables		\$10,000.00	\$10,000.00	\$10,000.00
Travel Reimbursement		\$10,000.00	\$30,000.00	\$10,000.00
Audit		\$10,000.00	\$15,000.00	20,000.00
Subtotal		\$150,000.00	\$200,000.00	150,000.00
Contingency Fund		\$100,000.00	\$500,000.00	\$100,000.00
Special Projects				
Conference costs		\$200,000.00	\$100,000.00	\$100,000.00
Minister's suggestion? (ie. Suicide crisis line)		\$250,000.00	\$250,000.00	\$250,000.00
Subtotal		\$450,000.00	\$350,000.00	\$350,000.00
Physician Education				
Creation - physician education guides		\$25,000.00		
Printing - physician education materials		\$425,000.00	\$100,000.00	
Printing - physician education CD		\$100,000.00		
Development, educational videos		\$50,000.00	\$100,000.00	
Continuing Medical Education course development			\$200,000.00	
Delivery		\$400,000.00	\$100,000.00	
Subtotal		\$1,000,000.00	\$500,000.00	

Expenses	Preparation Period	Year 1	Year 2	Year 3
Patient Education				
Printing - patient education materials		\$370,000.00	\$370,000.00	
Delivery		\$130,000.00	\$130,000.00	
Subtotal		\$500,000.00	\$500,000.00	
Public Education Materials				
Printing - brochures		\$100,000.00	\$100,000.00	
Development, educational videos		\$50,000.00	\$50,000.00	
Subtotal		\$150,000.00	\$150,000.00	
Public Awareness campaigns				
Posters, bookmarks		\$50,000.00	\$25,000.00	\$25,000.00
National advertising		\$300,000.00	\$100,000.00	\$100,000.00
Local Advertising		\$300,000.00	\$200,000.00	\$200,000.00
Medical Journals	\$	100,000.00	\$ 25,000.00	\$ 25,000.00
School nurses	\$	50,000.00	\$ 50,000.00	\$ 50,000.00
Legal community advertising	\$	50,000.00		
Reserve: special promo or polling	\$	50,000.00	\$ 50,000.00	\$ 50,000.00
Subtotal	\$	900,000.00	\$450,000.00	\$450,000.00
Research				
Research Funding - new use of start-up team line item			\$250,000.00	
Funding moved from Phys. Educ, Advertising, conference items			\$650,000.00	
Research Funding		\$100,000.00	\$100,000.00	
Research advertising (from ad budget)		\$50,000.00	\$50,000.00	\$50,000.00
Subtotal	\$	150,000.00	\$1,050,000.00	\$50,000.00
GST totals included above		\$ 291,683.00	\$ 206,143.00	
Year End Total		\$10,000,000.00	\$10,000,000.00	\$7,000,000.00

Prep. Period totals included in Year 1

Revenues from year 1+2 to be saved for year 3, or to be invested in research, or to be saved for longer term

Contingency budget, if unused, builds.

FM-CFS Canada is legally known as:
Compassion in Action

