

SPECIAL ISSUE:

STATISTICS 2010

*An in-depth look at the figures & findings of
the 2010 Canadian Community Health Survey*

The Canadian Community Health Survey

What we learned from CCHS 2005

In Issue 80 of *QUEST*, we presented statistics on Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM) and Multiple Chemical Sensitivities (MCS) from the 2005 Canadian Community Health Survey (CCHS). The CCHS is a major survey designed by health authorities across Canada. The information is collected and compiled by Statistics Canada which is considered by many people to be the best government statistical agency in the world.

The 2005 statistics carried two important messages about CFS, FM and MCS.

The first message was for patients, their families and their friends. The survey estimated that there were over 1.1 million Canadians with one or more of these three diagnoses. The survey found that these Canadians were consistently experiencing

challenges in a number of areas. The statistics told patients that they were not alone.

The second message was for health and social agencies in Canada. The message was that Canadians with these illnesses were not well served, even when compared to Canadians with other chronic illnesses. The inequities cried out for new and better services for these patients.

After the 2005 survey, the questions on CFS, FM and MCS were dropped from the ongoing questionnaire. They were included in the year 2010 and are scheduled to be asked again in the year 2014. We are pleased to present you with information from the 2010 CCHS survey.

see SURVEY page 2

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From SURVEY page 1

The basics of CCHS

Because readers of this newsletter are more interested in knowing what the data says than in knowing how the data is obtained, we have placed the technical notes at the end of this report. However, there are a few basic points that need to be kept in mind when viewing the data results:

- CCHS collects the data in interviews with ordinary Canadians selected more or less at random.

- Not all Canadians are in scope for the survey. Exclusions from the target population include children under the age of 12 and residents of long-term care homes.

- Respondents are asked if they have certain chronic health conditions. In the preamble, the interviewer says that s/he is only interested in long-term conditions that have been diagnosed by a health professional. If the respondent answers yes to a condition, there is no verification whether a health professional actually diagnosed the condition or whether the diagnosis was correct. If the respondent answers no, there is no follow-up to see if the person has been diagnosed or actually has the condition.

- A respondent can answer yes to any number of chronic health conditions and can therefore be in more than one chronic condition cohort.

- The questionnaire used the term "Chronic Fatigue Syndrome" and not "Myalgic Encephalomyelitis". Therefore, we use the term Chronic Fatigue Syndrome throughout this report.

- Because the survey is based on a sample of Canadians, the results are "plus or minus some percent, nineteen times out of twenty."

The 2010 Findings

Prevalence of CFS, FM and MCS

In Quest 80, we stated that the number of Canadians diagnosed with one or more of the conditions was equivalent to the population of Calgary, Edmonton, Ottawa-Gatineau or Manitoba.

Between 2005 and 2010, the target population increased by 7%, but the number of people reporting a diagnosis of CFS, FM and/or MCS increased by 25%. The number of people with one or more of these conditions jumped from 4.2% of the target population in 2005 to 4.9% in 2010.

	Prevalence in 2010	% of target population in 2010	Prevalence in 2005	% increase 2005 to 2010
Target Population	28,891,000	100.0%	27,126,000	7%
Chronic Fatigue Syndrome	411,500	1.4%	334,000	23%
Fibromyalgia	439,000	1.5%	390,000	13%
Multiple Chemical Sensitivities	800,500	2.8%	598,500	34%
Chronic Fatigue Syndrome and/or Fibromyalgia	756,000	2.6%	628,500	20%
One or more of CFS, FM, MCS	1,415,000	4.9%	1,135,000	25%

CFS, FM and MCS are not rare conditions. The following table shows the 2010 CCHS estimates of the prevalence of various chronic conditions in Canada among the target population.

DISCLAIMER:

All information in the National ME/FM Action Network newsletters in both *QUEST* and *The Journey* sections on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia (ME/CFS and or FM) and related illnesses is intended for your general knowledge only and is not a substitute for medical advice or treatment. The National ME/FM Action Network does not advocate or recommend adopting any treatment modality based solely on any of the information provided. You should seek prompt medical advice and care for any possible medical issues and consult your physician before starting any new treatments. The information is intended to provide broad personal understanding and knowledge and should not be considered complete. This information should not be used in place of a visit, call, consultation or advice from your physician or other health care provider. The National ME/FM Action Network does not recommend using only self-management of ME/CFS, FM or related illnesses without the expert advice from a physician or health care provider and strongly urge decisions are based on scientific back-up information for any treatments undertaken.

Chronic Condition	Prevalence 2010
Target population	28,891,000
Back problems (other than arthritis or fibromyalgia)	5,469,000
High blood pressure	4,931,000
Arthritis	4,454,000
Migraine headaches	2,882,500
Asthma	2,446,500
Mood disorder	1,882,500
Diabetes	1,841,500
Anxiety disorder	1,488,500
Heart disease	1,431,500
CFS, FM and/or MCS	1,415,000
Bowel disorder/Crohn's disease/colitis	1,238,500
Stomach or intestinal ulcers	807,500
Chronic bronchitis/emphysema/COPD	805,000
Multiple chemical sensitivities	800,500
Irritable bowel syndrome	696,000
Cancer	553,500
Fibromyalgia	439,000
Chronic fatigue syndrome	411,500
Effects of a stroke	312,500
Ulcerative colitis	138,000
Neurological condition caused by spinal cord injury	136,500
Epilepsy	134,500
Neurological condition caused by brain injury	133,000
Alzheimer's disease or other dementia	111,500
Multiple sclerosis	108,500
Crohn's disease	102,500
Neurological condition caused by brain tumour	43,000
Parkinson's disease	39,000
Cerebral Palsy	36,000
Spina Bifida	35,000
Muscular Dystrophy	26,000
Tourette's Syndrome	18,000
Dystonia	15,500
Neurological condition caused by spinal cord tumour	11,000
Hydrocephalus	10,500
ALS (Lou Gehrig's disease)	5,000
Huntington's disease	2,500

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Gender and Age Profiles

Overall, Fibromyalgia had the highest female rate of the chronic conditions profiled in CCHS 2005. This continued to be the case in 2010.

There was a slight decrease in the ratios for CFS and FM between 2005 and 2010. This could be due to a greater recognition of the illnesses among men, to a greater willingness among men to report the conditions, or simply to sampling.

The chart below shows females as percent of cohort.

	2010	2005
Chronic Fatigue Syndrome	66%	69%
Fibromyalgia	79%	83%
Multiple Chemical Sensitivities	72%	72%

In CCHS 2005, about half the people diagnosed with CFS, FM and/or MCS were between 45 and 64 years old while another quarter were in the 25-44 age group. These illness predominate in the years when patients would ordinarily be raising families and working. CCHS 2010 showed a slight increase in the ages of people with chronic conditions, consistent with the general aging of the population.

In many cases, it is difficult to compare cohorts because of the different age (and gender) profiles. Some chronic conditions are more common among seniors, while others are more common among younger people.

The chart to the right shows seniors as percent of cohort.

Chronic Condition	Prevalence 2010
Target population	28,891,000
Back problems (other than arthritis or fibromyalgia)	5,469,000
High blood pressure	4,931,000
Arthritis	4,454,000
Migraine headaches	2,882,500
Asthma	2,446,500
Mood disorder	1,882,500
Diabetes	1,841,500
Anxiety disorder	1,488,500
Heart disease	1,431,500
CFS, FM and/or MCS	1,415,000
Bowel disorder/Crohn's disease/colitis	1,238,500
Stomach or intestinal ulcers	807,500
Chronic bronchitis/emphysema/COPD	805,000
Multiple chemical sensitivities	800,500
Irritable bowel syndrome	696,000
Cancer	553,500
Fibromyalgia	439,000
Chronic fatigue syndrome	411,500
Effects of a stroke	312,500
Ulcerative colitis	136,000
Neurological condition caused by spinal cord injury	136,500
Epilepsy	134,500
Neurological condition caused by brain injury	133,000
Alzheimer's disease or other dementias	111,500
Multiple sclerosis	108,500
Crohn's disease	102,500
Neurological condition caused by brain tumour	43,000
Parkinson's disease	39,000
Cerebral Palsy	36,000
Spina Bifida	35,000
Muscular Dystrophy	26,000
Tourette's Syndrome	18,000
Dystonia	15,500
Neurological condition caused by spinal cord tumour	11,000
Hydrocephalus	10,500
ALS (Lou Gehrig's disease)	5,000
Huntington's disease	2,500

Illness/Condition	
Alzheimer's disease or other dementia	82%
Effects of a stroke	60%
Heart disease	58%
Cancer	53%
Diabetes	45%
High blood pressure	44%
Chronic bronchitis/emphysema/COPD	44%
Arthritis	43%
Chronic fatigue syndrome	24%
Bowel disorder/Crohn's disease/colitis	23%
Fibromyalgia	23%
Multiple chemical sensitivities	22%
Back problems	22%
Stomach or intestinal ulcers	22%
Asthma	14%
Mood disorder	13%
Anxiety disorder	12%
Migraine headaches	7%

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Measures of Disability

One key measure of disability is whether the individual needs help with basic tasks. In the survey, respondents were asked: Because of your physical condition, mental condition or health problem, do you need the help of another person with the following. Preparing meals? Getting to appointments and running errands such as shopping for groceries?

Doing everyday housework? Personal care such as washing, dressing, eating or taking medication? Moving about inside the house?

Looking after your personal finances such as bank transactions or paying bills? If an individual answered yes to one or more of those questions, they were considered to have difficulty with tasks: (In the 2005 analysis, this list also included “doing heavy household chores such as spring cleaning or yard work”. Because this was left out, the 2010 rates for this variable are lower.)

This data confirms that CFS and FM are very disabling illnesses. Two other conditions show high rates of disability – Alzheimer's and effect of stroke. Note that majority of people with these two conditions are seniors, while the majority of people with CFS and FM are of working age.

Percent of cohort needing help with tasks:

Illness/Condition	
Alzheimer's disease or other dementia	78%
Effects of a stroke	52%
Chronic fatigue syndrome	47%
Fibromyalgia	38%
Chronic bronchitis/emphysema/COPD	31%
Heart disease	30%
Cancer	27%
Mood disorder	26%
Arthritis	25%
Stomach or intestinal ulcers	24%
Anxiety disorder	24%
Multiple chemical sensitivities	24%
Bowel disorder/Crohn's disease/colitis	23%
Diabetes	23%
Back problems	20%
High blood pressure	19%
Migraine headaches	15%
Asthma	14%
Target population	9%

The 2005 questionnaire had a section exploring if an individual had difficulty in social situations. The data showed that patients with mood disorders, CFS, anxiety disorders, strokes, epilepsy and FM had high rates of social difficulty. Unfortunately, this set of questions was not repeated in 2010.

This report was prepared by Margaret Parlor, President of the National ME/FM Action Network. Margaret worked for many years as a professional data analyst. A list of data sources is provided in the Technical Notes. Thanks go Statistics Canada for preparing special tables for this analysis and to the Public Health Agency of Canada for providing funding for the preparation of the tables. Responsibility for the use and interpretation of the data provided is entirely that of the author.

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Access to Health and Home Care

In 2005, we found that patients with CFS, FM and MCS, along with those with anxiety

and mood disorders, reported the highest rates of unmet health care needs. These 5 conditions reported the highest rates again in 2010.

Percent of cohort reporting unmet health care needs over the past year

Fibromyalgia	31 %
Chronic fatigue syndrome	29 %
Anxiety disorder	27%
Multiple chemical sensitivities	25 %
Mood disorder	25%
Stomach or intestinal ulcers	22%
Chronic bronchitis/emphysema/COPD	22%
Bowel disorder/Crohn's disease/colitis	22%
Effects of a stroke	21%
Migraine headaches	20%
Back problems	20%
Asthma	17%
Arthritis	17%
Cancer	16%
Alzheimer's disease or other dementia	14%
Heart disease	13%
Diabetes	12%
High blood pressure	11%
Target population	11 %

There was one surprise. FM jumped five percentage points into first place. This jump could be due to sampling, but it is large enough to suggest that something might be going on. Between 2005 and 2010, new drugs came on the market to treat FM. One would think that would reduce the level of unmet health care needs. Perhaps patients had difficulty finding doctors to prescribe the medications, perhaps the medications did not meet their expectations, or perhaps there was too much emphasis on medication and not enough on other treatments. There are questions that need to be investigated.

In 2005, the CFS, FM and MCS cohorts reported high rates of unmet home care needs. In 2010, only Ontario residents were asked about unmet home care needs. Patients with CFS, FM and MCS continued to show rates that were several times higher than for the general public.

Improving access to health and home care is a central focus of the National ME/FM Action Network.

Food Insecurity

Food insecurity is a very concrete indicator of marginalization or deprivation in society. The 2005 data showed CFS, mood disorders and anxiety disorders as the chronic condition cohorts with the highest rate of food insecurity. These cohorts continued to have the highest rates of food insecurity in 2010.

In 2010, almost 2 million Canadians in the target population were found to be food insecure. The rate of food insecurity in the target population increased from 5% in 2005 to 7% in 2010. Increases were seen in the CFS, FM and MCS cohorts.

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Percentage of the cohort found to be food insecure	2010	2005
Target Population	7%	5%
Mood disorders	21%	16%
CFS	20%	17%
Anxiety disorders	19%	16%
MCS	15%	10%
FM	13%	11%

The 2005 data showed that 18% of the 55,000 Canadians who reported that they often did not have enough to eat had one or more of CFS, FM and MCS. In 2010, the number of Canadians who reported that they often did not have enough to eat doubled and CFS/FM/MCS patients accounted for about 16% of the group.

The National ME/FM Action Network identified food security as a matter of particular concern.

Income and Employment

Income and employment continue to be important and difficult issues for the ME/FM/MCS community.

In the 2005 report, we looked at personal income under \$15,000. The 2010 tables focus on household income under \$15,000. With both measures, the CFS, FM and MCS cohorts showed high rates of poverty. Income is related to variables like age, gender, family status, employment status and, of course, health. There is a need for multivariate analysis on the topic of income to disentangle the data to identify the role each of these variables is playing.

Around employment, respondents were asked: Last week, did you work at a job or business? Please include part-time jobs, seasonal work, contract work self-employment, baby-sitting, and any other paid work, regardless of the number of hours worked. Possible answers were: Yes, No, or Permanently unable to work. The question was asked of respondents aged 15-75.

Between the two time periods, the number of respondents reporting they were

permanently unable to work increased markedly. Factors could include the aging of the overall population and the economic downturn experienced in 2009-2010.

It would be useful to look at the income and employment issues for ages 18 to 64. The social safety net for people aged 65 and over includes Old Age Security and the Guaranteed Income Supplement which people receive on the basis of age. The social safety net for people in the 18-64 age group is Canada Pension Plan – Disability and various provincial/territorial welfare and disability plans. These programs have qualification criteria. This means that access to income support is not automatic for working aged Canadians with disabilities.

The 2005 survey showed that there were 392,000 Canadians in the 18-64 age group who said that they were permanently unable to work. Of these, 24% reported a diagnosis of CFS, FM, and/or MCS. This means that many of the people looking to CPP-Disability or provincial/territorial disability programs will have one of these conditions.

We also learn from a major evaluation of the CPP-Disability program conducted by Human Resources and Skills Development Canada and published in August 2010 that: .

- Only about two-thirds of working-age Canadians have CPP-D coverage.
- It is hard to qualify for CPP-D, with the approval rate at the initial stage of adjudication averaging only 45%.
- In 2005, only 295k Canadians were receiving CPP-D benefits (compared to 392k Canadians in the 18-64 age group who reported in the CCHS that they were permanently unable to

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work).

- Despite the fact that CPP-D is supposed to be only one element of income support, 12% of CPP-D recipients in a survey said that these payment was their sole source of family income.

- The maximum CPP-D payment in 2005 was \$12,123 and the average payment was \$10,390. The LICO (low-income cut-off) in 2005 was \$14,303 for a single person living in a rural area and \$20,778 for a single person living in a large city.

- 60% of a sample of applicants that were denied CPP-D had not returned to gainful employment during a three to four year period following denial, suggesting that many people who are denied payments could be genuinely disabled and incorrectly denied coverage.

- The evaluation found that CPP-D were not as large a disincentive to work as had been previously assumed.

Income and employment issues are of great concern to the National ME/FM Action Network and they will be a focus in the

coming year.

Sense of Community Belonging

Respondents were asked: How would you describe your sense of belonging to your local community? Would you say it is very strong? Somewhat strong? Somewhat weak? Very weak?

Having a very weak sense of belonging would indicate a failure of social support systems. The cohorts reporting the highest rates of alienation in 2010 were Alzheimer's, CFS, mood disorders, anxiety disorders, FM and MCS. The results were essentially the same as for 2005, with interesting shifts in two categories – upwards for FM and downwards for stroke patients. In both cases, the sample size is too small to draw firm conclusions but it appears something may be working well for stroke patients, while something may not be working well for FM patients.

Messages from CCHS 2010

For the Patient Community

From its onset in 1993, the National ME/FM Action Network has stood for fairness and equal treatment for the CFS and FM communities. We believe that those ill with CFS and FM deserves the same respect and consideration as those who have other illnesses and conditions.

Both the 2005 and the 2010 statistics show shortcomings and inequalities. What can be taken for granted by others, we must obtain by bringing awareness and education to researchers, medical and social service professionals, and even the general public.

For health and social service officials

The 2010 data confirms what the report on the 2005 data already pointed out.-- that there are serious health and social issues affecting Canadians with CFS and FM that that need to be addressed. New and better ways must be found to diagnose, treat and support patients. Initiatives are needed to reduce the current high rates of unmet needs, food insecurity, poverty and isolation. The questions on CFS, FM and MCS are scheduled to be asked again in 2014. We hope that the 2014 figures will show that progress is being made.

Lydia E. Neilson, MSM, Founder and CEO

Technical Notes

The model underpinning CCHS

A good way of understanding the CCHS is to look at the First Annual report of the Chief Public Health Officer of Canada (2008). The theme of that report was health inequalities in Canada. It starts off as follows:

This report is the Chief Public Health Officer of Canada's first annual report to Canadians on the state of public health in Canada. It explores the public health approach, the health of the Canadian population, variances in health status among the population and factors that contribute to health inequalities. Efforts to reduce these inequalities can be found across the country and at many levels. They include successful interventions that – through better understanding, collaboration and collective action – may serve to reduce Canada's health inequalities and improve quality of life for all Canadians.

It goes on to say:

Why do some people enjoy good health while others do not? These inequalities in health status are partially due to social and economic factors that influence health behaviours and health outcomes. Socio-economic and personal factors profiled within this report include:

- income;
- employment and working conditions;
- food security;
- environment and housing;
- early childhood development;
- education and literacy;
- social support systems;
- health behaviours; and
- access to health care.

The CCHS is designed by health authorities across the country to measure some of these factor and to identify sub-populations ("cohorts") experiencing health inequalities.

In our previous report, we looked at sub-populations based on 23 chronic health conditions. We looked at the income, employment, food security, social support

systems (community belonging) and access to health care (unmet health care and home care needs) situation for each of these cohorts. We saw striking differences. For instance, we saw poor access to health care and high food insecurity for Canadians with CFS, FM and/or MCS compared to Canadians in general. As the Chief Public Health Officer states, these inequalities are public health issues. The inequalities are human rights issues as well. The inequalities could be reduced through better understanding, collaboration and collective action.

Chronic health conditions

On the 2010 survey, there were two sets of questions asking about chronic health conditions.

In the first set of questions, respondents were asked: Now I'd like to ask about certain chronic health conditions which you may have. We are interested in "long-term conditions" which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional. The interviewer then read a list of chronic conditions and asked about each one.

The CCHS was introduced in 2001 as a biennial survey (2001, 2003 and 2005) with around 130,000 respondents in each cycle. In 2007, it was made an ongoing annual survey with around 65,000 respondents each year. At the time of the change, the list of chronic conditions was reviewed and a number were dropped including CFS, FM and MCS. In response to community interest, the three conditions were put back on the list during the year 2010. They are scheduled to be asked again in 2014.

A section on neurological conditions was also included in the 2010 survey. Respondents were asked: Now I'd like to ask about neurological conditions, which are conditions that affect the brain, spinal cord, nerves or muscles. Please do not include mental health conditions such as depression, anxiety

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disorder or schizophrenia. We are interested in conditions which are expected to last or have already lasted six months or more and have been diagnosed by a doctor or other health professional. A list of neurological illnesses was then read to the respondent. These conditions are shown in the prevalence table.

Note that an individual may report more than one condition and thus would appear in several cohorts.

Data sources:

The analysis in this report is based on the following Statistics Canada products:

- the CCHS data dictionary for the 2010 Master File 12-month (rounded)
- the CCHS data dictionary for the 2009-2010 Master File 12-month (rounded)
- the CCHS data dictionary for the 2005 Master File 12-month (rounded)
- the CCHS 2005 Public Use Microdata File which contains anonymized data from the 2005 CCHS
- tables specially generated by Statistics Canada

Because the 2010 data has not been released in a format that allows cross-tabulation, we asked Statistics Canada to prepare tables for us to update the information in Quest 80 to the extent possible. Some modifications were necessary because of the changes in the questionnaire and survey design. Statistics Canada extracted the requested data from their 2010 and 2009-10 Master Files and provided the data to us in worksheet format. The worksheet includes valuable information including coefficients of variation and confidence intervals. We have posted the worksheet on our website so you can see the detail. The cost of generating the tables was paid for by the Public Health Agency of Canada. We would like to thank both agencies for their contributions.

The compilation of this report from these data sources was carried out by the National ME/FM Action Network and the responsibility for the use and interpretation of these data is entirely that of the author.

Target population and sample size

The target population of the CCHS is Canadians age 12 and up living in the community. Excluded are

- Canadians aged 0-11
- Canadians living in institutions such as long-term care facilities,
- Canadians living on native reserves or in remote regions, and
- Full time members of the armed forces.

There were almost 29 million Canadians in scope for the survey in 2010.

It must be kept in mind that the figures in this report are estimates based on sampling. With a target population of almost 29 million and a 2010 sample size of around 63k, each respondent represents on average roughly 460 Canadians. (The sampling strategy is complex, so not all responses are given the same weight.) If two years worth of data is used, each respondent represents roughly 230 Canadians and, as a result, the estimates have smaller coefficients of variation and smaller confidence intervals. To improve data quality, Statistics Canada used combined 2009-2010 data in the tables it generated, except of course for CFS, FM and MCS.

The Journey

Life & Living with ME/CFS and FMS



Issue # 3

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Summer 2011

Vagus Nerve Stimulation shows promise for treatment-resistant fibromyalgia

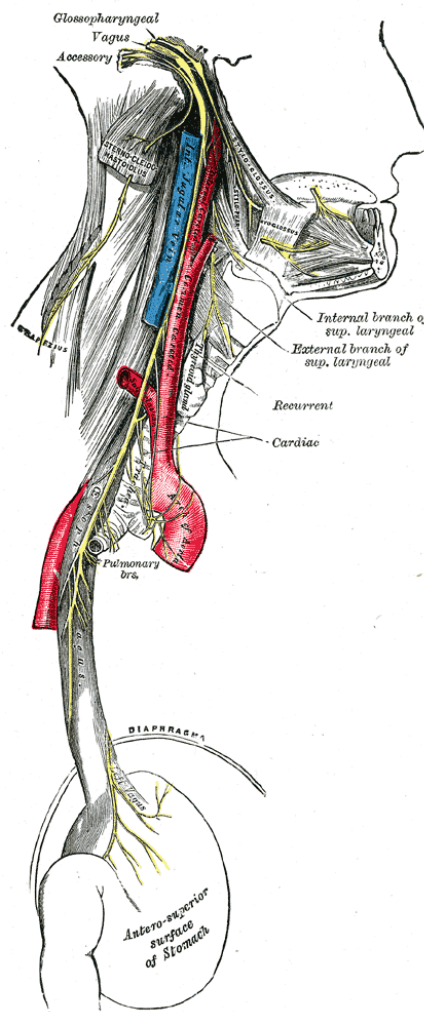
Study shows improvements in pain, wellness

A new study published in the latest issue of *Pain Medicine* shows that fibromyalgia patients may find relief from vagus nerve stimulation (VNS).

The vagus nerve is one of 12 cranial nerves, and is known to convey sensory information to the central nervous system regarding the body's organs. The study showed that stimulation of this nerve improved the subjects' pain, overall wellness and physical function.

According to the abstract for *Safety and Efficacy of Vagus Nerve Stimulation in Fibromyalgia: A Phase I/II Proof of Concept Trial*, the researchers "performed an open-label Phase I/II trial to evaluate the safety and tolerability of VNS in patients with treatment-resistant fibromyalgia (FM) as well as to determine preliminary measures of efficacy in these patients."

The methodology for the



An illustration from Gray's Anatomy showing positioning of the Vagus Nerve.

study involved implanting 14 patients with a VNS stimulator. Of the 14, 12 completed the initial three-month study of VNS, 11 returned for follow-up visits five, eight and 11 months

after beginning VNS. The abstract further states that therapeutic efficacy "was assessed with a composite measure requiring improvement in pain, overall wellness, and physical function. Loss of both pain and tenderness criteria for the diagnosis of FM was added as a secondary outcome measure because of results found at the end of three months of stimulation."

The study concluded that "side effects and tolerability were similar to those found in disorders currently treated with VNS. Preliminary outcome measures suggested that VNS may be a useful adjunct treatment for FM patients resistant to conventional therapeutic management, but further research is required to better understand its actual role in the treatment of FM."

The study was carried out by Gudrun Lange, PhD (from the Department of Radiology, New Jersey Medical School) and his team at the Pain and Fatigue Study Center, Department of Pain Medicine and Palliative Care, Beth Israel Medical Centre, New York City.

Independent Medical Examinations (IMEs) and You

Independent – What Does It Mean?

According to the Oxford Concise English Dictionary, the word “independent” is explained as “not depending on authority or control” and “not depending on another person for one’s opinion or livelihood”.

Is an IME really independent?

It therefore stands to reason that if an Independent Medical Examination (IME) assessor’s payment comes from the individual or business, then that person cannot be independent, according to the Oxford Concise English Dictionary. The IME is asked and paid for by either the insurer or claimant. No matter how honest an assessor is, payment is coming from a source connected to the results of the IME.

To-do list when going for an IME

- Before you go for your appointment with the doctor, check with the College of Physicians & Surgeons in your Province or Territory on the doctor’s credentials and any information reported on that doctor. It won’t help you with your appointment but this kind of search gives you some background on that individual for future reference, if needed;
- Be aware that insurance



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companies often place the insured under surveillance to coincide with an IME to see if the insured is involved in activities that they deny being able to do during the exam.

- After your appointment, make notes on your visit:

1. How long was the visit? When did it start and finish?
2. Was a medical history taken? What questions were asked, who asked them, and what answers did you give?
3. Was there was a physical exam? If there was, who conducted it; the doctor or a nurse? Record the details of the examination.
4. Were you asked how you have been getting along at work or home? What questions were asked, who asked them, and what answers did you give?
5. Were any tests taken? If so what were they and what were the results?
6. Will a copy of the final report be sent to your doctor?
7. Did your attendance at the examination affect your

ability to engage in activities the day of the examination or the day following the examination? If the answer is yes, record details.

Note: The doctor in the majority of cases will advise you that the report will go to the insurer only but you can request the insurer to send a copy to your doctor who then in turn can give you a copy of the report. However, the insurer may deny your request and a copy may only be obtained through your legal representative.

Frequently Asked Questions

Q: Can you get your own IME?

A: Your treating doctor(s) may be able to respond to the findings and opinions set out in the insurance company’s IME. If an insurance doctor has a different specialty than your doctor(s), you may want the opinion of a similarly qualified doctor. If this is the case your doctor can refer you for an IME but this would be at your expense.

Q: What can you when your disability insurer’s IME results in cutting off your disability pension?

A: You need to get a lawyer to represent you. Sometimes the legal representative can review your file and send out a letter pointing out the weakness of the insurance company’s position and the insurer may reverse its

New research points to benefits of multidisciplinary treatment

A recent study points to the potential of a multi-pronged approach as a more effective solution in treating fibromyalgia.

Efficacy of a multidisciplinary treatment program in patients with severe fibromyalgia, published in the current issue of *Rheumatology International*, details the results of research carried out at the Specialist Clinic of Cantabria in Santander, Cantabria, Spain.

The study involved two control groups of 17 patients each. The first group proceeded with their usual treatment program and took part in series of four information sessions. The experimental group also proceeded with their usual treatment, but also followed a treatment regime that included weekly sessions of massage therapy, ischemic pressure on the 18 tender points, aerobic exercise and thermal therapy.

According to the study's abstract, the researchers found little difference between the control groups, though at the end of the eight-week treatment "there was a significant improvement in the experimental

group in the following items: vitality, social functioning, grip strength and the 6-minute walk test." Furthermore, at one month after the end of treatment "the experimental group showed significant differences in overall health perception, social functioning, grip strength and the 6-minute walk test. At that time, considering the threshold for clinical efficacy set at an improvement of 30 percent or above for the analyzed variables, 25 percent of the patients met the requirement for improvement (on the)...Visual Analogic Scale for fatigue, Fibromyalgia Impact Questionnaire and Beck Anxiety Inventory."

The researchers concluded that "patients with severe manifestations of fibromyalgia can obtain improvement with a short-term, low-cost and simple-delivery multidisciplinary program." While this paints a promising picture, the researchers caution that "additional studies including higher numbers of patients are needed to confirm the beneficial effect of this treatment program."

decision. Your legal representative may also contact your physician for more details on your illness or condition in order to send more supporting medical information to your insurer.

However, very often more action needs to be taken by your legal representative which may also include getting an IME from a medical professional with the same credentials as the doctor who assessed you on behalf of the insurer.

Q: What do you need when going for legal help?

- The information booklet given to employees or insureds outlining your benefits;
- All letters from the insurer, including the one denying your claim;
- All of your letters to the insurer;
- Any notes of verbal communications (telephone calls or meetings) with your insurance adjuster;
- Any notes of verbal communications (telephone calls or meetings) with your any other person acting on behalf of your insurer (i.e. a rehabilitation consultant);
- A chronological summary of key events is helpful.

Q: What kind of lawyer do you need?

A: If you are dealing with a disability matter, you need a legal representative who practices disability law. This is a sub-specialty of Litigation that not every legal representative is experienced in. Ask if the legal representative has worked with clients who have been diagnosed with ME/CFS or FM.

Ten observations about recovery from CFS

Recovery is a concept that is viewed with doubt, suspicion and hope by many under the heel of Chronic Fatigue Syndrome. We want to get better. We have tried many treatments and techniques to do so. And most of us have crashed again after most of these attempts.

I have been moving slowly in recovery for a few years and have made surprising headway, in spite of the ups and down along the way. Am I There yet? No. But I am getting There.

Here are a few thoughts about this recovery process.

1. The thought of recovery is frightening. This is not because we don't want to recover. This is not because we are really suffering from depression and are in hiding. Rather it is because it is so hard to recover from CFS and for each step forward there is the real risk of a crash to end all crashes.

It is dangerous business to step up and step out. This makes it hard to hope.

2. Recovery does not follow a straight line. The path of recovery is a treacherous one. For every up there is a down. And with every down there is the reality-based fear that we'll never get up again.

3. Recovery is a fragile process. And it is a longer trip than you might think. When I first started getting significantly stronger I



Sara Smith photo

By Jody Smith
empowerher.com

thought, I will be healthy very soon. I began to do too much, stopped taking enough rest breaks and ended up flat on my face again for months at a time, compliments of Chronic Fatigue Syndrome.

4. I had forgotten pieces of myself. As I continued to heal, I would occasionally be brought face-to-face with aspects of myself from my old life that I had forgotten about. Whole segments of my personality had been submerged in the CFS quagmire for years.

At different points along the way I have been reminded of who I used to be and ... took a deep breath ... reached up ... and began to baby-step in my own former

footsteps.

5. We could use some help from the outside. I had lost my old communities due to my years of sickness. I didn't know anyone outside my family anymore.

What a big help it would have been if someone from my old life had stepped up and walked ...or even sat ... beside me during my trek back into the world. But no one did.

6. Open doors would be a help. I have stood at the top of a winding street in my town and looked down on the community below and felt ... locked out. I didn't know the people in the stores. I didn't have the energy to attend social events or spend an evening in a coffee house looking for conversation.

So I am in the paradoxical situation where I have a busy life on the net with people I work with, and friends who are part of the CFS ghetto ... but there is not as yet room for me in the town I have lived most of my life.

7. It can be done without community assistance but it's harder that way. I am having to do it alone. I am fortunate to have my husband and kids around me. We have started doing a few things together, Outside the House. It would be nice to have friends in my area, but I know that I will be able to rebuild my life, without them.

8. We've lost more than we

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<title>Welcome to National ME/FM Action
Network</title>
<link rel="stylesheet"
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system/jxtc_xmenu/xmenu.css"
type="text/css" />
<link rel="stylesheet"
href="/templates/ethos/thememagic/media/
```

Website profiles

Chronic Fatigue Treatments

(chronicfatiguetreatments.com)

Established in 2006, this website offers visitors a comprehensive portal into the world of ME/CFS information and contacts, be an A to Z list of topics or an online database that allows them to find a local doctor specializing in their condition.

The site also provides lists the top-five ranked topics or links, which at press time included:

- How Does Redbull Affect Your Energy Levels?
- Amygdala Retraining - Gupta Program Interview
- Treatment of Chronic Fatigue Syndrome with Valcyte
- D-Ribose
- Chronic Fatigue Doctor Database

According to Netcraft.com, www.chronicfatiguetreatments.com is

owned by a company called Driscoll Media Inc. (which specializes in "content, sales and lead generation"), and devotes much ad space to the Vitabase line of supplements. (In this regard, the site is no different than any for-profit media outlet, and thus it is up to the website visitor to gauge the integrity of the content.)

Ncubator Chronic Fatigue Syndrome

(ncubator.com)

This site is the online home of blogger (and empowerher.com contributor) Jody Smith. It features articles and blog posts chronicling her struggle for with ME/CFS over the years – as well as her eventual recovery.

As Smith says on her site: "A life with Chronic Fatigue Syndrome is a fragile life indeed. Needs a lot of protection and nurturing. But though we may be ill and often isolated, it helps to keep in mind that none of us are alone. If I have a core message, it is this: Health and restoration are possible. Hope is essential."

(Smith's recent article, *Ten observations about recovery from CFS*, is reprinted on page 4 of this issue.)

realize. We think we know how much has been stolen from us in this sickness but, in recovery, there is almost constant surprise at just how much farther there is to go.

9. We don't know how to get there. It's not just a matter of regaining strength and energy. It's not just a matter of physical healing from multisystem damage.

It is a matter of taking the tattered rags that remain of our old life and trying to rebuild in every area.

Mentally, physically, emotionally, socially and financially. Tall order.

10. There is no guidebook.

Like a person whose home has been destroyed by a natural disaster, we stand (or lay in a stupor) and survey the wreckage, and wonder where to begin. We need pioneers and guides who have made the journey to tell us how to do it. We need people who have recovered from Chronic Fatigue Syndrome who can tell us what to avoid, how to go straight

ahead, how not to get waylaid or stuck.

And so far, there are precious few of these CFS pioneers who have reached the destination of full recovery. I am angling to become one of them.

I spent 15 years losing the battle against Chronic Fatigue Syndrome. Four years ago, I found treatment that worked for me, and now I am making a comeback.

Reprinted with permission

Support Group News & Updates

From your community and around the world

M.E. Society of Edmonton welcomes Myrna Issac

The M.E. Society of Edmonton recently introduced clinical social worker Myrna Isaac, M.S.W., R.S.W. to its members at a recent meeting.

She will be facilitating their support group meetings, and give members the benefit of her experience as part of the team at Edmonton's Cornerstone Counselling Centre, where she specializes in individual and relationship counselling, depression, anxiety and concurrent disorders.

Myrna Isaac has been working in this field since 1985, and is affiliated with the Alberta College of Social Workers.

Fibromyalgia Wellspring Foundation moves meetings

Fibromyalgia Well Spring Foundation has moved its monthly meetings to the Chilliwack Landing Leisure Centre. The organization meets the fourth Wednesday of every month (Aug. 24) from 11 a.m. to 1 p.m. For more information please call toll free 1-800-567-8998.

League makes fibromyalgia donation



Ballymena Times photo

Ballymena, Northern Ireland – Davy Wilson, secretary of the Ballymena, Harryville & Districts Darts League (BHDDL), is pictured here presenting a cheque for £300 to Caroline Campbell, of Ballymena Fibromyalgia Support Group (BFSG). Also seen here is BHDDL treasurer David Martin, his daughter Holly, and BFSG members. The donation was made at the BHDDL's recent meeting at the Ballykeel Business Centre.

(Reprinted with permission from the Ballymena Times)

Fibromyalgia Support group of Winnipeg Upcoming Events

October 3 Research study update:
*Acceptance-based Behavioural Therapy in
Patients with Fibromyalgia*

November 7 “Disability Tax Credit”
- Shonna Pepper and Cheryl Kehler

December 5 Seasonal Party

January 2010 No meeting

February 6 Zumba Dance Exercise Class

March 5 Dr. M. Bailly, Psychologist:
Fibromyalgia and the Family

Call (204) 975-3037 for more information.

Support Group News & Updates

From your community and around the world

'24 Hours in the Enchanted Forest'

Mountain bike race raises money for CFS

On June 18 mountain bike racers took to the trails of the Zuni Mountains (near McGaffey, New Mexico) to raise money for Chronic Fatigue Syndrome in the second annual "24 Hours in the Enchanted Forest: A Race to Solve CFS".

Male and female racers, working in teams and solo, pedaled for 24 hours non-stop for the event, held amidst the Cibola National Forest.

As Solo Male singlespeed winner Jeff Wood told Mountain Flyer Magazine, "This event is incredible, everyone is here for a reason. It's like everyone here is friends and they came to hang out. It's unlike any other event I've ever been to."

A video of the event, produced by video artist Ken Holmes, can be viewed at <http://vimeo.com/26042017>.

Sponsors for the event included High Desert Bicycles, (with locations in Albuquerque and Rio Rancho), Bikeworks Albuquerque, Santa Fe Brewing, Hammer Nutrition, Clover Leaf Environmental Solutions, Nite Rider, White Industries, Keps Balls, Enzo's Cycling Products, Cliff Sampling Program, LaraBar, Reflect Sports, Raw Indulgence and PS ink.

Support group gets storefront in shopping district

Charities and not-for-profit groups in Preston, Lancashire, England have been finding storefront homes in the city's Guild Hall Arcade shopping district at a lower rate than their for-profit counterparts, where currently more than half of the shops sit empty.

One such group is the Preston and District Fibromyalgia Support Group (PDFSG). Speaking for the PDFSG to the *Lancashire Evening Post* for its Sept. 17 issue, Margaret Schofield said that if it weren't for the not-for-profit groups moving in, the shops would otherwise sit empty. "We are paying rent on it," she said. "And even if we are not paying rates it is better to have some in there than no-one."

YMCA manager Andrea Brown agreed, telling the *Post*: "You do not tend to see as many empty shops in Preston as other places. It can only be a positive thing to have a shop with something in it, rather than having high streets with empty shops."

Are you Type A or Type B?

Online survey aims to discover true ME/CFS and FMS personality

On the fun side of things, web columnist Adrienne Dellwo is asking her readers with Chronic Fatigue Syndrome or Fibromyalgia to take part in her online personality type survey. The results may show one way or the other whether the above patients tend to be either Type A (ambitious, aggressive, competitive, high strung, intense) or Type B (laid back, relaxed, patient).

The survey submission is available at chronicfatigue.about.com/b/2011/08/25/poll-personality-types-in-fibromyalgia-chronic-fatigue-syndrome.htm. The survey results are updated in realtime, and we could tell you what they showed at the time of writing, but we'd rather you submit your answer and find out for yourself.

Dellwo is an experienced journalist who has been plying the tools of her trade to better understand fibromyalgia, with which she was diagnosed in 2006. In addition to her column at www.about.com, she also writes for the UK-based *The Fibromyalgia Magazine*.

Is your support group doing something, fun, informative, innovative or inspiring? Please submit all support group news, events and updates to:

mefm.jamesdeagle@yahoo.com

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Bee stings to reduce fibromyalgia pain?

Proponents claim ancient therapy treats a variety of ills

~

Medical columnist says more research needed

Syndicated health columnist Dr. Peter Gott was recently asked by a reader about the validity of “bee sting therapy” for the chronic pain associated with fibromyalgia.

Dr. Gott replied that the therapy in fact can go back more than 3,000 years ago to China, where originally it involved placing bees on strategic pressure points on the body. He added that the poison from bees can improve blood circulation, ease pain and reduce inflammation.

“Following a sting,” said Dr. Gott, “adrenal glands produce cortisol, a natural hormone with anti-inflammatory properties. Supposedly the therapy jump-starts the immune system to trigger the production of endorphins, the body’s natural painkiller. Some specialists think a characteristic of the venom is the presence of dopamine, serotonin and norepinephrine, which help heal conditions involving nerve disorders.”

He recommended that due to potential allergic reaction, patients should be tested before pursuing this therapy, and noted that the therapy is still quite new in North America and has not been thoroughly researched. Thus, he concluded, “the jury is still out on whether it is the answer to a more pain-free existence” for those with fibromyalgia.

The practice of using bee venom (and other bee and hive products) for medical treatment is known as apitherapy. According to the American Apitherapy Society website (www.apitherapy.com), “The ancient rock art of early hunter-gatherers depicts the honeybee as a source of natural medicine. Bee venom therapy was practiced in ancient

Egypt, Greece, and China—three Great Civilizations known for their highly developed medical systems. Hippocrates, the Greek physician known as the ‘Father of Medicine’, recognized the healing virtues of bee venom for treating arthritis and other joint problems. Today, growing scientific evidence suggests that various bee products promote healing by improving circulation, decreasing inflammation, and stimulating a healthy immune response.”

In addition to using bee venom to relieve pain, medical benefits from other bee and hive products, including honey, pollen, royal jelly, propolis, and beeswax, which they say can be used to treat a variety of conditions, including multiple sclerosis, arthritis, wounds, pain, gout, shingles, burns, tendonitis, and infections.

DISCLAIMER:

All information in the National ME/FM Action Network newsletters in both *QUEST* and *The Journey* sections on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and/or Fibromyalgia (ME/CFS and/or FM) and related illnesses is intended for your general knowledge only and is not a substitute for medical advice or treatment. The National ME/FM Action Network does not advocate or recommend adopting any treatment modality based solely on any of the information provided. You should seek prompt medical advice and care for any possible medical issues and consult your physician before starting any new treatments. The information is intended to provide broad personal understanding and knowledge and should not be considered complete. This information should not be used in place of a visit, call, consultation or advice from your physician or other health care provider. The National ME/FM Action Network does not recommend using only self-management of ME/CFS, FM or related illnesses without the expert advice from a physician or health care provider and strongly urges decisions are based on scientific back-up information for any treatments undertaken.

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The Final Word:

The true meaning of life is to plant trees, under whose shade you do not expect to sit.

**-Nelson Henderson
Manitoba pioneer**



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