NATIONAL ME/FM ACTION NETWORK
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2011 International Conference
on ME/CFS and related illnesses

This newsletter is dedicated to Canadians who wanted to attend the Biennial International Conference of the IACFS/ME hosted by the National ME/FM Action Network September 22-25, 2011, Ottawa, Ontario but were unable to do so.

We would like to thank the many people who contributed to making the conferences a success. In particular, we would like to thank the Ontario Trillium Foundation for its grant toward the patient conference.

This event was very exciting and very complex. Take several hundred professionals who are leaders in research, diagnosis and treatment of ME/CFS and related illnesses from around the world. Add several hundred patients, advocates and members of the public. Put them in the same building for a few days. Positive energy was flowing in all directions.

To understand the whole event, you have to consider how many activities were going on:

-the Conference for Patients, advocates and the public on Thursday

-the Workshops for Professionals on Thursday

-the Professional Conference on Friday, Saturday and Sunday

-Poster Presentations during the Professional Conference

-the Banquet on Saturday evening

-meetings on special topics (lunch-times, late in the day), and

-informal networking.

Thursday, September 22, 2011

Day 1 of the conference was in two parts.
For clinicians and researchers there were a variety of professional workshops conducted by ME/CFS experts from across North America and around the world, including:

-How to Apply for Grants (Dennis F. Mangan, Ph.D & Cheryl L. McDonald, M.D.)

-Treating Sleep, Pain and Fatigue in ME/CFS Patients (Charles W. Lapp, M.D. & Lucinda Bateman, M.D.)

-Pediatrics and ME/CFS (Rosamund Vallings, MNZM, MB BS & Teruhisa Miike, M.D., Ph.D)

-Fibromyalgia Theory and Practice (Daniel J. Clauw, M.D.)

-Behavioral Assessment and Treatment of ME/CFS (Fred Friedberg, Ph.D & Leonard Jason, Ph.D)

-Exercise Intolerance: Guide to Management Treatment (Staci R. Stevens, M.A., Christopher R. Snell, Ph.D, J. Mark VanNess, Ph.D & Brian D. Moore, Ph.D., ATC)

-Fibromyalgia Assessment and Treatment (Roland Staud, M.D.)

-Treating Sleep, Pain and Fatigue in ME/CFS Patients (Charles W. Lapp, M.D. & Lucinda Bateman, M.D.)

For patients, advocates and the public, there was a full day of presentations in the main hall. Several hundred people attended, including people from eight provinces, the US and several European countries. All the presentations were in English with simultaneous translation into French.

In welcoming everyone to the patient conference, IACFS/ME President Fred Friedberg pointed to the organization's efforts at improving the overall state of affairs for patients, doctors and researchers. "The IACFS/ME," he said, "has increased it's advocacy efforts the past few years, and is now publishing an online peer-reviewed journal." He added that they are also working to "advance recognition of ME/CFS and improve treatment of our patients."

Some highlights of the Patient Conference included:

- Byron Hyde, M.D., Founder and Chairperson of the Nightingale Research Foundation, spoke of the prevailing notion in some medical circles that ME/CFS is a psychological disorder, rather than a physical illness, and then provided evidence of the physical nature of the syndrome. This sentiment was echoed by Eleanor Stein, M.D., Psychiatrist and Clinical Assistant Professor, Dept. of Psychiatry, at the University of Calgary. ME/CFS "is not a psychiatric condition," she said. The syndrome, compared to psychiatric

Contents

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conditions, have different clinical symptoms, she noted.

- Anthony L. Komaroff, M.D. (Simox-Clifford Higby Professor of Medicine, Harvard Medical School) spoke on the search for causes of ME/CFS, opining that "infectious agents can trigger and perpetuate, but there is no proof yet."

-Dr. Alison Bested, M.D. and author of Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia, spoke of the need for ME/CFS patients to pace themselves to help mitigate the effects of their illness. "Listen to your body and stop before you crash," she said. Dr. Bested drew a standing ovation when she broke into song, singing The Way to Pace / Boundaries to the tune of The Way We Were.

-The day's speeches were wrapped up by Lydia Neilson, Founder and CEO of the National ME/FM Action Network, who spoke on the art of advocacy. When approaching agencies for help, she said, "ask yourself 'what's in it for them?'. If there's no answer to that question, don't even bother. Start your way up from the bottom and work your way up, always keeping in mind 'what's in it for them?'. I promise you - it works."

Two members of the patient and support group in attendance were were Betty Cirne and Carol Nix of the Brockville ME Association. Cirne noted that it was great to see some of the key people in person, and lauded speakers such as Dr. Klimas and Dr. Friedberg, both of whom she said helped show that "there's still some hope out there." Nix commented that the large crowd on hand for the patient and support group sessions shows that there is a desire in the patient community for more information.

Recordings of the Patient Conference are now available on our website. Go to **http://mefmaction.com**, videos & podcasts.

DVDs of the Patient Conference are also available. You can phone, e-mail, or mail us to request a copy. NOTE that these DVDs require Internet Explorer or Mac Safari. They do not work on an ordinary TV DVD player.

A. Martin Lerner, M.D. and Lydia Neilson

IACFS/ME President Fred Friedberg

Friday, September 23, 2011

While Thursday's presentations were geared to the general public, the presentations on Friday, Saturday and Sunday were aimed at researchers and clinicians. Having said that, a number of patients and advocates stayed for the presentations and benefited from them.

Friday got underway with discussions of retroviruses and the possible connection between XMRV and ME/CFS. Part of this was the release of a study by the Blood XMRV Scientific Research Working Group. Blood samples, some with XMRV and some without, were sent to 7 laboratories. The laboratories were inconsistent in identifying the XMRV samples, pouring cold water on the XMRV theory for ME/CFS. Even if the XMRV theory is losing support, it is important to remember that health officials and researchers have a greater appreciation of the seriousness of ME/CFS and of the need to explain the illness.

Another presentation was by Harvey Moldofsky, M.D. (Professor Emeritus, Faculty of Medicine, University of Toronto). He has been dealing with patients who contracted SARS during the 2002-3 outbreak in Toronto. Some of them continue to experience widespread musculoskeletal pain, fatigue, depression and disordered sleep, symptoms parallel to ME/CFS and Fibromyalgia. Thus, SARS is being added to the list of infections that seem to trigger ME/CFS and Fibromyalgia.

The afternoon was marked by a lively - and at times light-hearted - debate on the necessity of "tender points" in diagnosing Fibromyalgia. (The 1990 definition developed by the American College of Rheumatology uses tender points, but the 2010 proposed alternate definition does not.) While there was technically a "for" and "against" side, neither was fully convinced that tender points capture the complexity of the illness.

Roland Staud, M.D. (Professor, University of Florida, Gainsville), argued that tender points have value for research, but conceded that "for clinical purposes, however, tender points seem to provide little mechanistic information about an individual's pain and associated symptoms." He reiterated the point, saying that "tender points were meant for research, but were taken over by insurance providers and clinicians." In 1990, when the use of tender points came into vogue, it "was a great advancement, but that's not to say we haven't moved on."

Daniel Clauw, M.D. (Professor of Anesthesiology, University of Michigan, Ann Arbor), provided a lively retort with a slide presentation entitled *Ten Things I Hate about Tender Points*, and also noted that it is easy

Conference attendee T.J. Rose and Dr. Alison Bested.

for a subject to fake tender point symptoms. "I don't know one good thing tender points have done" for diagnosis, he said. "We have to push back when insurance companies ask us to do things not based on science."

Saturday, September 24, 2011

Day 3 of the conference started with a discussion of case definitions for research and practice.

Leonard Jason, Ph.D. (Professor, DePaul University, Chicago, IL) contrasted several competing case definitions, and concluded that the Fukuda (1994) definition, which is also widely used, may cast too wide a net, and that a narrower definition may be needed in order to isolate patients with "a more homogenous and severe symptomology and functional impairment." He touched on the 2011 "international" definition, suggesting that studies are needed to evaluate its pros and cons. He also talked about "data mining", the use of artificial intelligence techniques to find symptom patterns from a database of patient symptoms.

Other sessions presented throughout the day included:

-the role of exercise challenge in testing and diagnosis,
-the latest research in immunology,
-new developments in pediatric ME/CFS, and
-new developments in epidemiology.

Sunday, September 25, 2011

The day started with a session on research developments in genomics and genetics. Next up was a session on advances in brain and neuroendocrine functioning, including a talk on decreased basal ganglia activation in CFS subjects by Andrew Miller, M.D. (Director, Psychiatry and Behavioral Sciences, Emory

Teruhisa Miike, M.D, Ph.d and Rosamund Vallings, MNZM, MB, BS.

University School of Medicine, Atlanta, GA).

After lunch, IACFS/ME President Fred Friedberg, Ph.D. (Research Associate Professor, Stony Brook University, Stony Brook, NY) chaired a discussion and update on the organization's efforts to create a clinical practice primer for general practice physicians to facilitate the diagnosis and treatment of ME/CFS patients. "Our primary goal," Dr. Friedberg said, "is to put out something that physicians would want to read." The primer, on the other hand, may also be helpful to patients who believe they may have ME/CFS. Patients, Dr. Friedberg added, "have to be very focussed in what (they) bring to the doctor." With the primer, "we're trying to teach the doctors (about ME/CFS). But as a matter of fact the patient also has to know how to handle the doctor" in order to get meaningful results.

Primer committee member Alan Gurwitt, M.D. (Faculty, Boston Psychoanalytic Society and Institute, Boston, MA), said "one of our struggles is to find knowledgeable physicians" to refer to ME/CFS patients. "We are only now emerging from a dark cloud, and that dark cloud is (the notion that ME/CFS) is a psychological condition." Part of the problem, he said, is that physicians have largely failed to differentiate secondary psychological symptoms (where they exist) from the primary physical symptoms associated with ME/CFS. "It has contaminated and confused the literature in a harmful way."

The conference concluded with a summary speech by Anthony L. Komaroff, M.D. (Simcox-Higby Professor of Medicine, Harvard Medical School, Boston, MA), who praised the diversity and excellence of the research studies that were presented. He observed that "There was a lot more interest globally than there had been at this meeting two years ago.

For more information:
The abstracts of the presentations can be found at:
http://iacfsme.org/LinkClick.aspx?fileticket=%2bG6GTkbP33I%3d&tabid=499
The audio and the slides of Dr. Komaroff's wrap-up speech can be found at:
http://iacfsme.org/Conferences/2011Ottawa/PostConferenceSummary2011Ottawa/tabid/503/Default.aspx
Two more summaries of the conference can be found at:
http://drlapp.com/news/iacfs-2011-summary/
http://www.masscfids.org/resource-library/15-conference-reports/350-summary-of-2011-iacfsme-conference-by-rosamund-vallings

Special discussions

In addition to the advertised main presentations, there were other special purpose discussions. These included:

- discussion of the impact of ME/CFS and FM on young people
- discussion of the classification of ME/CFS under the International Classification of Diseases (which is a particular issue in the US which is updating it classification structure.)
- discussion of common standards for data so that information can be better shared

Poster Presentations

The main presentations went on in the main conference room, but a lot of dialogue took place in the poster room next door. Presenters prepared posters on a wide variety of topics. Conference participants would walk down the aisles, view the posters, and have the opportunity to discuss the topics with the authors.

There were presenters from ten countries. Eight of the presenters from Canada:

Dr. Stein (Calgary) had two posters, one talking about the relationship between patient and doctor in the context of of a contested illness, the other suggesting teaching tools for health professionals.

Dr. Hyde (Ottawa) also had two posters, one alerting health professionals to watch for thyroid malignancies in ME/CFS patients, and one on how to investigate and diagnose the illnesses.

Dr. Gordon Ko (Toronto) talked about the need to individualize treatment for Fibromyalgia patients along these dimensions - structural, biochemical, psychoemotional and neurological.

Dr. Gordon Broderick (Edmonton) looked at biological pathways in Gulf War Illness and CFS patients.

Corneliu Rusu (Ottawa), a statistician with the Public Health Agency of Canada, painted a portrait of CFS patients using statistics from the 2005 Canadian Community Health Survey.

Manraj Kaur, a student at McMaster University, looked at the multi-disciplinary philosophical models behind osteoarthritis and found that practice has not caught up to the theoretical models

Margaret Oldfield, a student at the University of Toronto, displayed her research into attitudes toward Fibromyalgia in the workplace.

Dianna Campbell-Smith (Calgary) discussed the use of whole body vibration machines as a component of treatment for Fibromyalgia and ME/CFS.

"We were able to show that the Post-SARS symptoms were very similar to those with ME/CFS and FMS."

-Harvey Moldofsky, M.D.

Networking

There were so many wonderful people at the conference. We got to meet international leaders like Fred Friedberg, president of IACFS/ME, Ellen Piro, the remarkable patient advocate from Norway, and Beth Unger, the new Chief at the US CDC. But it was not all about the big names. One very special time was a lunch hour in the quiet room set aside for rest - complete with chairs and beds. There were just a few of us there, and the discussion was personal and supportive.

Most of the National ME/FM Action Network directors were in attendance - Sherri Todd from BC, Judi Day from the Atlantic region, as well as Lydia Neilson, Lynda Cregan and Margaret Parlor from Ottawa. John Wodak, our CPP-Disability specialist came from Edmonton, and he and Margaret took a little time to meet with a Member of Parliament to raise CPP-D issues. In addition, there were representatives from the BC, Ontario and Quebec provincial associations, along with representatives of some local associations.

There were a number of wonderful community leaders from the US in attendance. The situation there is in flux. The CFIDS Association of America has decided to focus on research and has dropped its role in advocacy, leaving a bit of a vacuum at the national level. There are some very good people in the US, and hopefully they will find a way to fill the vacuum soon.

The Banquet (Saturday evening)

The following awards were presented at the banquet :

Governor Rudy Perpich Memorial Award - Leonard Jason, Ph.D.

Nelson Gantz Memorial Award - Nancy Klimas, M.D.

Junior Investigator Award - Ekua W. Brenu, Ph.D. Candidate

Research Excellence Award - Mary Ann Fletcher, Ph.D.

Special Service Award - Lydia Neilson, M.S.M., Founder and CEO of the National ME/FM Action Network

Special Service Award - Ellen Piro, President, ME Association of Norway.

Lydia was recognized for her contributions over many years, notably her role in the development of the Canadian Consensus Guidelines for ME/CFS and FMS, but she was also recognized for the tremendous effort she put into making this conference as successful as it was.

There is another Canadian connection. Ms Brenu, who won the Junior Investigator award and is currently doing her PhD in Australia, completed her undergraduate degree at the University of Toronto.

Byron Hyde, M.D. gave the keynote speech entitled Ten Important Facts Derived from ME/CFS History and That Can Improve ME/CFS Research.

Dr Moldofsky on Post-SARS

The Severe Acute Respiratory Syndrome (SARS) outbreak of 2002-3 drew worldwide attention to the city of Toronto. A Toronto resident returning from Hong Kong inadvertently brought the virus with her. Within months, over 400 people in the Toronto area had caught the illness.

Although the lasting image of this flu-like viral disease was that of people wearing face masks, there was a second wave of of symptoms that largely escaped the media's attention.

According to Harvey Moldofsky, M.D., Professor Emeritus of the University of Toronto's Faculty of Medicine, this post-SARS syndrome displayed a cluster of symptoms marked by widespread musculoskeletal pain, fatigue, depression, and non-restorative sleep. These symptoms will seem familiar to those with Fibromyalgia (FMS) and ME/CFS.

Dr. Moldofsky led a study of 22 post-SARS subjects, including 21 healthcare workers who were unable to return to their jobs 13 to 36 months after their initial bout of SARS. This study found that these subjects were similar to a second group of 21 drug-free female patients with FMS.

The first group of subjects, he said in an interview with QUEST, "were perfectly well and functioning in their careers." After the initial flu-like stage, however, "they showed many of the features that we see in people with ME/CFS, and overlap with Fibromyalgia." Whether it was diffuse myalgia, disordered sleep, fatigue and depression, "we were able to show that in all of these dimensions they were very similar to those" with ME/CFS and FMS.

With the onset of SARS having been a traumatizing experience for many, each control group member completed the same self-graded questionnaire used by the US military to test for Post-Traumatic Stress Disorder (PTSD) in order to ascertain if post-SARS syndrome is specifically a psychological phenomenon. Out of the 22 subjects, said Dr. Moldofsky, only two fulfilled the PSTD criteria.

Taken all together, the results of this study bolsters the case that ME/CFS and/or FMS can be viral-triggered and that they are not psychologically-based.

Hugh Scher on Legal Issues

Hugh Scher, legal advisor to the National ME/FM Action Network, spoke on Day One of the conference on the progress that has been made in getting ME/CFS recognized by the courts and insurance companies alike, but also provided useful advice for those fighting for benefits coverage.

In the early years "it was a question of proving the existence of the disease," said Scher. Since then "the transition has occurred slowly." He pointed to his experience with the Keays vs. Honda case, in which the plaintiff was found to have been wrongfully dismissed for having ME/CFS, with punitive damages of $500,000.

Nevertheless, the battle continues. "I've learned there are major impediments" to ME/CFS patients getting benefits, he said, adding the patients (and their advocates) need to be aware of what the insurance companies need to know. Someone representing a patient, he said, has "to ask the appropriate questions of the patient and doctor" in order to give the right information to the insurance company.

All to often, he concluded, "the insurance companies haven't been given the proper foundation of information."

"In the early years it was a question of proving the existence of the disease."

-Hugh Scher, legal advisor to the National ME/FM Action Network

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