THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

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Agreement Number 40665071

REACHING OUT

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Charitable Registration Number 89226 7568 RR0001

REACHING OUT - FALL 2006

Greetings Everyone!

With the traditional Holiday Season fast approaching, everyone is looking forward to renewing their respective activities, rituals and traditions that make this time of the year a very special time for each and every one of us.

On behalf of the Board of Directors and The Myalgic Encephalomyelitis Association of Ontario I would like to extend to all of you the very best possible Holiday Season, and wish you much health, happiness and peace throughout the up-coming year of 2007.

As 2006 quickly draws to a close, I would like to acknowledge all of the individuals who have duly supported our Association during this past year. In fact, I would like to extend a sincere and heart-felt thank you to:

1. All who continued to financially support our Association through their memberships and donations,
2. All who actively volunteered for the Association throughout 2006 and
3. All who unselfishly donated their personal time, energy and talents in 2006 to serve on the Board of Directors for the Association.

The fact is that The Myalgic Encephalomyelitis Association of Ontario is much more successful and financially stable because of your continued financial support and your steadfast commitment to volunteering within the Association!

Looking ahead to 2007, I am excited at the possibility of partnering with the Ontario Trillium Foundation in further strengthening and expanding our programs and services to meet the needs of people with M.E./CFS throughout the province of Ontario. We will keep you posted on the success of our discussions with OTF. In 2007, we also hope to begin working (given the availability of funds and personnel) on some of the suggestions that many of you made in our recent 2006 Membership Survey.

The Association is always looking for new volunteers. I thus encourage all of you to carefully review the section of this newsletter entitled "Volunteers, Volunteers, Volunteers" and then, if your health permits, seriously consider becoming a volunteer within the Association. If this is not possible, I encourage you to explore the possibility of recruiting members of your family, your friends or your colleagues. You, who have the illness, can probably appreciate, more than anyone else, the value of having more people working to advance the cause of M.E./CFS.

Sincerely,
Anthony Rovito, President
The Myalgic Encephalomyelitis Association of Ontario

M.E./CFS EDUCATIONAL VIDEOS AND DVD:

Video #1: **Sept. 12, 2001 M.E./CFS Medical Information Session** with Dr. Alison Bested F.R.C.P. (C), Dr. Alan Logan ND and Lawyer, Russell Howe as speakers.
Video #2: June 21, 2003, M.E./CFS Medical Information Session with Dr. Alison Bested F.R.C.P (C), Dr. Alan Logan ND and Dr. Peter Powles**,** Past Chief of Medicine, St. Joseph's Health Care, Toronto and Sleep Disorder Specialist. Dr. Powles also speaks on the possibility of mitochondria dysfunction in M.E./CFS.
Videos #1 and #2 are $20.00 for members and $25.00 for non-members. S&H and tax included.
Video #3 and DVD- Dr. David Bell: Dr. Bell is an Internationally known expert on children/youth and adults with M.E./CFS. Question and Answer session provided by Dr. Bell and Dr. Alison Bested (see video #1).
Video #3 and DVD are $15.00 for Members and $25.00 for non-members. S&H and tax included.

MEMBERSHIPS: Our Annual Membership is $20.00 and donations are greatly appreciated, as they are crucial in increasing the education and awareness of M.E./CFS throughout Ontario. Charity receipts are issued for income tax purposes. If someone is experiencing financial difficulties and would like to be a member, a complimentary membership is available.

BROCHURES: Our ENGLISH M.E./CFS Brochures, containing the Canadian M.E./CFS Definition, is now available in ENGLISH, CHINESE and PORTUGUESE (Brazilian). The FRENCH translation will be available the first week of January and posted on our web site.

Dr. Angelou stated the following on the Oprah Show:
"I've learned that no matter what happens, or how bad it seems today, life does go on, and it will be better tomorrow.
I've learned that regardless of your relationship with your parents, you'll miss them when they're gone from your life.
I've learned that making a "living" is not the same thing as making a "life".
I've learned that life sometimes gives you a second chance.
I've learned that you shouldn't go through life with a catcher's mitt on both hands; you need to be able to throw something back.
I've learned that whenever I decide something with an open heart, I usually make the right decision.
I've learned that even when I have pains, I don't have to be one.
I've learned that every day you should reach out and touch someone. People love a warm hug, or just a friendly pat on the back.
I've learned that I still have a lot to learn.
I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

UPCOMING EVENTS

Event:	**11th Annual Women's Health Matters Forum & Expo**
Location:	Metro Toronto Convention Centre South Building, Exhibit Hall E Bremner Street, Toronto ON
Date(s):	Friday, January 19th – 9:00am – 8:00pm Saturday, January 20th – 9:00am – 6:00pm

Here is the link http://www.womenshealthmatters.ca/forum/.

I am happy to announce that **Dr. Alison C. Bested** will be speaking with **Mr. Russell Howe, lawyer** specializing in medical disability cases, on **Saturday, January 20th @ 2:30 – 3:30pm in Room 803A**.

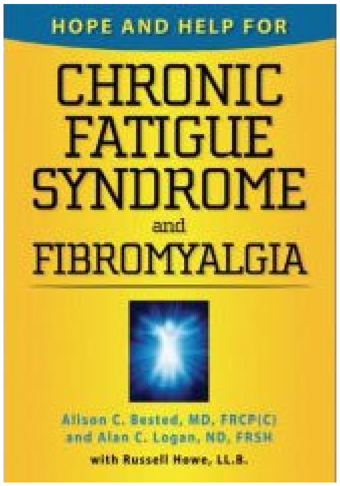
She will be speaking on the book that she, Dr. Alan Logan and Mr. Russell Howe co-authored:
Title: Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia
Description: Everything you want to know about Chronic Fatigue Syndrome and Fibromyalgia, but couldn't find anyone to ask. This session will help patients, family and health professionals learn how to cope better physically, emotionally and legally with these chronic illnesses.

Hope and Help For Chronic Fatigue Syndrome and Fibromyalgia provides a complete guide for anyone struggling with CFS/Fibromyalgia, who is seeking information about their illness as well as coping skills in order to improve their well-being.

Topics include: Symptoms to look for, common physiological side-effects, the potential role of medications, diet and lifestyle, the value of complementary medications and supplements, as well as how to handle insurance issues.

Co-authored by Dr. Alison C. Bested, Dr. Alan Logan and Mr. Russell Howe.

Here is the link to learn more about Alison and the book she will be speaking on - http://www.thedoctors.ca. Thank you for your continued support with all our events and stay tuned for more updates . . .



THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
WILL HAVE A DISPLAY
at the Women's Health Show next to the Environmental Health Clinic's Display.
We thank the Environmental Health Clinic for sharing their space with our Association.

(US) CENTER FOR DISEASE CONTROL AND PREVENTION (CDC) STATES "CFS IS REAL"!

On November 3rd, 2006, the CDC launched its $4,000,000 CFS Awareness Campaign. This was picked up by newspapers and the media throughout the world.

This is important as the CDC has so much influence in the world. The challenge now is to convert this announcement into research dollars.

Please read 'Some Past and Present Historical M.E./CFS Facts' for further comments that were made at this Press Conference on pages 13-16.

No doubt there were other newspapers and media coverage of this, but we are aware that the Global TV station announced this campaign on their 6 PM news; the Globe and Mail stated it in one of their editions and CP24 had it running on their ticker tape at the bottom of the screen.

8th INTERNATIONAL IACFS CONFERENCE ON CHRONIC FATIGUE SYNDROME, FIBROMYALGIA AND OTHER RELATED ILLNESSES

January 12-14, 2007

Bahia Mar Beach Resort, Ft. Lauderdale, Florida, USA
KEY UPDATES

New Case Definition for Pediatric CFS to be presented at the Conference with panel discussion and case studies

Conference Offers:
* Latest clinical research * Treatment protocols and updates * Internationally recognized faculty * Educational Poster sessions with oral discussions * Networking with peers and leaders in the field * Awards Banquet * Preceded by two day Patient Conference

Sessions Include:
* Fatigue * Sleep * CFS Research Funding * Clinical Trials * Pain
* Epidemiology & Case Definition * International CFS Forum * Brain Function
* Behavioral Health * How to Manage a Successful Practice * Pediatrics
* Gender Aspects of CFS * Genetics / Proteomics * New Methods for Evaluating the Fatigue State * Viral and Immune Interactions and Health

January 10 & 11, 2007

Patient Conference:
Co-sponsored by the IACFS and the Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy (P.A.N.D.O.R.A., Inc.)
This Conference intended for Patients, Caregivers, Students and CFS / FM Advocates will consist of group sessions and workshops designed exclusively to better understand the difficult health issues persons with CFS/FM are faced with daily. These include Advocacy and Leadership Training, Understanding and Living with CFS/FM, Family Issues and Pediatrics, and Medical Research and Treatment Updates, Managing Your Quality of Life. Visit http://www.iacfs.net/ for additional information.

www.iacfs.org

This is will be a very interesting Conference as all the well-known and respected researchers and physicians from around the world will be presenting.

Dr. Alison Bested F.R.C.P (C) will be presenting a Poster at the Conference entitled *Case-Controlled Study of Genotypes in MCS.*
Other researchers involved in the Study were Gail McKeown-Eyssn, Cornelius Borins, David EC Cole, Nicole Riley, Lynn Marshall and V. Jazmaji.

In our first Newsletter in 2007, a full report will be included of the IACFS Conference.
In addition, a summary of Dr. Bested's talk at our AGM will be in the next newsletter.
Dr. David Bell of Lyndenville, New York, noted paediatric physician and researcher, dropped in to hear Dr. Bested's talk and say hello.

PLACEMENT OF THE JOURNALS OF CFS VOLUME 11 (1)

HOTEL-DIEUX HOSPITAL, WINDSOR
Chief of Anesthesia - Dr. Bill Taylor; Diagnostic Imaging Dr. F. Netherton; Chief of Emergency Dr. D. Ng; Chief of General Practice Dr. S. Doyle; Chief of Medicine Dr. E. Morgan ; Chief of Neurosciences Dr. H. Desai; Chief of Psychiatry Dr. W. Cassidy; Chief of Surgery Dr. R. G. Stapleford;
Sub-Section Heads:
Cardiology Dr. A. Glanz; General Surgery Dr. A. Forse; Internal Medicine Dr. O. Tarabain
Neurosurgery Dr. A. Shamisa; Ophthamology Dr. B. Emara; Oral Surgery Dr. Stapleford;
Orthopedics Dr. J. Pepin; Otolaryngology Dr. L. Tietze; Plastics Dr. H. Adams
Director of Nursing, Director of the Social Work, Occupational and Physiotherapy Departments and Head of Employee Health Department and Physician Resource Library.

PLACEMENTS OF THE TEACH-ME:SOURCEBOOKS

Multiple TEACH-ME: Sourcebooks will be placed in the month of January as we felt that teachers, principals, etc. would be busy with upcoming holiday events in December and the Sourcebook may not receive the attention that we want them to have.

CFS EDUCATIONAL BUS INTERIOR CARDS

Our Educational Bus interior cards continue to be shown in buses in Ottawa, Sarnia, London, Windsor and Toronto, thus increasing awareness of M.E./CFS in these cities.

RESEARCH

Low-resolution electromagnetic brain tomography (LORETA) of monozygotic twins discordant for chronic fatigue syndrome.

Journal: Neuroimage. 2006 Dec 12;

Authors: Leslie Sherlin [a,*], Thomas Budzynski [c], Helen Kogan Budzynski [c], Marco Congedo [b], Mary E. Fischer [e] and Dedra Buchwald [d]
Affiliations:
[a] Nova Tech EEG, Inc., 8503 E Keats Ave, Mesa, AZ 85208, USA
[b] Nova Tech EEG, Inc., Grenoble, France [c] The Department of Psychosocial and Community Health, University of Washington, Seattle, WA, USA [d] The Department of Medicine, University of Washington, Seattle, WA, USA [e] The Division of Epidemiology and Biostatistics, University of Illinois, Chicago, USA [*] Corresponding Author: LeslieSherlin@aol.com

Received 14 September 2005; revised 28 October 2006; accepted 2 November 2006.
Available online 13 December 2006.

NLM Citation: PMID: 17169580

BACKGROUND: Previous work using quantified EEG has suggested that brain activity in individuals with chronic fatigue syndrome (CFS) and normal persons differs. Our objective was to investigate if specific frequency band-pass regions and spatial locations are associated with CFS using low-resolution electromagnetic brain tomography (LORETA).

METHODS: We conducted a co-twin control study of 17 pairs of monozygotic twins where 1 twin met criteria for CFS and the co-twin was healthy. Twins underwent an extensive battery of tests including a structured psychiatric interview and a quantified EEG. Eyes closed EEG frequency-domain analysis was computed and the entire brain volume was compared of the CFS and healthy twins using a multiple comparison procedure.

RESULTS: Compared with their healthy co-twins, twins with CFS differed in current source density. The CFS twins had higher delta in the left uncus and parahippocampal gyrus and higher theta in the cingulate gyrus and right superior frontal gyrus.

CONCLUSIONS: **These findings suggest that neurophysiological activity in specific areas of the brain may differentiate individuals with CFS from those in good health. The study corroborates that slowing of the deeper structures of the limbic system is associated with affect. It also supports the neurobiological model that the right forebrain is associated with sympathetic activity and the left forebrain with the effective management of energy. These preliminary findings await replication.**

Keywords: Chronic fatigue syndrome; Twins; Electroencephalography; Low resolution electromagnetic tomography; LORETA [This work was partially funded by grant U19AI38429 from the National Institutes of Health (Dr. Buchwald) and Nova Tech EEG, Inc.]

* * *

MINISTRY OF EDUCATION RE EXERCISE POLICY

Margaret Parlor, our Coordinator of Youth and Educational Issues received the following email from the Program and Policy Branch of the Ministry of Education in response to her excellent letter to the Ministry of Education:

December 08, 2006
Margaret Parlor, Myalgic Encephalomyelitis Association of Ontario

Dear Margaret Parlor,

Thank you for your response to my letter addressing your concern about mandatory physical activity in publicly-funded elementary schools across Ontario. I am pleased to respond, on behalf of the Ministry, to your concern about students' protection as they participate in daily physical activities.

You mentioned in your letter, dated October 24, 2006, that it must be recognized that there are some students with health issues that would exclude them from participating, others that can only handle a reduced program and others who should be closely monitored.

As you may be aware, daily physical activity is a component of Ontario's Health and physical education curriculum for students in grades 1-8. This curriculum area identifies that, "students should begin early on to acquire basic knowledge about a wide variety of health-related topics and to develop relevant skills. They need to understand how their actions and decisions affect their health, fitness, and personal well-being, and how to apply their learning to make positive, healthy decisions in all areas of life and personal development" (p.2). All areas of the health and physical education curriculum, including daily physical activity, must ensure that the skills taught are appropriate for the students' age and stage of development, and to their learning styles and special needs. In order to do this, teachers must use a variety of instructional approaches to ensure that all students are given every opportunity to learn and perform to their full potential.

Resources were developed for teachers, principals and school board leaders to support the implementation of daily physical activity in elementary schools. Each resource provides supports in the area of Inclusion of All Students in Daily Physical Activity that is consistent with the Ministry of Education policy.

You stated in your letter that for a student with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, forcing participation is disrespectful and harmful. It is important to remember that no child should be required to participate in inappropriate levels of exercise nor should they need to be removed from school to avoid participation. Communication with parents and with school staff is important in determining any accommodations and adaptations to daily physical activities. Helping young people lead healthy, active lives is a shared responsibility in which schools play a critical role and daily physical activities is only one of the components of the government's Healthy Schools Initiative.

Your concerns are of importance to me and I appreciate the time you have taken to bring them to my attention.

Thank you for writing.
Sincerely,

[Signed By]
Elizabeth Harding,
Director,
Policy and Program Branch [Ministry of Education]

SOME PAST AND PRESENT HISTORICAL M.E./CFS FACTS

In our members survey, you wanted to know what is happening in other countries regarding M.E./CFS. The following will you provide with an overview for some of the countries:

M.E./CFS DIFFICULTIES IN THE UK

The following is a brief summary of the history of M.E./CFS definitions and the difficulties that M.E./CFS patients are encountering in the UK.
The UK Governments plans to set up Cognitive Behavioural Therapy (CBT) and Graded Exercise (GET) Programs throughout the country at the expense of millions of dollars. M.E./CFS Support organizations, associations and support groups are spending an enormous amount of effort to try and stop this from happening and divert the money to biomedical research. The CBT/GET programs will be set up according to the (UK) NICE guidelines that recommends CBT/GET as an effective treatment for M.E./CFS. Psychiatrist, Simon Wessely, etc. al, have caused so much pain in the UK M.E./CFS community. He has been adamant that it is a psychiatric/psychological illness. He also happening to be on the (UK) Scientific Research Council and seems to yield a great deal of power.

A MEDICAL MORASS?

By Margaret Williams 17th November 2006
http://www.meactionuk.org.uk/A_Medical_Morass.htm

Whilst not written in relation to the current confusion about ME/CFS, an NHS consultant physician recently responded to an article in the BMJ on the issue of "policy versus evidence": "Over the past few decades the practice of Medicine has moved from a basis of experience and understanding of the disease process and its treatment towards the application of authorised protocols and guidelines. (This) raises concerns about the situation in which an inadequate evidence base has become canonised into established guidelines (and) Government policy. It takes a bold man indeed to challenge this set of Emperor's clothes" (Nick Hardwick: eBMJ re BMJ 2006:333:912-915).
Can anyone doubt that it is the transformation of "protocols and guidelines" into "canonised policy" that has resulted in the morass that is ME/CFS?

For what disorder is NICE preparing its Guideline on "CFS/ME"? Is it ME or is it "CFS"? Are they the same disorder? NICE is relying on two definitions of "CFS" (the 1991 Oxford criteria and the 1994 Centres for Disease Control criteria), neither of which defines authentic ME. A quick look at the evidence makes interesting if disturbing reading.

1988

It is commonly accepted that in 1988, the disease that had previously been called ME was renamed "CFS" by Holmes et al from the US Centres for Disease Control, but is this true, or has there been one of the most devious subterfuges perpetrated in the history of medicine?

It has long been believed that the introduction of the name "CFS" in 1988 emerged from a collaboration involving Dr Stephen Straus from the US Centres for Disease Control (CDC) with the medical insurance industry, the intention being to curtail benefit payments for the rapidly increasing incidence and prevalence of an existing (and chronically incapacitating) disorder that was known as ME. It was apparently anticipated that such curtailment could be achieved by focusing on the single symptom of chronic "fatigue" (a ubiquitous symptom for which benefit payments could expediently be denied).

That people were seriously sick with what international ME experts regarded as ME is not in doubt (see Osler's Webb: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic. Hillary Johnson. Crown Publishers Inc, New York: 1996). Quite certainly the advisory committee that was to produce the 1988 case definition of "CFS" included two of the leading experts in ME, Dr Alexis Shelokov from the US and Dr Gordon Parish from the UK.

However, both these experts withdrew from the deliberations as they were unable to endorse the new definition of "CFS" because it was so far removed from what, as experts, they knew ME to be, since it excluded the cardinal and well-documented neurological and vascular features of ME and focused instead on "fatigue". The experts were dismayed that the essential characteristics of ME were no longer to feature in the "new" definition that was claimed to be preferable, ostensibly because it made no assumptions about aetiology.

It is recorded that Holmes himself wanted to keep the term ME but was over-ruled.

If in 1988 "CFS" was indeed meant to be a new name for ME, in 2005 it was acknowledged to have been a major error by one of the physicians on the committee, Professor Anthony Komaroff: "None of the participants in creating the 1988 CFS case definition, and the illness name, ever expressed any concern that it might trivialise the illness. We simply were insensitive to that possibility, and we were wrong"

(http://www.cfidsreport.com/Articles/NIH/NIH_CFS_4.htm).

In that definition (Chronic Fatigue Syndrome: A Working Case Definition.Gary P Holmes et al. Ann Intern Med 1988:108:387-389), no mention was made of ME or of its cardinal features (either in the text or in the references), only of the chronic Epstein-Barr Virus Syndrome: "We propose a new name for the chronic Epstein-Barr virus syndrome - the chronic fatigue syndrome" (EBV being one of the herpes family of viruses seen in mononucleosis, not one of the enteroviruses more commonly seen in ME).

Holmes et al also stated that their case definition described "a possibly unique clinical entity", but how could such a description apply to ME, given that ME had been documented in the medical literature since at least the 1930s and had been formally classified as a neurological disorder in the International Classification of Diseases since 1969 and had been recognised as a nosological entity in 1978 by the UK Royal Society of Medicine?

Further, the listed symptoms of the newly-defined "CFS" included fever; sore throat; painful lymph nodes; generalised muscle weakness; myalgia; sleep disturbance; headaches; depression; decreased memory and prolonged generalised fatigue after exercise, all of which might result from EBV infection. In other words, the symptoms were those seen in a typical (and commonly transient) post-viral state that were usually of little consequence.

Was the over-riding intention to deflect medical and scientific attention away from the world-wide explosion of the devastating and chronic disorder ME and to create a "new" disorder called "CFS" that was of considerably lesser significance and impact, and therefore of less financial consequence for the CDC and the insurance industry?

In the 1988 "CFS" definition, no mention was made of the fact that in ME, there is a sub-normal temperature (not fever), nor of the additional signs and symptoms that define ME (for example, difficulty in standing and walking; neuro-muscular incoordination; vertigo and balance problems with observable nystagmus; abnormal reflexes; blurred vision; frequency of micturition and other evidence of autonomic instability; fasciculation; marked tremor; difficulty swallowing; hair loss; respiratory, cardiac and vascular problems; pancreatic problems; liver involvement; bowel problems including explosive diarrhea; increased allergies and hypersensitivities; marked variability of symptoms; sensory storms, and the cardinal symptom of angor animi - a feeling of imminent death).

A further notable difference is that patients who develop CFS following EBV may succumb to every opportunistic infection and sore throat doing the rounds, whereas those with ME rarely, if ever, get a sore throat or common cold (as noted in the literature on ME, as well as in patients' own accounts).

Of interest is that in November 2006, the CDC "CFS Toolkit" launch noted that there are two distinct types of "CFS", one with rapid post-viral onset and the other with a gradual onset and - significantly -- that the two types appear to differ genetically.

The question therefore arises as to what disorder the 1988 "new" case definition was defining if, according to the ME experts, it was not ME?

The alternative question is whether the key features of ME were deliberately omitted in order to portray "CFS" as a less serious (and therefore less expensive) disorder?

It seems that in 1988, ME was considered to be a physical disease that was henceforth to be renamed "CFS", but whether this in fact occurred (or whether a different entity from ME was created) is open to conjecture.

1991

In 1991, the much-criticised "Oxford" case definition appeared, having been compiled by psychiatrists Michael Sharpe, Peter White and Simon Wessely, amongst others (A report - chronic fatigue syndrome: guidelines for research. MC Sharpe et al. JRSM 1991:84:118-121). This report makes it clear that Holmes et al were indeed referring to ME in their 1988 case definition of "CFS". However, the 1991 criteria state that the authors were looking at patients "with a principal complaint of disabling fatigue" and that "the aim of the meeting was to seek agreement amongst research workers for future studies of patients with chronic fatigue". As in the 1988 case definition of "CFS", the key symptomatology of ME was missing, yet Sharpe et al claimed to be including "ME" in their definition. How could they be looking at ME when the cardinal features were specifically excluded from their definition? (It is this 1991 "Oxford" definition that NICE relies upon in its Draft Guideline for "CFS/ME").

It is important to remember that Wessely School source -- under one umbrella, because they want to determine the role of "fatigue" in psychiatric disorders.

In this respect, why are patients with ME so relentlessly targeted for psychotherapy as the management regime of choice, when patients with leukaemia or multiple sclerosis (both of which cause fatigue) are not so targeted and admonished that they must "exercise back to fitness"?

It is also important to recall that Wessely's cherished aim has long been to "eradicate" ME as a distinct entity: if a disorder does not officially exist, then no-one can suffer from it and there would be no need for expensive provision for it and benefits need not be paid for it. This also seems to have been his modus operandi in the case of Gulf War Syndrome.

1992

In July 1992 the WHO published the tenth revision of the International Classification of Diseases (ICD-10), in which an alternative term for ME was listed as "CFS", which subsequently gave rise to the term "ME/CFS".

Also in 1992, the US Physicians' Handbook published by the National Institutes of Health (NIH) stated: "CFS does not appear to be a new disorder. Epidemics (most often called myalgic encephalomyelitis or ME) have been described in the medical literature for at least 60 years".

1994

During one of the meetings at which the 1994 CDC revised definition of "CFS" was formulated, in response to a direct question from a physician who was present, Dr Keiji Fukuda (not an ME expert, but lead author of the CDC 1994 definition) stated that the numerous ME epidemics, including the one at the Royal Free Hospital in London in 1955, were definitely not CFS. As in the CDC 1988 case definition, the CDC 1994 revised case definition makes no mention of ME or of its key signs and symptomatology. Instead it emphasises that the exclusion of persons with psychiatric disorders including depression and anxiety "would substantially hinder efforts to clarify the role that psychiatric disorders have in fatiguing illnesses", adding for good measure that "chronic fatigue cases preceded by some, but not all, psychiatric syndromes can be classified as the chronic fatigue syndrome". Of significance is the fact that the 1994 CDC revised criteria for "CFS" state unequivocally: "We dropped all physical signs from our inclusion criteria. Whether to retain any symptom other than chronic fatigue generated the most disagreement among the authors". Thus it seems beyond doubt that ME was not included within the compass of the 1994 CDC revised case definition of "CFS", no matter what Sharpe (one of the 1994 authors), Wessely, White et al claimed in 1991 (and subsequently). It is, however, this definition that has been used in research that has revealed the major pathology that underlies (ME)CFS.

Why therefore does the ME community use the composite term "ME/CFS"? For two reasons: firstly because the WHO ICD states that they are the same disorder and secondly because the international research literature makes little mention of "ME", thus to refuse to use the term "CFS" would exclude the major research literature spanning the last two decades.

So - in 1988, ME was not the same disorder as CFS (because the ME experts said so), but in 1991 and 1992 (according to Wessely School psychiatrists, the WHO and the NIH), ME was the same disorder as CFS, yet in 1994, according to Fukuda, ME was not the same disorder as CFS (even though Wessely School psychiatrists continue to claim that it is).

In other words, CFS was not ME when ME was deemed to be a physical disorder, but as soon as ME came to be considered a psychiatric disorder (by Wessely School psychiatrists), suddenly CFS was ME after all.

Given this conundrum, for what disorder is NICE producing its Guideline?

On what rational grounds does NICE refuse to accept the advancement of medical science and take as its starting point the Canadian case definition (Carruthers, Klimas et al 2003) that incorporates the cardinal features of authentic ME with the international biomedical research on "CFS" into a composite entity?

Confusion over case definition has resulted in confusion over the safety of management regimes

The NICE Draft Guideline for "CFS/ME" is clear that the only recommended interventions are cognitive behavioural therapy, graded (aerobic) exercise and "activity management".

Is it safe for people with authentic ME to engage in graded exercise?

In a submission to NICE on behalf of the UK 25%ME Group for the Severely Affected, mention was made of the 5th edition (2002, reprinted 2004) of a medical textbook that is likely to be on the desk of every GP in the country (having won the "Highly Commended" BMA Award) and to the fact that it contained statements about ME by psychiatrists Peter White and Anthony Clare that are insupportable. The 6th edition (2005) of the same medical textbook is equally inaccurate. Within the section on CFS (in Functional or Psychosomatic Disorders starting on page 1281), White and Clare talk about "dysfunctional beliefs and behaviours" and refer to the "management of functional disorders" as being "rehabilitative therapy" which includes CBT (to "challenge unhelpful beliefs and coping strategies") and they recommend three months' GET "to reduce inactivity and improve fitness".

This is in line with the NICE draft recommendations about aerobic exercise and also with the NHS Plus Policy Document of October 2006 concerning the occupational aspects of CFS that reflect the Wessely School psychiatrists' strongly-held beliefs.

However, Dr Derek Enlander MD (a former virologist who specialises in ME/CFS, previously Assistant Professor at Columbia University and then Associate Director of Nuclear Medicine at New York University; currently Physician-in-Waiting to the Royal Family and to members of HM Government when they visit New York) is on record about aerobic exercise for patients with ME/CFS: "I do not want my patients in an aerobic class. I feel this causes considerable damage to (ME)CFS patients". (Derek Enlander: Update on the Treatment of Chronic Fatigue Syndrome and Fibromyalgia, 8th November 2006).

Equally, Dr Paul Cheney, who has been studying the disorder since the Lake Tahoe outbreak in 1984, is adamant that such patients should not engage in aerobic exercise: indeed they are unable do so, because the lack of energy generation results in low cardiac output that is not equal to the metabolic demand created by aerobic exercise.

(For further information on Cheney's evidence, see http://www.meactionuk.org.uk/Klimas_Wessely_and_NICE_-_Redefining_CBT.htm).

The Canadian Guidelines are unequivocal: graded exercise showed the highest negative rating of all management interventions: "The question arises whether a formal CBT or GET programme adds anything to what is available in the ordinary medical setting. A well-informed physician helps (the patient) achieve optimal exercise and activity levels within their limits in a common-sense, non-ideological manner which is not tied to deadlines or other hidden agenda" (ME/CFS: Clinical Working Case Definition, Diagnosis and Treatment Protocols. Bruce M Carruthers, Kenny L De Meirleir, Nancy G Klimas et al. JCFS 2003:11:1:7-115).

Moreover, the CDC "CFS Toolkit" released at the beginning of November 2006 is equally clear: "This kind of exercise (aerobic) can precipitate a full-scale relapse that lasts for weeks or months".

It is already known that ME/CFS experts agree that aerobic exercise can cause serious relapse and that it can be dangerous to the extent that it could be life-threatening for some such patients.

CBT/GET is already known not to be effective.

CBT/GET has already been shown to have no lasting benefit.

CBT/GET is already known to be very expensive.

It is already known that, logistically, CBT/GET cannot be delivered without recruiting, training and supervising many more therapists at vast expense.

It is therefore a misuse of funds that could - and should - be better spent on biomedical research.

Why, therefore, is NICE continuing to pay no heed to the evidence and to recommend CBT/GET as the only management regime for those with "CFS/ME"?

Is it because NICE is taking advice from only one source ie. from the Wessely School, whose members are, on their own admission, heavily engaged in social engineering and to which they are so committed? (see "Biopsychosocial Medicine: An integrated approach to understanding illness" edited by Peter White; OUP 2005; chapter 12).

It is such social engineering that turns an inadequate evidence-base into canonised Government policy.

Is this social engineering taking place because the truth is not to be tolerated under any circumstances (the truth being contained in a memo sent on 17th November 2006 from the Director of the **US CDC**, **Dr Julie Gerberding, to CDC staff: "When we launched the national CFS awareness campaign this month, we demonstrated credible evidence of a genomic and an environmental basis for this condition".**

In other words, ME/CFS is environmentally acquired. Why is no research permitted in the UK into the "environmental basis" of the condition, but only denial of its very existence?

Already there is evidence that patients are suffering as a direct result of the NICE Draft Guideline: Professor Leslie Findley from the Essex Neurosciences Unit at Romford has confirmed that in this last week, two Primary Care Trusts have altered, or turned down, treatment for patients with ME/CFS on the basis of the content of the Draft Guideline and asks that people should be made aware that the Draft Guideline is currently being misused.

At the All Party Parliamentary Group on ME held at Westminster on 16th November 2006, a representative from NICE was instructed by the APPG Chairman (Dr Des Turner MP) to report back to NICE that NICE would be very unwise to publish its Draft Guideline on "CFS/ME" as it stands, and that Turner was at a loss to know why NICE was doing this and also about what NICE hoped to achieve by it. Sir Michael Rawlins, Chairman of NICE, was to be invited to attend the next APPGME.

For a brief comparison of the difference in the UK and the US about the validity and reality of ME/CFS, the following quotations are taken from the Press Conference held on 3rd November 2006 at the launch of the CDC "CFS Toolkit":

Dr Julie Gerberding, Director of the US CDC:
"One of the things that CDC hopes to do is to help patients know that they have an illness that requires medical attention, but also to help clinicians be able to understand, diagnose and help people with the illness. But more importantly, to be able to validate and understand the incredible suffering that many patients and their families experience in this context".

"I have heard from hundreds and hundreds of people who are telling their stories - their courage, their commitment to try to live the best possible life they can (and) the tremendous impact that this is having on their ability to function".

"We are committed to improving the awareness that this is a real illness and that people need real medical care and they deserve the best possible help that we can provide".

"The science has progressed (which has) helped us define the magnitude and understand better the clinical manifestations (and this has) led to a sorely needed foundation for the recognition of the underlying biological aspects of the illness. We need to respect and make that science more visible".

Dr William Reeves, Chief of Chronic Viral Diseases Branch at CDC:
"We've documented the prevalence of (ME)CFS - the illness affects at least a million Americans".
"(ME)CFS is responsible for an impact of about $9.1 billion annually in lost earnings".

"We've documented, as have others, that the level of impairment in people who suffer from (ME)CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well-known, very severe medical conditions".

"We found that (ME)CFS follows a pattern of remitting and relapsing symptoms, the symptoms can change over time, and that spontaneous recovery is rare".

"We found that the best predictor for (ME)CFS was intensity of the initial infectious disease. The sicker the patient when s/he first got infected, the more likely they were to have persisting chronic symptoms. There were no other factors, psychological or biological, that held up under thorough analysis".

Professor Anthony Komaroff of the Harvard Medical School:

"There are now over 4,000 published studies that show underlying biological abnormalities in patients with this illness. It's not an illness that people can simply imagine that they have and it's not a psychological illness. In my view, that debate, which was waged for 20 years, should now be over".

"A whole bunch of studies show that the hormone system is different in patients with (ME)CFS than in healthy people, people with depression and other diseases".

"Brain imaging studies have shown inflammation, reduced blood flow and impaired cellular function in different locations of the brain".

"Many studies have found that the immune system appears to be in a state of chronic activation (and) genes that control the activation of the immune system are abnormally expressed in patients with this illness".

"A number of studies have shown that there probably are abnormalities of energy metabolism in patients with this illness".

During the Question and Answer session, the question was asked: "You've cited quite a bit of research that validates that (ME)CFS is actually a real disease. **Why is there still such a level of scepticism in the medical community?** Is it simply a lack of awareness among health professionals?"

Komaroff replied: "There are an awful lot of sceptics I've met who really just haven't read the research literature (and) don't even know there are 4,000 peer-reviewed published papers out there. I think that's probably the biggest factor, combined with the fact that those people took a stand early on as to what they believe and have been reluctant to back off in the face of the evidence that they've not made themselves aware of".

Professor Nancy Klimas, Professor of Medicine, University of Miami:

"I've treated over 2,000 (ME)CFS patients. I've seen patients (who) were angry, frustrated, trying to convince their physicians, their families, their friends that this is a real illness. I've seen other patients (who) hid their diagnosis because of the stigma attached and suffered in silence. It's been the lack of credibility in this illness that has been one of the major stumbling blocks to making progress".

"Today, there is evidence of the biological underpinnings. And there's evidence that the patients with this illness experience a level of disability that's equal to that of patients with late-stage AIDS, patients undergoing chemotherapy, patients with multiple sclerosis. And that has certainly given it a level of credibility that should be easily understood".

"I'm less enthusiastic about the advances in the clinical care of patients".

"We need disability insurance carriers to believe this is an illness – a disabling illness and do what they should do, and pay our patients when they are disabled".

"There are diagnostic criteria that enable clinicians to diagnose (ME)CFS in the primary care setting".

"Key to the effective management of illness is the effective partnership with the patient and the physician. It's also important for patients to take a proactive role and become informed and seek appropriate care to manage the illness and its impact on their lives".

"I call on my colleagues in the medical profession to treat (ME)CFS patients with the kind of respect and compassion necessary to make this first step".

The full Press Conference transcript is available at
http://www.cdc.gov/od/oc/media/transcripts/t061103.htm?id=36410

Whatever the motives or mistakes in the past, it is apparent that whatever it is called, ME/CFS can no longer be regarded as a behavioural disorder as the Wessely School has insisted for the last two decades.

It might be wondered what will be the reaction of Wessely, White, Sharpe et al to know that it has been publicly recognised that from their irrefutable published record (although not named personally), they must be included amongst those responsible for the debate that was waged for twenty years against severely physically - and not mentally - sick people, a debate that has both caused and prolonged incalculable suffering and which, despite all the contrary evidence, Wessely et al are still endeavouring to promote under the auspices of NICE, Government Policy Documents and textbooks of medicine.

Editor's Note: The (US) CDC has not always been on our side. In the late 90's, the (US) National Institute of Health gave the CDC $23,000,000 to Research CFS. On a fluke, someone caught that the CDC had diverted over $17,000,000 of this research money to other illnesses. The CDC was hauled up on the carpet by the US Government, but no one at the CDC was fired for doing this.

The long awaited report from the UK Gibson Inquiry has generated many postings on co-cure discussion group. The Gibson Inquiry was to offset the NICE Guidelines emphasizing CBT/GET, but there is much unhappiness within the UK M.E. communities – some want to accept as it is despite being flawed, while others are fighting hard to discredit it. The report is very important as it may set the stage for M.E./CFS research funding in the UK.
After the final conclusion has been decided, I will report what finally happened to the Report from the Gibson Inquiry in our Newsletter.

Editors note: Please note that this is NOT the same CBT therapy that Dr. Bested practices in her Support Group. Dr. Bested's CBT is directed at conserving energy.

ADDITIONAL INFORMATION ON WHAT'S HAPPENING IN THE U.S.

NAME CHANGE

For several years, there has been a US Name Change Committee that has been trying to come up with a new name for CFS. All of the committee members want to get rid of the name 'Chronic Fatigue Syndrome', some consider keeping 'Myalgic Encephalomyelitis'. This will discussed at the upcoming IACFS conference in Florida in January.
Other physicians want to keep the name until research defines definitely what M.E./CFS is, and most of the published research in the medical Journals refer to the name CFS and/or M.E./CFS.

From the CFIDS Association of America Web site:
http://www.cfids.org/advocacy/cfsac-nov06.asp

CFSAC: Chronic Fatigue Syndrome Advisory Committee

Report on the Nov. 20-21, 2006 Meeting of the DHHS CFS Advisory Committee

The CFS Advisory Committee (CFSAC) to the Department of Health and Human Services (DHHS) met on Monday, Nov. 20, and Tuesday, Nov. 21, 2006 in Washington, D.C. This was the Committee's third meeting with its current membership and its 11th overall since being chartered under the Federal Advisory Committee Act in 2002. Committee chairman Dr. Nahid Mohagheghpour was unable to attend the meeting, so new Executive Secretary, Dr. Anand Parekh, representing the Department's Office of Public Health and Science, acted as meeting chair. Dr. Parekh made brief introductory comments and took a roll call, with Dr. Morris Papernik unable to attend due to a death in the family. The other nine members of the Committee were in attendance. Dr. Parekh reviewed the two-day meeting agenda and welcomed two invited guests to provide remarks to the Committee. Members of the Committee were able to question these guests and engage in dialogue with them after each presentation.

Dr. Mary Schweitzer described the onset of CFS in 1993 when she was a Villanova professor. She spoke about the difficulty of obtaining a diagnosis and the steadfast support of her family, even as their lives changed due to her disabling condition. She attributed a moderate return in function to treatment with Ampligen, which costs her family approximately $20,000 per year for the drug and related tests not covered by insurance. She restated how "lucky" she considers herself to be in comparison with others she has befriended who have CFS and fewer support systems. Dr. Schweitzer called attention to several shortcomings of federal efforts, including the CDC's web site and materials for health care professionals. She noted that her remarks were based largely on material developed for a book she is writing titled, "Slightly Alive."
Her testimony has been posted on the Internet at http://www.cfids-me.org/cfscc/cfsacf06.html

Ms. Meghan Shannon addressed the Committee next, expressing anger about the way she had been treated the last time she spoke before the Committee on Dec. 8, 2003. She had vowed at that time never to return to a CFSAC meeting and had nearly kept that promise in spite of the invitation to offer remarks. Ms.Shannon reviewed her onset of symptoms, reporting that she was exposed to adenovirus infection in her work as a pediatric respiratory therapist, later resulting in CFS. She also mentioned poor care she had received in emergency rooms based on having CFS as her diagnosed condition. Her research and advocacy into CFS had taken her to several countries and she stated her belief that she suffers from myalgic encephalomyelitis and postpolio syndrome, citing classic and more recent articles from published medical literature in support of these statements. She also drew attention to material about CFS contained in the well-known book on women's health, "Our Bodies, Our Selves."

After a short break, Dr. Parekh turned to reports from the federal agencies. Dr. Marc Cavaille-Coll from the Food and Drug Administration (FDA) reported that the number of products under review for CFS was still small and addressed changes at FDA related to the physicians labeling rule to provide more useful information on the inserts for pharmaceutical drugs. Dr. Cavaille-Coll mentioned the Office of Special Health Issues, available to answer questions about the drug approval process, and other FDA resources. Asked his opinion about the obstacles to greater development of specific CFS treatments, he cited the lack of animal models and specific biologic targets. In response to a question about special provisions for Orphan Drug status, Dr. Cavaille-Coll indicated that the prevalence of one million Americans with CFS put CFS out of this category; however, he suggested that it was possible the case could be made that drugs to treat subsets of CFS might qualify for such classification. The use of approved products for off-label treatment of CFS was discussed, with several Committee members suggesting that off-label use of pharmaceuticals often creates problems for insurance reimbursement for these costs. Safety and efficacy in such circumstances were also concerns and the need for more clinical trials was highlighted. Dr. Cavaille-Coll reminded the Committee that FDA does not initiate such trials and that its function is the regulation of such products.

Dr. Eleanor Hanna reported on recent NIH activities, including the announcement of seven new CFS grants in response to proposals submitted under the special Request for Applications (RFA) issued by NIH in 2005. She reported that these investigators will be required to participate in an annual meeting to exchange information and form the basis of a collaborative research group. She offered the Office of Research on Women's Health's web site as a resource for patients and researchers and mentioned that a new CFS flyer will become part of NIH's Science Series. In discussing the NIH's Roadmap Initiative, she indicated that she will be working with Trans-NIH CFS Working Group to develop a proposal for centers that would bridge basic and clinical research, as well as provide training opportunities for young investigators. This initiative would be submitted to the new Office of Portfolio Analysis and Strategic Initiatives (OPASI) for consideration as a project under the Roadmap Initiative. She suggested that it was premature to plan another consensus or state of the science conference and recommended that some of the new research get under way to plot promising next steps.

Dr. Laurence Desi from the Social Security Administration (SSA) stated that physicians and consultative examiners who participate in disability decisions at the state and federal level were being encouraged to take the continuing medical education program offered by CDC and the CFIDS Association of America. He listed other CFS-related training opportunities and educational resources for staff.

Following the lunch break, Dr. William Robinson, representing the Health Resources and Services Administration (HRSA), announced his January 2007 retirement and stated that this would be his last meeting with the Committee. He introduced Dr. Deborah Willis-Fillinger who will replace him as the HRSA representative. He then provided a history of HRSA's involvement in CFS in the context of its mission to equalize the distribution of health care services. He commended the CDC and the CFIDS

Association in supporting activities to address the Committee's recommendations related to training health care professionals in light of the fact that HRSA has no financial resources dedicated to CFS-specific activities. He distributed a letter he had sent in August to all of the federally funded Community Health Centers which provide subsidized medical services to underserved populations in rural and urban settings, encouraging health care professionals working in those centers to use the resources developed by CDC and the CFIDS Association to become informed and knowledgeable about CFS and appropriate patient care.

Dr. William Reeves of the Centers for Disease Control and Prevention (CDC) provided an update on research and education activities led by his group, including studies of prevalence, illness severity, medication and medical services usage, economic impact, genes implicated in CFS, changes in cognitive function, allostatic load and overlap with metabolic syndrome, and mathematical modeling of CFS. He described two new phases of an ongoing study of CFS in rural, metro and urban Georgia, including one of clinical course of CFS patients and a pilot patient registry to be enrolled by multidisciplinary health care professionals. He also reported on the Nov. 3 press conference hosted by CDC and the CFDS Association as the public launch of the national awareness campaign and the media response so far. Dr. Reeves presented his logic model for how all these activities fit into a "control" strategy for CFS, a multipronged approach to decrease illness prevalence, duration, severity, impairment and economic impact. He then provided additional details on the education activities aimed at primary care professionals, including grand rounds, participation at professional conferences, continuing education programs, and evaluation of activities and project efficacy. When asked about funding for all these activities, Dr. Reeves indicated that his group's funding had dropped to $4.4 million for the upcoming fiscal year and that some projects would be put in jeopardy at that funding level, particularly the long-term follow-up of patients identified in the Georgia study and the patient registry being piloted.

Dr. Parekh thanked all the federal representatives for their work and their reports and welcomed **Dr. Lucimar Cose-Cannon, a representative of the Pan-American Health Organization (PAHO) and the World Health Organization (WHO),** invited to present an international perspective on CFS and the education of professionals about conditions such as CFS. She provided an overview of the mission of the PAHO, indicating that a search of PAHO and WHO programs turned up little specific to CFS. She attributed this condition within **PAHO, which serves countries of Mexico and Latin and South Americas**, to the competition for resources strapped by programs to address and control treatable and vaccinatable conditions that have high mortality rates and high prevalence in these countries. While she acknowledged the existence of and problems associated with CFS, she was candid about the challenges of initiating new activities in light of urgent realities of communicable diseases. She suggested that providers' attitudes about CFS were likely similar to those in the U.S., yet her recent conversations with colleagues in Brazil indicated an awareness of CFS as well as the suffering of people with it. Dr. Parekh and the Committee thanked her for her presentation and perspective.

For the remainder of the afternoon session the Committee raised and discussed a large number of tactics to expand education of health care professionals, addressing a wide range of disciplines and practice settings. Experience with other conditions or other organizations was shared, generating a large list of means by which to reach providers in training (students/residents) and providers in practice. Discussion also flowed to public awareness, with concerns raised about serving patients who don't have access to the Internet and the missing infrastructure to provide one-on-one support to patients in need of additional resources. The appropriate balance of outreach and fulfillment was considered. The role of third party payers (including Medicare/Medicaid), on both the provider side and public side, was reviewed, as were means by which to reach these influential institutions. Throughout the days' discussions, Kim McCleary and Terri Lupton from the CFIDS Association of America offered clarifications about public and provider education efforts and historical information pertinent to the dialogue. Dr. Parekh made helpful suggestions to guide development of recommendations and future meeting agendas. At 4:45 p.m. the first day's session was adjourned after a review of the next day's schedule.

Day Two:
After Dr. Parekh called the meeting to order, the Committee reviewed minutes of the April and July meetings, providing corrections and clarifications. Committee management issues were addressed in response to concerns by members about past handling of administrative issues and the lack of continuity in leadership from the department at a staffing level. Dr. Parekh handled these issues with directness and made an express commitment to improve service to the Committee through his personal involvement and oversight of other staff functions. Dr. John Agwunobi, Assistant Secretary for Health, then joined the meeting, thanking Dr. Parekh for joining his staff and accepting responsibility for supporting the CFSAC. He thanked the five outgoing members of the Committee, presenting each individual with a plaque and letter of appreciation signed by Secretary for Health Michael Leavitt. He announced that new Committee members would be named before the end of the year to replace those whose terms had been extended beyond their Sept. 30, 2006 expiration date. Dr. Agwunobi talked with the Committee about the new schedule of two two-day meetings per year and promised to reevaluate this if it impeded participation in the meetings or had other negative effects on its productivity. He then left the meeting to attend to other commitments.

Dr. Parekh presented a letter from Dr. Agwunobi to Dr. Mohagheghpour dated Nov. 3, 2006, a formal response to the Committee's past recommendations. (Note: This letter will be posted to the Committee's web site at http://www.hhs.gov/advcomcfs/index.html) He reviewed with the Committee the point-by-point response and engaged discussion on several topics, including further NIH efforts to stimulate research, ICD coding issues, workshops planned by NIH and CDC, and means by which the current awareness campaign could be expanded to better serve those without Internet access. Following a short break, the Committee viewed a recording of two of the six presentations delivered at the Nov. 3 press conference: those made by Dr. Julie Gerberding, CDC Director, and Dr. Agwunobi. The response was very favorable, sparking discussion about broader distribution of the press conference recording and the expansive media response so far. Mary Schweitzer expressed concerns about the Toolkit for Health Care Professionals, but commended the media articles that had been generated. A lunch break followed.

The afternoon session was dedicated to formation of three subcommittees and drafting of four formal recommendations. Because of the turnover in Committee membership anticipated within the next six weeks, only those continuing on the Committee were assigned to subcommittees. New members will be assigned to subcommittees after their appointments to the full Committee are announced. Each subcommittee is required to have at least one federal agency participant. The following subcommittees were formed:

Research Subcommittee: James Oleske, MD (chairman) and Rebecca Artman, with ex-officio participation from NIH (Dr. Eleanor Hanna) and CDC (Dr. William Reeves).

Education Subcommittee: Kristine Healy, PA (chairman) and Lucinda Bateman, MD, with ex-officio participation from NIH (Dr. Eleanor Hanna), CDC (Dr. William Reeves) and HRSA (Dr. Deborah Willis-Fillinger).

Patient Care/Quality of Life Subcommittee: Rebecca Artman (chairman), James Oleske, MD and Jason Neufeld, JD, with ex-officio participation from SSA (Dr.Laurence Desi).
As the Committee brainstormed topics for recommendations, several were referred to subcommittee for further exploration and discussion. Four recommendations were put forward (subject to refinement as the formal statement is prepared for transmission to Secretary Leavitt). The CFS Advisory Committee recommends to the Secretary for Health that:

1. The FY08/FY09 budgets of the CDC for CFS research be restored to at least the FY05 level in order to sustain the CDC's remarkable momentum, including the ability to complete the Georgia study (especially its longitudinal phase).
2. The FY08/09 budgets of the CDC for public awareness/education be restored to at least the FY06 level based on the positive initial response to the November 2006 campaign launch.
3. CFS be included in the NIH's Roadmap Initiative.
4. Based on the positive response to the Request for Applications (RFA) issued in July 2005, the Committee recommends equivalent funding for a second RFA.

Dr. Parekh then offered time to the public for brief testimony. Only Ramona Hahn addressed the Committee. She is a former IRS employee who became disabled due to CFS in 1997 and is having difficulty finding part-time employment now that she has recovered enough to work a reduced schedule. Rebecca Artman, chair of the newly formed Patient Care/Quality of Life Subcommittee, expressed her intent to address such needs through this subcommittee. With no further business on the agenda, Dr. Parekh stated his intention to begin planning for the spring 2007 meeting and to follow-up on several action items identified over the course of the two days. He thanked the thanked the Committee for its work and productivity and members of the public for their participation and attentiveness. The meeting was adjourned at 3:30 p.m.

MINISTRY OF HEALTH AND LONG TERM CARE

The Ontario Ministry of Health and Long Term Care announced the establishment of an Agency similar to the US Center for Disease Control and Prevention in Atlanta, Georgia. The Agency will be for Health Protection and Promotion including Environmental Health. It was stated that the Agency will be a "leader in Infectious Disease and must serve the public".
The location is yet to be announced.
Let's hope this will have a positive impact for M.E./CFS in Ontario.

ENVIRONMENTAL HEALTH

In the Toronto Star and in the Globe and Mail, it was reported that Ottawa will "crack down on toxic chemical".

WOMEN'S COLLEGE CONNECTS!

In a September, 2006 issue of the Women's College Hospital newsletter entitled *Women's College Connects,* there had been a sentence " Some patients have pre-existing psychiatric conditions which are intensified by a newly diagnosed medical condition, while others are experiencing unexplained and complicated psychosomatic symptoms from illnesses such as Chronic Fatigue Syndrome and

Fibromyalgia." Needless to say, this has generated <u>much</u> correspondence with the editor of the newspaper and Dr. M. Gupta. Our Association is eagerly awaiting the follow-up article in one of their upcoming newsletter.

VOLUNTEERS, VOLUNTEEERS, VOLUNTEERS

Volunteers are needed in the following program and administrative areas. Interested individuals can submit their names and personal information by e-mail to the president (Anthony Rovito) at a.rovito@sympatico.ca or, they can leave a detailed message on our Help-Line at 416-222-8820 or 1-877-632-6682 and a member of the Board will follow-up on the information provided.

We are very aware that many of you are not well enough to personally volunteer for our Association. However, many of you do have, in fact, family members, friends and colleagues who, through you, have learned to appreciate the importance and the need to continually advocate the cause of M.E./CFS. We are thus very hopeful that these same caring and loving individuals, who have much more energy than most of us, will commit to making a conscious decision to actively volunteer for our Association.

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Secretary for the Association

This individual would be required to attend the monthly Meetings of the Board, record the minutes of the meeting, type up the minutes and then forward them by e-mail to the Directors of the Board. Applicants for this position would need to have their own computer, they would need to have a good command of the English language, good spelling and grammar skills and, as well, have access to the internet. Other than attending the actual monthly meetings which are usually held at Women's College Hospital, <u>the bulk of the work for this position can be carried out from the person's home</u>.

Provincial Coordinator of M.E./CFS Brochure Distribution

This individual would be responsible for the <u>printing</u> and <u>mailing</u> of our M.E/CFS Information Brochures (currently available in English, Portuguese, Chinese and French) to volunteers across the province of Ontario. He/she would be working closely with our current network of <u>local volunteers</u> in cities and centres throughout the province. This network of volunteers, in turn, obtains permission to display and maintain a supply of the brochures in local public venues such as medical clinics, community centers, doctors' offices, libraries, special events, conferences and other locations frequented by the general public.
Access to a vehicle would be an asset for this position. <u>The bulk of the work for this position can be carried out from the person's home.</u>

Volunteers to place and "re-stock" Brochures in LOCAL venues
These individuals would be responsible for obtaining permission from proprietors/managers at their local public (eg public library) or private venues (eg Medical Clinics, pharmacies, health food and supplement stores) to initially display and thereafter maintain a supply of our M.E./CFS Information Brochures.
These individuals would be added to our current network of volunteers who are currently distributing our brochures across the province.

Provincial Coordinator of Public Transit Advertising
This individual would be responsible for strategically placing our bus and streetcar cards and our subway poster in the various transit systems across the province. The coordinator places orders with the respective transit contacts in cities across the province, and arranges for the printing and mailing of cards and posters when required. She/he would be taking direction from the Board of Directors and would be expected to communicate regularly by phone and email with the respective transit contacts in cities across the province.
The bulk of the work for this position can be carried out from the person's home

Education Display Volunteers
These individuals would be taking direction from our Education Display Coordinator and would be expected to set up public displays (using materials provided) at locations or events such as hospitals, clinics, conferences or other appropriate gatherings in Toronto or the cities in which they live. In some cases the displays are staffed, and volunteers are required to attend the display and answer questions. Access to a vehicle would be an asset for this position.

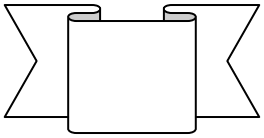
Help-Line Volunteers
These individuals would be trained by our Volunteer Coordinator and would be assisting our current Help-Line Volunteers in "picking up" messages left on our Help-Line. These individuals must be good listeners, patient, mature, compassionate and be very knowledgeable of the illness- Chronic Fatigue Syndrome, so as to appropriately respond to and follow-up on the Help-Line calls. The work for this position can be carried out from the person's home.

Chocolate Sales Fundraisers
These individuals would be working under the direction of our Chocolate Sales Team Leader and would be involved in assisting other volunteers in selling chocolates for the Association at public gatherings such as Conferences, Workshops, Information Displays and other events.

Association Representative
A French Speaking Volunteer is needed to sit on an Advisory Committee at the Conseil Scolaire De District Catholique Centre-Sud. This individual would represent the Association on a Committee whose mandate is to offer input to the French Board of Education regarding programs/accommodations for students who have M.E./CFS.

Web Site Designer
This volunteer would redesign the look and structure of our web site in order to make it more effective as a resource for learning about M.E./CFS and related issues, particularly for people in Ontario. The web site designer would plan and implement changes to the web pages and graphics in consultation with members of the Board of Directors and with the assistance of our webmaster. A computer and experience with the creation of web pages and graphics is required.

VOLUNTEER RECOGNITION



Our Volunteer Recognition this issue goes to our ‘unsung’ heros and heroines’ - the Support Group Leaders! both past and present.

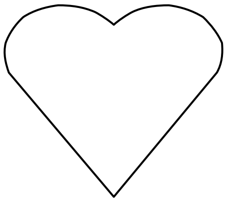
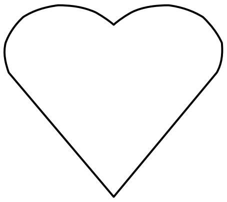
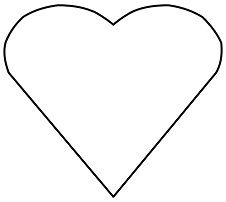
In the earlier days, when the Internet was not available to many, Support Groups were the main source of connecting with people who had M.E./CFS and FM. I’m sure this must have felt like a cool drink of water when one is very thirsty. Finally - someone knew what you were going through with physicians, Insurance companies, etc.!

The countless hours the Leaders spend on the phone, while themselves very ill, trying to help everyone - guidance on how to handle just about everything that is happening in the lives of their members.

Exhausted themselves, arranging a speaker, initiating fundraising, or just trying to get someone to help them arrange the chairs or put out the refreshments. But, they soldier on, knowing that in the final analysis, that what they are doing is needed -they are building a M.E./CFS and FM community in their area where people can feel they belong.

To these heros and heroines, may we express our heart-felt thanks to you for providing years of understanding, compassion and critical assistance to those who attend your meetings.

You are truly making a positive difference in some many lives!

CONTINUING MY JOURNEY WITH M.E./CFS

This coming year, I have to rethink how I will use my limited energy for my life activities. My operative word this year, is FOCUS. With reduced energy, I have to utilize what energy I have to accomplish what is needed – not so much what I would like to do, but what I have to do. And to do this, I have to remember to keep focused on my job at hand. How easy it is to wander about and waste precious energy on doing nothing constructive. Yes, having fun is important but knowing there are things that have to be done and not doing them causes too much stress. There are too many times that have I sat on the side of my bed just looking at the wallpaper and using up precious energy and the scary part is that I don't realize that I have been just sitting there doing nothing!
So, out will come my pen, paper and red marker, and the making of lists will begin. Not lists that are overwhelming with 25 things to do, but writing 4 or 5 items at a time and making a red mark beside the one(s) that are to be done first – and when they are done, write another 4 or 5.
Sounds simple, doesn't it? …let's hope it works.

PS: Remember to wash your hands to prevent flus and colds.

GENERAL INFORMATION

1. **Full Press Conference of the (US) CDC's Launching of the $4,000,000 campaign:**
   http://www.cdc.gov/od/oc/media/transcripts/t061103.htm?id=36410

2. **ME-NET Web site:**
   http://www.me-net.dds.nl/library/literature.html#popular
   This web site has a listing of the most popular publishing of CFS. They note that the first popular publishing was in 1901.

INCOME TAX BENEFITS

The following information is from the booklet entitled ***Services for People with Disabilities*** published by the Government of Canada. I have listed only a few of the services available, for the complete guide, **to view or download this guide: http://servicecanada.gc.ca** Click on "I am: A Person with a Disability". Call 1-800-622-6232 TTY: 1-800-926-9105 to order one.
Available also in large print, Braille, audio cassette, or computer diskette.

Use the **Benefits Online Calculator** to get an estimate of the amount of GST/HST credit you may be entitled to receive.
http://www.cra.gc.ca/benefits-calculator

Use the **Benefits Finder** to learn about the full range of federal and provincial/territorial programs for people with disabilities, such as hearing devices, visual devices, special services at home, rehabilitation services and more!
http://www.canadabenefits.gc.ca

FREE INCOME TAX PREPARATION

The **Community Volunteer Income Tax Program** of the Canada Revenue Agency provides a free tax return preparation service to low- and modest-income Canadians who have a simple tax situation. If you want more information on federal income taxes or these programs, or **if you have questions about your income tax return**, contact the CRA:
1-800-959-8281 TTY: 1-800-665-0354
http://www.cra.gc.ca

Editors note: To contact the various Federal departments in Revenue Canada, please use the above telephone numbers and web site, unless otherwise stated.

Canada Pension Plan disability benefits

If you have a severe and prolonged disability that regularly stops you from doing **any** type of work, and you contributed to the Canada Pension Plan (CCP), you may be eligible for monthly **disability benefits**. Your children may also receive benefits if they are under 18, or between 18 and 25 and attending school.

To receive these benefits, **you must apply for them.**
1-800-255-4786 TTY: 1-800-255-4786
http://www.sdc.gc.ca/ Click of “Form” on the left menu and then on “Canada Pension Plan” to download Form 1151 or search by form number.

Editor’s note: Slowly, it is becoming easier to receive CPP Disability Benefits for individuals with M.E./CFS. Just remember, CPP doesn’t really care what illness you have but how your symptoms prevent you from working. As an example, thoroughly explain your cognitive impairment and how this symptom would prevent you from working, that is, how you would be unable to understand or remember instructions.

Did you know?
There are employment supports for you if you are receiving these benefits. See “Support for individuals”.

Federal tax credits, deduction and exemptions

Information for people with disabilities

The **Disability Tax Credit** (usually called the disability amount) reduces the income tax that a persons with a disability has to pay. If you don’t need to use some or all of the tax credit because you have little or no income, you may be able to transfer all or part of it to your spouse, common-law partner or other supporting person.

To get the credit, you must complete a Disability Tax Credit Certificate (Form T2201), have it signed by a qualified medial doctor, optometrist, audiologist, occupational therapist, psychologist or speech language pathologist, and return it to the Canada Revenue Agency.
Editors Note: If you have been on CPP Disability Payments, request Canada Revenue Agency to back date your Disability Tax Credit to 1996, the year it began.
If you have been previously refused the Disability Tax Credit, continue to apply for it.

If you are under 18 and qualify for the Disability Tax Credit, they may be eligible for the **Child Disability Benefit.** The benefit, of up to $166.66 a month, is tax-free. The Child Disability Benefit is a

supplement to the Canada Child Tax Benefit and Children's Special Allowance payments. It helps low-income and modest income families who care for a child with a severe and prolonged mental or physical impairment. To apply, families must obtain a signed Disability Tax Credit Certificate and the Canada Child Tax Benefit application form (RC66) for the child.
Canada Child Tax Benefit enquiries:
1-800-387-1193 TTY: 1-800-665-0354
To order Forms T2201 and RC66
1-800-959-2221 TTY: 1-800-665-0354
http://www.cra.gc.ca/disability/
To get the forms you need, click on http://www.cra.gc.ca/forms/

If you have **medical expenses associated with a disability**, you may be able to claim them to reduce your taxes. Or, a supporting person such as your spouse, common-law partner or other family member may be able to claim them.

Some examples, of allowable medical expenses are:
- payments for certain assistive devices;
- a portion of the cost of adapting a new van for wheelchair use;
- costs of an attendant who cares for you, or costs of care in an institution;
- certain expenses related to helper animals, such as guide dogs;
- a portion of fees paid to a group home for a dependant with a disability;
- certain building and renovating costs so that you have better access and mobility in your home.

If addition, you may be eligible for the **Refundable Medical Expense Supplement** if you have low income and high medical expenses.

The **Disability Supports Deduction** allows you to deduct certain expenses for supports that enable you to work or go to school. Such expenses include sign-language interpretation, teletypewriters, certain assistive devices for computers, optical scanners to read print and electronic speech synthesizers. You may be able to claim these deductions if they meet certain conditions, and as long as you or anyone else has not claimed them as a medical expense. And you do not have to be eligible for the Disability Tax Credit to claim them, unless you are claiming part-time attendant care expenses. To claim the Disability Support Deduction, you have to complete Form T929.

Many goods and services used by people with disabilities are **exempt from the goods and services tax /harmonized sales taxes (GST/HST).** Some examples are health and personal care services, programs like 'Meals on Wheels", guide and hearing-ear dogs, some recreational programs and camps, and medical devices and supplies including wheelchairs, walkers, hearing aids, patient lifters and specially designed clothing.
GST/HST Information 1-800-959-5525 TTY: 1-800-665-0354
To order forms: 1-800-959-2221 TTY: 1-800-665-0354
http://www.cra.gc.ca/disability/ To get forms you need, click on http://www.cra.gc.ca/forms/

Information for those who support people with disabilities
Do you support someone with a disability? You may be able to claim allowable medical expenses, as well as other deductions and credits, including:
- child care expenses;
- caregiver amounts;

- disability amount transferred from a spouse, common-law partner, or a dependant;
- amount for infirm dependants age 18 or older;
- amount for an eligible dependant;
- tuition and education amounts.

Find out more about allowable medial expenses, deductions, and tax credits, and how you can use them if you support people with disabilities,
Canada Revenue Agency general information
To order forms: 1-800-959-2221 TTY: 1-800-6665-0354
http://www.cra.gc.ca/disability/ To get the forms you need, click on http://www.cra.gc.ca/forms/

Medical expense tax credit for moving expenses

You can claim, as a medical expense on your tax return, reasonable moving expenses up t $2,000 to move a person:

- who has severe and prolonged mobility impairment, or
- who lacks normal physical development,

to housing that is more accessible, or in which the person is more mobile or functional
http://www.cra.gc.ca/disability

Modifying Your home

The Government of Canada can help eligible building owners to make housing accessible to people with disabilities through the following programs:
The **Residential Rehabilitation Assistance Program (RRAP) for Persons with Disabilities** financially helps eligible homeowners and landlords make their dwellings accessible to low-income people with disabilities. It also provides assistance to create secondary and garden suites for low-income seniors and adults with disabilities.
If you are a low-income senior with a disability, the **Home Adaptation for Seniors' Independence Program** helps homeowners and landlords pay for adaptations that will help you to stay longer in your home. To find out more about these programs:
Canada Mortgage and Housing Corporation (CMHC) at:1-800-668-2642 TTY: 1-800-309-3388
http://www.cmhc.ca

They have the following publications:
FlexHousing: Pocket Planner for home buyers and builders helps you plan and create a Flexhouse that is adaptable, accessible and affordable.
A Modification Checklist: Accessibility Using RRAP for Persons with Disabilities contains nearly a hundred practical suggestions for improving accessibility. It's a must for any family with a member who has a disability.
To get these free publications and to find out more about these programs:
contact Canada Mortgage and Housing Corporation (info above)

Federal Gasoline Tax Refund Program

If you can't safely use public transportation because of a permanent disability, you can apply for a partial **refund of the federal excise tax on gasoline** you purchase. You must have a medical certificate confirming your disability.
1-866-330-3304 TTY: 1-800-665-0354
http://www.cra.gc.ca/exciseduty/ T o get the forms click on http://www.cra.gc.ca/forms/

Travel planning

Useful information for people with disabilities and other travellers with special needs is available on the Access to Travel website.
http://www.accesstotravel.gc.ca

Did you know?
People with disabilities who hold a valid parking permit in Canada can use it in the 40 member countries of the European Union. You will enjoy the same benefits as citizens of these countries. If you're travelling to Europe and planning to drive, bring your accessible parking pass with you.

Through the **Intercity Bus Code of Practice,** Canadian bus operators commit to serving people with disabilities in a safe and dignified manner. The Code covers transporting people between cities. It does not cover charter, tour, school and urban buses. Contact Transport Canada for advice on resolving complaints about intercity bus service.
1-800-665-6478 TTY: 1-800-823-3823

To obtain more information on the Code or to get the online Complaint Guide and form:
http://www.tc.gc.ca/ Click on "About Us" from the top menu bar, on "What we do" and then on "Policy overview". Click on "Corporate Relations" on the left menu. Click on "intergovernmental Relations and Accessible Transportation".

For additional Information:
Accessible Ontario
Ministry of Community and Social Services
1-888-520-5828 TTY: 1-888-335-6611
http://www.mcss.gov.on.ca/mcss/english/pillars/accessibilityOntario/index.htm
For information on all other topics:
Government of Ontario Information Services
1-800-267-8097 TTY: 1-800-268-7095
http://www.serviceontario.ca

It is noted in this booklet, that about 3.6 million Canadians have one or more disabilities and states that's one in every eight Canadians.

THE COOK'S CORNER

CARROT AND ORANGE SOUP

2 oz/55g butter 2 onions grated salt and pepper
11/2 lb/700 g carrots, grated 1 large potato, grated 2 tbsp. grated orange rind
6-7 cups of boiling water Juice of l large orange 2 tbsp. chopped fresh parsley to garnish

1. Melt the butter in a large heavy bottom pan. Add the onions and cook over medium heat, stirring constantly for 3 minutes. Sprinkle with a little salt, add the carrots and potato, then cover, reduce the heat, and cook for 5 minutes.

3. Stir the orange rind into the pan, then add enough boiling water to cover. Return to a boil, cover, and let simmer briskly for 10 minutes. Add the orange juice.

4. Remove the pan from the heat and let cool slightly, then pour into a food processor and process until a smooth puree forms. Alternately, use a hand-held electric blender to puree the soup in the pan. Return the soup to the pan, adding a little more boiling water if it is too thick. Return to a boil, taste and adjust the seasoning if necessary, and ladle into warmed soup bowls. Garnish with chopped parsley and serve immediately.

MARSALA ROAST CHICKEN

Salt and freshly ground pepper 4-5 lb. chicken (2 to 2.5 kg) 1 lemon, sliced
One 2-inch thick piece of ginger, sliced 10 cloves garlic, peeled 1 tsp.(5ml) vegetable oil
1 tbsp (15ml) garam marsala 1 tsp. sea salt

1. Preheat oven to 450 degrees F (230 C)

2. Salt and pepper the cavity of the chicken and stuff with lemon, ginger and garlic.
Place the chicken on a rack in a roasting pan, breast-side up. Tie legs together with kitchen string. Rub with oil. Combine garam marsala and salt in a small bowl, then sprinkle over oiled skin.

3. Roast 15 minutes at 450 degrees F., then reduce heat to 375 degrees F (190 C) and roast 65 minutes more or until juices run clear.

DISCLAIMER

As a resource group, the function of our organization is to provide you with current information on M.E./CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your illness with your attending physician.

HAPPY HOLIDAYS AND IMPROVED HEALTH IN THE NEW YEAR !
MAY YOU BE AS COZY THIS WINTER AS THE FOLLOWING FRIENDS SEEM TO BE.

THE

MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

2005
ANNUAL REPORT

2005 ANNUAL REPORT

OFFICERS AND DIRECTORS

PRESIDENT:	Audrey MacKenzie
SECRETARY:	Maries St. Paul
TREASURER:	Bob Slimmon
DIRECTORS:	Katherine Cartwright Diane Meitz Anthony Rovito Dan Watts
COORDINATOR OF YOUTH AND EDUCATIONAL ISSUES:	Margaret Parlor
YOUTH/PARENT RESOURCE PERSON:	Cathy Prescott

MISSION STATEMENT

- To provide Myalgic Encephalomyelitis sufferers with support, current information and direction to the best professional services;
- To educate the public about the illness, its debilitating effects and concomitant social and economic consequences;
- To promote, facilitate and raise funds for research on the causes and cure for Myalgic Encephalomyelitis.

HISTORY AND PAST ACTIVITIES

The Myalgic Encephalomyelitis Association of Ontario was formed in 1990, became incorporated in April, 1992 and is governed by a set of by-laws, mandate and mission statement. The organization is a volunteer run, not-for-profit registered charitable organization whose mandate is to provide education and information to a wide range of groups including M.E./CFS patients, families, caregivers, Governments, allied agencies, institutions, medical practitioners, the general public and the media.

The following is a brief overview of some of the highlights of previous years' activities:

1994

- The Myalgic Encephalomyelitis Association of Ontario held the first press conference at Queen's Park to increase public awareness of M.E./CFS and to initiate lobbying for M.E./CFS Clinics in Ontario. Our Association also initiated a massive campaign to the Provincial government.

1995

- A campaign was organized by The Myalgic Encephalomyelitis Association of Ontario, the National ME/FM Action Network and the Northern Ontario Fibromyalgia Network to petition the Federal Government for national policies to ensure care, treatment, comfort and dignity for persons afflicted with M.E., Fibromyalgia and Multiple Chemical Sensitivities.
- The fund raising committee of The Myalgic Encephalomyelitis Association of Ontario held a very successful event for the production of our very popular Youth Brochure entitled: 'Youth Living with Chronic Illness' and is available on our web site.

1998

- The Provincial government provided funding to the Environmental Clinic of Sunnybrook and Women's College Health Sciences Centre to enable M.E./CFS and Fibromyalgia patients to attend.
- We established a toll-free line for incoming calls outside of the GTA area. As many with M.E./CFS are experiencing financial difficulties, the toll-free line has enabled them to receive M.E./CFS Information at no cost to them. The toll-free line has also increased the availability of our Association to the medical and legal communities, and interested parties throughout Ontario.
- Our Association assisted with the planning and presentation of the Ontario Human Rights Commission's Workshop for Person's with Disabilities. The purpose of the Workshop was to educate the Investigating Officers on the barriers faced by a complainant in lodging their case with the OHRC. This was an important workshop as the Ontario Human Rights Commission formally recognized M.E./CFS as an authentic illness. Following the Workshop, the OHRC, requested our Association to voice an opinion of a Supreme Court Decision and to assist with the OHRC's Guidelines for Assessing Accommodation Requirements for Persons with Disabilities in the workplace. M.E./CFS Information was sent to all Ontario MPPs, Federal Party Leaders and Ontario and Federal Health Ministers.

- The Myalgic Encephalomyelitis Association of Ontario collaborated with the Environmental Health Clinic in designing a 'Needs survey' for M.E./CFS, FM and EI patients. In addition, we arranged for M.E./CFS focus groups and for phone consultations with M.E./CFS Support Group Leaders and patients throughout Ontario. Among the several recommendations from the Survey results, the most requested need was for physician education that M.E./CFS is a serious debilitating illness. Statistical Analysis was compiled by the University of Toronto.

2000-2001

- The Myalgic Encephalomyelitis Association of Ontario placed Volumes 8 and 9 of the Journal of Chronic Fatigue Syndrome, published by Haworth Press, New York, in Ontario's five University Medical Libraries to be available for medical and nursing students to review. The Universities stated they would continue the subscription for the Journal of Chronic Fatigue Syndrome. M.E./CFS Information was mailed to all 72 Ontario Schools of Nursing with the request that M.E./CFS be added to their Nursing School programs.
- The Myalgic Encephalomyelitis Association of Ontario has implemented an Access and Equity Policy, an Anti-Discrimination and Harassment Policy, and an Anti-Discrimination and Harassment Committee was formed.
- Due to our own health difficulties with M.E./CFS, we are unable to travel throughout Ontario. However, through various avenues we have taken measures to increase M.E./CFS awareness. After completing a pilot project to see if the general public would take M.E./CFS information from public libraries, we began placing M.E./CFS Information sheets in 327 public libraries outside of Toronto and in Toronto's 96 public libraries. As many of our vulnerable M.E./CFS sufferers are having difficulty with Coordinators of the Community Access Centres (CCAC), we provide M.E./CFS information to the Coordinators of Ontario's 22 CCACs.
- On September 2001, we hosted a Medical/Legal Information Session at Women's College Campus of the Sunnybrook and Women's College Sciences Centre, Toronto. The speakers were Dr. Alison Bested F.R.C.P.(C), Dr. Alan Logan ND and lawyer, Russell Howe. The video of this session is very popular and sales of the video are on-going.
- As we live in a multicultural society, we were concerned that most of the M.E./CFS information in North America was available only in English. After speaking with multiple translating services and hospital translation services, we found that Chinese was the most requested language for translation in Toronto and Ottawa. In addition, Portuguese was the other most requested language for translation in Toronto. As a result, our Association produced Chinese and Portuguese M.E./CFS brochures with the translation services provided by the City of Toronto's Translation Coordinator. The translated brochures have been shared with the National ME/FM Action Network and the CFIDS Association of America. The translated brochures have been placed in hospitals, and multiple medical and community centres and are also available on our web site.
- Representatives of our Association attended a Community Town Hall given by the Federal MP, Dr. Carolyn Bennett, Sub-chair of the Federal Disability Committee for Person with Disabilities. We raised the issue that individuals with M.E./CFS are having difficulty obtaining CPP Disability Benefits. In addition, we requested that the qualifying

terms of CPPD Benefits be changed from 'severe and prolonged' to 'severe, prolonged and recurring' as many M.E./CFS sufferers symptoms fluctuate.

- We continued to request that a notice of our Association be placed in the free community newspaper columns in newspapers throughout Ontario. This proves to be an excellent method of reaching M.E./CFS sufferers in areas where there was not a Support Group.

2002

- 2002 saw the launching of our web site that is linked to multiple American and International M.E./CFS web sites. We have received thousands of visitors to our site. We are fortunate that we have Dan Watts on our Board of Directors with his web site expertise. Audrey MacKenzie wrote the content.
- We designed an Educational Subway Poster that is placed at the track level in Subway Stations throughout Toronto and is being rotated continuously. The purpose of our Subway Poster was to raise awareness of CFS and that it is a multi-system illness that affects adults and children. On different occasions, our board members visited the sites to observe and ask questions of the transit riders to ascertain if they understood the Poster's message. We are pleased to learn that the public understands the message and that they observed that children are also affected.
- Throughout 2002, with the assistance of the Community Service Order Volunteers, thousands of M.E./CFS Brochures were placed around Toronto. In addition to our English brochures, Chinese and Portuguese M.E./CFS Brochures are placed in hospitals in Toronto and Ottawa and in medical and multicultural community centres in Toronto. Thanks to our volunteers outside of Toronto, M.E./CFS brochures continue to be placed in numerous locations throughout Ontario. This is important since many towns and cities do not have a support group and we wanted to reach M.E./CFS sufferers in as many locations as possible in Ontario who may be suffering alone with their illness.
- In 2002, Adult and Paediatric M.E./CFS information packages were placed in 92 Hospitals and we assisted the Sault and District Accessibility Network by offering support for NDP MPP Tony Martin's (Sault St. Marie) Bill 118 in the Provincial Legislature to have the cost of living indexed in Ontario Disability Support Program payments. If our members agreed with Bill 118. Sadly, Bill 118 was defeated 38 to 30 on June 13 2002. In 2004, ODSP payments were increased 3%. However, additional lobbying is needed to request that an annual cost-of-living be indexed into the payments
- It came time when we had to choose a name for our Newsletter…and the winner was…'Reaching Out'. We are acutely aware that many of you spend a good deal of time isolated, not only because of your illness, but because of other circumstances beyond your control. And it is with this in mind that we chose the name 'Reaching Out' for our newsletter. It is our heart-felt wish to reach out to you, through our newsletters, bringing helpful information and ideas and perhaps a joke to lighten your day. Our newsletters are now mailed using Canada Post Publications mail to reduce our postage and many of our members receive our Newsletter by e-mail, thus reducing our postage even more.
- In 2002, for May 12th, ME Awareness Day, letters were mailed to both the Provincial and Federal Ministers of Health requesting research funding and that clinics be established in Ontario for M.E./CFS. This was followed with Board members and Dr. Alison Bested having a meeting with Heather Devlin, Policy Advisor to the Hon. Tony Clement, past Minister of Health to discuss many of our concerns of M.E./CFS. Our most urgent

request was for the education of physicians in Ontario on M.E./CFS, the establishment of M.E./CFS clinics in Ontario, research funding and an OHIP Billing Code for M.E./CFS.

- For the June 15th, 2002 Symposium on M.E./CFS and Post- Polio Syndrome hosted by the National ME/FM Action Network, our Association assisted with the notification of this event.
- The Teach-Me: Sourcebook Project, produced by the National ME/FM Action Network: We learned that many parents were struggling with the school system. The teachers were not accepting M.E./CFS as being an authentic illness. Thus our project was vital in helping our children/youth with M.E./CFS. The Sourcebooks were placed with all the Special Education Consultants in both Toronto's Public and Catholic School Boards. Cathy Prescott, our Youth/Parent Resource Person keeps our Youth/Parent Information Package current and assisted parents in understanding the difficulties that children/youth face having M.E./CFS.
- In 2002, we began to compile statistical data. It is our goal to develop our Association to be similar to other Provincial Health Organizations. As part of this process, our Association meets with other Provincial Health organizations to raise awareness of M.E./CFS and to exchange helpful information. The development of our Association will take time. It has taken the MS Society 30 years to arrive at the stage where they are now.
- Thanks to one of our volunteers, our Association was successful in having M.E./CFS on CTV'S Prime Time news at 6 PM in 2002.The segment highlighted children and M.E./CFS. In addition, we had a phone-in TV talk show on CP24 with David Onley hosting the show. Dr. Alison Bested F.R.C.P. (C), Dr. Tracey Beaulne, ND, and teenager Fran Prescott were the guests. This was a very successful show with the TV station's phone-lines jammed with callers.
- We initiated conducting telephone surveys of our members to see if they were satisfied with our M.E./CFS educational and awareness programs and to learn if they had suggestions for increasing M.E./CFS education and awareness and if they speak a second language. The Survey of our members will be on-going.
- Throughout 2002, our Association had multiple M.E./CFS Public Awareness Displays. At these displays, we reach not only people in Toronto, but also visitors to Toronto hospitals from outside of the city.

RESEARCH

1995— The Myalgic Encephalomyelitis Association of Ontario assisted Gloria Sterling MA, David Reid, John Pollard, Mirka Ondrak MSc with the 1995 M.E./CFS Community Based Study of M.E./CFS sufferers in Ontario to compile the Symptoms and Characteristics of CFS which was published in the (US) CFIDS Association of America's 'CFDIS Chronicle' Department of Psychology, York University, Ontario and the Institute of Social Research, North York, Ontario.
1999— Our Association assisted the National ME/FM Action Network with recruitment and notification to M.E./CFS patients for the research study of Dilnaz Panjwani's on the red blood cell metabolite 2, 3-DPG diphosphoglycerate as a possible marker for M.E./CFS.
2000— We assisted Janette Collier (Doctoral Candidate in Adult Psychology), with her study entitled 'Needs Study of Coping and Adjustment to Chronic Fatigue Syndrome'. The results of her study are available on our web site. Our Association gave notification to our members and

M.E./CFS Support Groups in Ontario of the Isoprinosine research study conducted by Dr. B. Campbell in Niagara Falls. Dr. Byron Hyde had conducted the initial study of Isoprinosine in Ottawa. The Abstract of Dr. Hyde's Isoprinosine Research publication can be viewed on our web site.

PROJECTS AND ACTIVITIES

Year 2003 found our Association increasing the challenge of having M.E./CFS recognized in government institutions.

- On March 19, 2003, Alison Bested MD FRCP (C), William Leeming Ph.D and Audrey met with Dr. David McCutcheon to emphasize the need for physician education of M.E./CFS, research and the need for a OHIP Billing Code for M.E./CFS. Journals of Chronic Fatigue Syndrome Volume 11 (1) which contains the new Canadian M.E./CFS Clinical Working Case definition, Diagnostic and Treatment Protocols, initiated by the National ME/FM Action Network, were given to Dr. McCutcheon to present to the Guidelines Committee of the Ontario Medical Association along with letters of support from M.E./CFS Support Groups and physicians. Our Association requested that if the Journal was approved that the Ministry of Health distribute the Journal to all physicians in Ontario. The Guideline Committee gave the Journal a 3 out of 4 rating. However, due to the provincial debt load, the Journal at this time will not be distributed. As a result of this, the work of The Myalgic Encephalomyelitis Association of Ontario in distributing the Journals within the Medical Communities throughout Ontario became even more crucial. As funding is limited, our Association decided to place the Journals with the Chiefs of Hospital Medical Services in Ontario, Department Heads of Physiotherapy, Occupational Therapy, Social Work Department, Directors of Nursing, Hospital Physician Resource Library, and Employee Health Services. It is our hope that the Chiefs will educate their Medical Residents on M.E./CFS. We are pleased to learn that the Journals of Chronic Fatigue Syndrome Volume 11 (1) are being well received by the Chiefs of the Medical Services. In addition, Journals have been given to all 22 Coordinators of the Community Care Access Centres in Ontario and multiple government institutions, such as the Ontario Human Rights Commission, Ministry of Education, etc., Nursing Organizations and other non-profit Health organizations.

  We are thankful to the Volunteers who obtained the names of Chiefs of the hospitals for us. This is not an easy task, and we thank them for their patience in dealing with the Hospitals. A listing of the placement of the Journals is published in our Newsletter and is available on our web site, with additional names being added regularly. Thanks to the generosity of our Members our Association is able to continue this critical project.
- M.E./CFS Displays. Due to SARS, our Association was limited in the number of Awareness Displays. We managed a few displays by joining with the Environmental Health Clinic for the January Women's Health Show, and a display at the Royal Bank in Bloor West Village. Tiina organized a display at a Community Health Centre. In addition, due to SARS, our opportunity to have another phone-in talk show for M.E./CFS was cancelled on TV Station CP24.

- Youth/Parent Support
  Our Association is very fortunate to have Volunteers, Margaret, Parlor, Cathy Prescott, Janice Ekeland as a Committee for Youth/Parent support and addressing the educational needs of children/youth who have M.E./CFS. In addition, we have our Directors, Tony Rovito and Susan Kurin assisting. After the *TEACH-ME: Sourcebook* was given to Elizabeth Witmer, past Minister of Education, Tony, Susan and Audrey met with Mr.Alex Bezzina, Director of Special Education Branch, Ministry of Education, to discuss the needs of students who have M.E./CFS in May, 2003 and to request that students with M.E./CFS have a 'Multiple' (having both physical and cognitive difficulties) listing. At this meeting, due to financial restraints of the School Boards, we were informed that it would be up to our Association to provide the placement of the Sourcebooks within the Education system in Ontario. He suggested that all principals in Ontario and Special Education Teachers should have the Sourcebook. He also provided a list of Educational Institutions that should receive the Sourcebook and this has been done.
  Again, thanks to the generosity of our Members, our Association is in the process placing the Sourcebooks. Maries and Susan coordinated this project. A list of the names receiving the Sourcebooks are published in our Newsletter and is available on our web site. However, as there are over 3,000 Principals in Ontario, this is a huge project that will be an on-going.
  Margaret Parlor, our Coordinator for Youth and Educational Issues gave a presentation to the Ottawa District Carleton School Board's (OCDS), Special Education Advisory Committee (SEAC) in September, 2003. Following Margaret's presentation to the Board, Ottawa Carleton District School Board increased their funding for Home Instruction. Margaret wanted to encourage individuals to work with their local School Boards to raise awareness of M.E./CFS. She also contacted a representative of the 'Multiple Exceptionalities' of the Ministry's Advisory Council on Special Education (MACSE) regarding students with M.E./CFS.
  As many children/youth with M.E./CFS are isolated, we have initiated a project of connecting them with each other. This project is on-going. In addition, Cathy and Margaret have been providing support to parents of M.E./CFS children in both assisting parents to cope with their child's illness and in providing support to the parents as they 'battle' the school system on behalf of their children.
- For May 12th, ME Awareness Day, we had a MPP give a Member's Statement in the Legislative Assembly of Ontario to raise awareness that M.E./CFS is a serious, debilitating illness. In addition, we provided Blue Ribbons for the MPPs to wear.
  Margaret Parlor, our Coordinator for Youth and Educational Issues, gave a presentation to the Trustees of the Ottawa School Board. She prepared an excellent presentation and it is available to anyone who would like to make a presentation at their local School Board.
- Environmental Health Clinic (EHC), Women's College Ambulatory Care Centre
  Our Association continues to collaborate with the EHC under the direction of Dr. Lynn Marshall, Medical Director.
- June, 21, 2003 M.E./CFS Medical Conference – Council Chamber, City Hall, Toronto Dr. Alison Bested F.R.C.P. (C), Dr. Peter Powles F.R.A.C.P., F.R.C.P.(C), Chief of Medicine, St. Joseph's Hospital, Toronto, and Sleep Disorder Specialist, and Dr. Alan Logan ND, were the speakers. Thanks to the ehn-inc, manufacturer of greensplus+, we were able to give a Journal of Chronic Fatigue Syndrome to all who attended the Conference.

Videos of the Conference are still available for sale thanks to Dan Watts who provides the copying and mailing of the videos. In this informative video, the physicians speak slowly and clearly. Dr. Powles speaks also on the possibility of mitochondria dysfunction in M.E./CFS.

- Various fundraising options were explored. We were delighted that members of the Baird Park Family Dog Group in High Park, initiated by our Volunteers, Lene Desfor, Elaine Kilbourne, and Nam Su Kim, organized multiple garage sales combined with a fundraising event at a local restaurant, Back to the Garden, with the teenage band 'Don't Jump' providing music. With their hard work they were very successful and raised funds for the placement of the *TEACH-ME: Sourcebooks,* produced by the National ME/FM Action Network, with Special Education Teachers. At these events, hundreds of M.E./CFS Brochures were distributed to raise awareness of M.E./CFS. 2003 was the launching of our Annual Sale of Chocolates as a Fundraiser, organized by Diane and we are thankful to all who purchased these chocolate. Thank you!
- Our Newsletter '*Reaching-Out'* was published quarterly. We thank our volunteer, Carlos Rajkumar, for arranging the printing, assembling and mailing of the Newsletter.
- The distribution of M.E./CFS Brochures throughout Ontario continues thanks to volunteers placing them in their local communities. Tony and Volunteer Rita Rovito support these initiatives.
- Our Subway Poster was on display at various Toronto Subway Stations throughout 2003. We also initiated a project for Bus Interior Cards to raise awareness of M.E./CFS and they will be placed in London, Sarnia, Windsor and Toronto in December, 2004. In addition, 3' x 3' M.E./CFS washable Displays will be available in December, 2004 to place in multiple Community Health Centres throughout Ontario.
- Dan Watts and Tiina Leivo Watts wrote Volunteer Descriptions.
- Ontario Community Newspapers.
  As in the past, we have found that placing a notice of our Association is an excellent means of reaching M.E./CFS sufferers throughout Ontario and this project continued in 2003. Our Member, Donna Englehardt, in Sarnia, was able to have an excellent almost full-page article on M.E./CFS in Sarnia's 'Observer' Newspaper. As a result, she has now organized a support group in Sarnia.

2005 ANNUAL REPORT

The 2005 Annual Report of The Myalgic Encephalomyelitis Association of Ontario attempts to highlight the primary activities and initiatives of the Association undertaken within the following major categories and ending December 31, 2005:

- M.E./CFS EDUCATION AWARENESS
- YOUTH/PARENT SUPPORT
- M.E./CFS SUPPORT GROUPS
- LEGAL ISSUES
- COLLABORATION WITH OTHER ORGANIZATIONS
- PUBLICATIONS
- ENVIRONMENTAL HEALTH CLINIC, TORONTO
- FUNDRAISING
- VOLUNTEER DEVELOPMENT
- AKNOWLEDGEMENTS

M.E./CFS EDUCATION AWARENESS

- In January, the Association issued a press release regarding the new OHIP Diagnostic Billing Code (#795) for CFS.
- In cooperation with the Environmental Health Clinic, Women's College Hospital, the Association organized an M.E./CFS Awareness Display at the Women's Health Show in January.
- M.E./CFS Bus Interior Cards were displayed in the Sarnia, Windsor, London, Ottawa and Toronto transit systems.
- M.E./CFS Display Posters (3x3) were circulated in Health Care Centres across the Greater Toronto Area, the Ontario Nurses Association and the Kitchener-Waterloo Market. The Sarnia M.E./CFS Support Group arranged for placement of one of our 3x3 displays in the Bruce Water Community Health Centre, followed by the 3x3 being placed in a shopping mall in Sarnia. Anne Spik, our Northern representative, arranged for a 3x3 to be in the Algoma Community Health Centre, Sault. St. Marie and in Bruce Mines, Ontario.
- Requests for "M.E./CFS Public Awareness" notices were forwarded to over 100 of Ontario's community newspapers in the month of January.
- Over 3000 M.E./CFS brochures in English, Portuguese and Chinese were mailed out to volunteers across the province who, in turn, placed the brochures in local Health Care Centres, Doctors' offices, Pharmacies and Public Libraries, etc.
- The Association facilitated the Annual City of Toronto *May 12 -M.E./CFS and FM Awareness Day.*
- The Association forwarded Journals of CFS on "M.E./CFS Awareness Day" to the London Free Press, the Windsor Star and the Toronto Star.

- The Association mailed out copies of the ***Journal of Chronic Fatigue Syndrome,* Volume 11 (1)** to all Chiefs of Multiple Medical Services, Directors of Nursing Education, Department Heads of Social Services, Occupational, Physiotherapy Departments, Employee Health Services and Physician Resource Libraries within the Peterborough General Hospital, the Brockville General Hospital, the Access Centre for Community Care in Lenark-Leeds-Grenville, St. Vincent De Paul Hospital in Brockville and the Missionary Health Institute in Toronto. In addition, several Journals were mailed to various physicians throughout the province.
- The Association facilitated the May 16, Monday Health Show TV program on CP24 (City TV), with Dr. Alison Bested and Dr. Lynn Marshall as guests.
- Cathy Prescott continued to provide telephone support to parents of children/youth with M.E./CFS and mailed out requested Youth/Parent Information packages.
- At the beginning of 2005, our Association submitted Tony Rovito's name to the Special Education Policy and Programs Branch and the Ministry's Advisory Council on Special Education to partake in advocating on behalf of M.E./CFS students. As of Dec, 2005, we had not heard back from the Ministry of Education as to whether they were going to follow-through on this Advisory Council.
- On May 1, 2005, Audrey MacKenzie and Eleanor Johnston, President of the Hypersensitivity Association of Ontario, met with Dr. Carolyn Bennett, Federal Public Minister of Health to request a meeting to discuss the needs of M.E./CFS, FM and Environmental Research and Education. This request was followed shortly with a meeting in Toronto on May 25, 2005 with The Myalgic Encephalomyelitis Association of Ontario, Dr. Bennett, Dr. L. Marshall, Medical Director of the EHC, Dr. A. Bested, Eleanor Johnston, Maries St. Paul and Margaret Parlor. Many avenues were explored, one main topic was 'where does our illness fit within the health care system', in addition, requests for research funding, medical fellowships, help for the volunteer sector and physician, education of M.E./CFS, FM and MCS were discussed. A summary letter of the meeting was given to Dr. Bennett's office in Ottawa by Margaret Parlor.
- On October 1, 2005, our Association hosted a seminar with speaker Dr. David Bell, leading expert on children/youth with M.E./CFS, from Lyndonville, New York. Dr. Bell and Dr. Bested provided an informative question and answer period from the audience. A DVD and Video were produced of this seminar.
- The Association held its Annual General Meeting on November 26 and featured Dr. Alison Bested as the Keynote speaker presenting on M.E./CFS, Fibromyalgia and Multiple Chemical Sensitivities.

YOUTH/PARENT SUPPORT

- Through the fine work of Margaret Parlor, our Coordinator of Youth and Educational Issues, the Ontario Human Rights Commission (OHRC) acknowledged in their final report that students with "invisible illnesses" such as those having M.E./CFS or Multiple Chemical Sensitivities (MCS) also need to be accommodated in their respective school systems.
- Margaret Parlor gave a presentation in Ottawa to Ontario Disability Directorate (ODA) in February raising further awareness of our "invisible" illness and strongly suggested that

M.E./CFS and FM be included in their final report of the Ontario Disability Act (2001). Friends of the Association, Dr. Lynn Marshal and Lawyer Lynn Kaye also made similar presentations to the ODA in Toronto.

- The Association's on-going advocacy has resulted in the Ministry of Education recognizing M.E./CFS and FM students as "exceptional". Such a designation enables M.E./CFS and FM students to receive special education assistance within their home school.
- Margaret Parlor began distributing The Teacher's and Administrator's resource text entitled the ***TEACH ME: Sourcebook,*** published by the National ME/FM Action Network, to the Principals of Public and Separate Secondary schools within Toronto. As there are over 700 Principals within Toronto, this will take some time to complete as funding permits. Our Association previously distributed the Sourcebook to the Special Education Consultants within Toronto. In addition, Margaret distributed Sourcebooks to the Simcoe and Muskoka area Boards of Education.

M.E./CFS SUPPORT GROUPS

- The Association tries to work closely with all M.E./CFS and FM Support Groups throughout the province. Unfortunately, due to health reasons, the Barrie & District Myalgic Encephalomyelitis Support Group Inc. officially closed in 2005. At their last meeting, President Charmaine Noel and their Board of Directors felt it appropriate to direct their surplus funds to The Myalgic Encephalomyelitis Association of Ontario. Our Association, in turn, used their funds designated for education to purchase and distribute within the Barrie and Simcoe County area, both the *Teach-Me; Sourcebook* document and the *Journal of Chronic Fatigue Syndrome,* Volume 11 (1). The Barrie Support Group, initially founded by Albert Blom, provided invaluable service to people with M.E./CFS in Barrie and surrounding area.

LEGAL ISSUES

- In compliance with the provisions of the City of Toronto Community Services Grant, an Anti-Discrimination and Anti-Harassment Committee was struck to address possible complaints brought against the Association. The Committee is comprised of Anthony Rovito, Maries St. Paul and Dan Watts.

- After a meeting with the President, Audrey MacKenzie, lawyer Hugh Sher offered his professional services for free to The Myalgic Encephalomyelitis Association of Ontario. Mr. Sher is very familiar with M.E./CFS and is also the official layer for the ME/FM Action Network and the Fibromyalgia Society of Ontario.

- Haworth Press, New York, has given The Myalgic Encephalomyelitis Association of Ontario official permission to place the FM graphic on our website. Official permission was also given to publish both the FM Graphics and the FM definition in our Association's Information Package.

COLLABORATION WITH OTHER ORGANIZATIONS

In 2005 The Myalgic Encephalomyelitis Association of Ontario continued to work cooperatively with all like-minded organizations and individuals whose objectives focused on increasing public awareness of M.E./CFS and/or were involved in providing services to people living with M.E./CFS. Our Association, in 2005, worked very closely with the following organizations:

1. M.E./CFS and FM Support Groups across the province of Ontario by disseminating current information particularly the Journal of Chronic Fatigue Syndrome, Volume 2 (1) to key doctors within their jurisdictions.

2. The National ME/FM Action Network in purchasing and distributing their Teach-Me document to key personnel within the school boards of the province.

3. The Environmental Health Clinic, Women's College Hospital, in advocating for a fully staffed medical facility to provide on-going diagnose and treatment for people living with M.E./CFS, Fibromyalgia and Multiple Chemical Sensitivities (MCS).

4. At the beginning of the year, our Association explored the possibility of joining M.E./CFS and FM organizations in Ontario at the request of Rochelle Van Essen of the North York FM Support Group. At a meeting facilitated by the Ontario March of Dimes, Dr. Bested, Dr. W. Appleton, lawyer Hugh Sher, physiotherapist Iris Weaverman, Audrey Mackenzie, Tony and Rita Rovito, members of Toronto and Brampton FM Support Groups attended a meeting where this possibility was explored at length. Unfortunately, due to family commitments, Rochelle had to leave Toronto and this initiative did not proceed further.

PUBLICATIONS

- The Association's quarterly newsletter, ***Reaching Out***, produced by Audrey MacKenzie is a significant and important publication that is very much anticipated and appreciated by our members and the M.E./CFS community at large. In a recent survey of the membership (July and June 2006) 92% reported reading the newsletter while 72% of those reported being satisfied or very satisfied with the content of the Newsletter.
- The Association's ***M.E./CFS brochures*** in English, Portuguese and Chinese were updated in 2005 and were distributed widely across the province. Currently the brochure is being translated in French and consideration is being given to translating it into Spanish as well.
- The Association's brochure, ***Youth Living with Chronic Illnesses*** was made available by Cathy Prescott on request, through our Help-Line.

ENVIRONMENTAL HEALTH CLINIC, TORONTO

As stated in our Newsletter, _Reaching Out_, a great deal of time and effort was placed into exploring a potential new home for the **_Environmental Health Clinic_** when we were advised by the Administration of Women’s College Hospital that there might be a possibly of the EHC having to leave WCH. Audrey MacKenzie and Eleanor Johnson met with the Administration of the Hospital, submitted comprehensive documents and explored new locations for the Clinic. The final result of this effort is that the Clinic is still located at Women’s College Hospital. We wish to thank everyone who wrote to the Administration of Women’s College Hospital and the Ministry of Health and in particular, those who requested that funding be increased to the Clinic to permit on-going treatment-currently, funding only permits one assessment and one-follow up appointment.

FUNDRAISING

In 2005, The Myalgic Encephalomyelitis Association of Ontario struck a fundraising Committee with A. Rovito as chair. The Committee selected multiple key Financial Institutions, Foundations, Biomedical Companies and Others to which individualized Grant Proposals were prepared and then submitted. As of December 31, 2005, the
Association had, unfortunately received “negative” funding responses from the following corporations (i.e. …must decline the opportunity… …at this time we are unable to support your request… …we will not consider taking any new requests, at this time…):

*BMO Financial Group
*RBC Financial Group
*TD Bank Financial Group

*DuPont Canada
*Constrada

*The Atkinson Foundation
*The Citigroup Foundation
*The Donner Can. Foundation
*The Laidlaw Foundation
*The Li Ka Shing (Can) Foundation
*The Zuckerman Family Foundation

*The Biovail Corporation
*Gamma-Dymacare

Our funding proposal to _OTIP (Ontario Teachers’ Insurance Plan)_ although it was officially declined, nevertheless resulted in a $250.oo, a one-time donation.

As of December 31st, official responses for our Grant Submission to the following corporations and foundations had not, as yet, been received:
*California Walnuts
*Canadian Vitamins
*Novartis Pharmaceuticals
*The Kahanoff Foundation
*The M-A-C Aids Foundation

It is with hope that our future grant applications will meet with more success since awareness of our illness has recently received increased publicity when in November 2006, the (US) Center for Disease Control and Prevention has now officially given M.E./CFS their ‘official stamp of approval’ as being a ‘real illness’. Multiple Newspapers and TV stations have picked up this recent announcement by the CDC. Beginning in 2006, The CDC in collaboration with the CFIDS Association of America launched a $4,000,000 CFS Public Awareness Campaign.

In 2005, preliminary work also began in preparing a Grant Submission to *The Ontario Trillium Foundation.* A. Rovito and A. MacKenzie attended two full day workshops at the Ontario Trillium Foundation office to gather current information to help prepare the submission.

Also, in 2005, The Myalgic Encephalomyelitis Association of Ontario, under the leadership of Maries St. Paul and her committee, successfully planned and facilitated **a** M.E./CFS ***Snowflake Craft and Gift Sale***. The Sale was held on Saturday, November 5th at Swansea Town Hall in the Bloor West Village area. In addition, The Bloor West Villager Newspaper published an article on M.E./CFS. The sale netted an overall profit of $1,907.35 for the Association. As well, through the efforts of Diane Meitz and her Chocolate Sales campaign, the Association received a donation of over $800.oo.

VOLUNTEER DEVELOPMENT

As in previous years, volunteer development in 2005, proved to be both labour intensive and very frustrating for those actually doing the training. The fact continues to be that it is very difficult to secure reliable volunteers who can fulfill their duties on a consistent basis given the fluctuations in their state of health. The resulting effect, in a number of situations, was that the “volunteer trainers” were then faced with having to retrain additional new volunteers (if others were, in fact, available) or they ended up having to take on additional work themselves. In the end, the increased “volunteer work load” began to affect their own individual personal health. Possible solutions to this on-going concern of Volunteer Development might be to either significantly increase the number of volunteers in order to more adequately distribute the work of the Association, or, to possibly hire paid staff who would then take on some of the work of the Association. The latter would, of course, involve raising significant funds. Realistically, a combination of the two approaches would work best. However, regardless of our approach in addressing the important area, the responsibility for maintaining a viable and effective provincial M.E. Association rests with all of us. It rests not only with those who actually have the illness but also with their caregivers, their friends and colleagues and with the medical, educational and social organizations that support and work with people who have M.E./CFS. All of us, in fact, would need to do our part!

ACKNOWLEDGEMENTS

As Acting President of The Myalgic Encephalomyelitis Association of Ontario, I extend a heartfelt thank you to all of you who so willingly contributed you time, energy and expertise, to effectively enable our Association to serve all of the children, youth, men and women, who were dealing with the illness of M.E./CFS, in 2005.

- To our members who gave so generously to our Association through their memberships and donations, I extend a personal and sincere thank you.
- To Mr. Steward Brown of Genuine Health Inc. and to the City of Toronto's Community Services Program who continue to support our Association, I extend our appreciation.
- To the Officers and Directors of our Association, I extend to you a heartfelt thank you for volunteering you time, energy and expertise despite the challenges of being ill or having to care for a loved one. We truly appreciate your commitment to the Association.
- To Margaret Parlor for relentlessly advocating for our children and youth who are dealing with M.E./CFS and to Cathy Prescott who continues to provide telephone support to parents of children/youth with our illness and mail requested Youth/Parent Information packages, thank you so much.
- To Dr. John Prescott Ph.D. for his time and expertise in reviewing the Research Papers that are published in our Newsletter.
- To Rita Daniel, of Management Advisory Services, Toronto, for her expertise and time spent with the Board of Directors, thank you for caring.
- To all of the personnel within other like-minded organizations with whom we work so closely, particularly Dr. Lynn Marshall, the Staff of the Environmental Health Clinic and Lydia Neilson, President and CEO of the National ME/FM Action Network, I extend to you a very sincere thank you.
- To Dr. Alison Bested F.R.C.P.(C) for her unwavering support, advice and guidance as well as her professional advocacy of M.E./CFS within the Medical Profession, I extend a heartfelt thank you on behalf of all who are affected by the illness of M.E./CFS.

Respectfully submitted by:
Anthony Rovito, Acting President
The Myalgic Encephalomyelitis Association of Ontario
November 25, 2006.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

FINANCIAL STATEMENTS

DECEMBER 31, 2005

F W JOHNSON
CHARTERED ACCOUNTANT

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AUDITOR'S REPORT

To the Members of
The Myalgic Encephalomyelitis Association of Ontario
Toronto, Ontario

I have audited the balance sheet of The Myalgic Encephalomyelitis Association of Ontario as at December 31, 2005 and the statements of income and cash flows for the year then ended. These financial statements are the responsibility of the association's management. My responsibility is to express an opinion on these financial statements based on my audit.

I conducted my audit in accordance with Canadian generally accepted auditing standards. Those standards require that I plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In my opinion, these financial statements present fairly, in all material respects, the financial position of the association as at December 31, 2005 and the results of its operations and its cash flows for the year then ended in accordance with Canadian generally accepted accounting principles.

Orangeville, Ontario
November 8, 2006

F W Johnson
Chartered Accountant

Celebrating
31
Years
1975 2006

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Balance Sheet
As at December 31, 2005

ASSETS

	2005	2004
Current Assets		
Cash (note 2)	$ 9,489	$ 7,707
Accounts receivable	881	498
Prepaid expenses	-	289
Total Assets	$ 10,370	$ 8,494

LIABILITIES

	2005	2004
Current Liabilities		
Accounts payable and accrued liabilities	$ 1,078	$ 1,021
Total Liabilities	1,078	1,021

MEMBERS' EQUITY

	2005	2004
Opening balance	7,473	9,084
Net income (loss) for the year	1,819	(1,611)
Closing balance	9,292	7,473
Total Liabilities and Members' Equity	$ 10,370	$ 8,494

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Statement of Income
For the Year Ended December 31, 2005

	2005	2004
Revenue		
Donations - General (note 3)	$ 5,992	$ 7,120
Donation - Barrie & District Myalgic Encephalomyelitis Support Group Inc.	3,292	-
Donation - CIBC World Markets Children's Miracle Foundation	-	500
Donation - Genuine Health Inc.	1,000	-
Donations - Other Corporations	600	-
Fundraising	3,330	-
Grant - City of Toronto	7,000	7,000
Memberships	2,640	2,750
Videos	495	480
Interest	1	1
Total Revenue	24,350	17,851
Expenses		
Administration and General Expenses		
Annual dues (note 3)	70	70
Annual general meeting	802	516
Bank charges and interest	80	139
Fundraising	1,286	142
Office	923	799
Postage	275	163
Professional fees	1,242	1,035
Rent (note 3)	1,050	1,050
Volunteer expenses	697	534
	6,425	4,448
M.E./CFS Education/Awareness Program Expenses		
Education/awareness information	12,192	11,840
Postage	2,814	2,177
Telephone	1,100	997
	16,106	15,014
Total Expenses	22,531	19,462
Net Income (Loss) for the Year	$ 1,819	$ (1,611)

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Statement of Cash Flows
For the Year Ended December 31, 2005

	2005	2004
Cash Provided By (Used For)		
Operating Activities		
Net income (loss) for the year	$ 1,819	$ (1,611)
Changes in non-cash working capital balances:		
Accounts receivable	(383)	53
Prepaid expense	289	(289)
Accounts payable and accrued liabilities	57	(29)
Increase (Decrease) In Cash	1,782	(1,876)
Cash, Beginning of the Year	7,707	9,583
Cash, End of the Year	$ 9,489	$ 7,707

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

Notes to the Financial Statements

For the Year Ended December 31, 2005

1. Purpose of the Organization

The Myalgic Encephalomyelitis Association of Ontario provides support and education for patients, their families, the medical profession, government, media and the general public. The entity is incorporated under the Canada Corporations Act as a not-for-profit organization and is a registered charity under the Income Tax Act.

2. Cash

Cash includes restricted reserves of $4,502 which are funds designated for a specific purpose by the various donors.

3. Donations and Fundraising

The donations and fundraising includes donations in-kind of $1,050 from the Environmental Health Clinic of Sunnybrook and Women's College Health Service Centre for the use of a board room for the organizations board meetings and of $20 from the CFIDS Network for an annual membership, also a donation in-kind of $50 for the appraised value of a used telephone/fax/answering machine.