Good Morning / Bonjour

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ME/FM Fundamentals

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Patient perspective

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Research perspective

National ME/FM Action Network

Registered charity founded in 1993 to support Canadians with

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
- Fibromyalgia

Many accomplishments

- spearheading diagnostic and treatment protocols,
- appearing before the Supreme Court,
- hosting an international conference,
- creating resources (website, newsletter, documents)
- supporting patients (phone, email)
- etc.

Funded through memberships and donations

No paid staff.

CCHS 2010
(Canadian Community Health Survey)

Who has a diagnosis of CFS?

- 411,000 Canadians
- 66% female
- 74% of working age (18-64)

Who has a diagnosis of FM?

- 439,000 Canadians
- 79% female
- 77% of working age (18-64)

Diagnosing ME/CFS

Competing definitions

(CDC, Oxford, Canadian, International)

Requirements:

- Debilitating fatigue
- Post-exertional malaise
- Pain
- Cognitive problems
- Sleep dysfunction
- Immune/neurological and autonomic dysfunctions
- Chronic

Diagnosing FM

Competing Definitions
(1990 ACR, 2004 Canadian, 2010/11 ACR alternate criteria)

- Widespread pain
- Existence of Tender points
- Fatigue
- Waking unrefreshed
- Cognitive symptoms
- Other symptoms

Disability and Disadvantage

Out of 23 chronic condition groups, CFS ranked

#1 (worst!)
- Unmet health care needs
- Unmet home care needs
- Food insecurity
- Very weak sense community belonging

#2 Need help with tasks
- Difficulty in social situations
- Permanently unable to work

#3 Personal income under $15k

CCHS 2005

Out of 23 chronic conditions, FM ranked

#2 Unmet home care needs
#3 Need help with tasks
#4 Unmet health care needs (moved to #1 in 2010)
    Permanently unable to work
    Personal income under $15k
#5 Food insecurity
#6 Difficulty in social situations
#7 Very weak sense community belonging

CIHR Funding of Research

Condition	per patient funding Apr2010 to Mar2013
Parkinson	$399.49
Alzheimer	$237.71
Muscular dystrophy	$157.87
Epilepsy	$78.89
Multiple Sclerosis	$73.09
Tourette	$53.54
Crohn	$47.47
Cerebral palsy	$44.07
Diabetes	$38.93
Spina Bifida	$26.61
Heart Disease	$25.25
Dystonia	$20.26
Bronchitis, Emphysema, COPD	$9.12
Asthma	$6.90
Arthritis	$5.85
Fibromyalgia	$1.38
Chronic Fatigue Syndrome	$0.35
Multiple Chemical Sensitivities	$0.01

ME/CFS and FM – what's the situation?

Severe, disabling illness 400k+ Canadians each

- lack of understanding of causality
- lack of research to find cause
- shortage of information/ actual misinformation
- lack of public awareness
- no diagnostic tests
- no medical specialty taking ownership
- no coordinated approach
- doctors unfamiliar and often unsympathetic
- spotty surveillance

ME/CFS and FM in Canada

Decade 1990s - good start

Decade 2000s - officials step back waiting for issues to get sorted out. Patients feel forgotten/ ignored.

Decade 2010s – opportunities to re-engage