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Written by Administrator

Monday, 26 September 2011 00:00 - Last Updated Thursday, 29 September 2011 15:40

IACFS/ME 10th International Research & Clinical Conference September 22nd to 25th, 2011 • Ottawa, Ontario, Canada



Translating Evidence into Practice hosted by The National ME/FM ACTION NETWORK

September 22, 2011

Day One Dispatch from the IACFS/ME Biennial International Conference: Translating Evidence into Practice □ **September 22-25, 2011**

Delta Ottawa City Centre Hotel, Ottawa, Ontario, Canada

This conference was organized by the International Association of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME) and hosted by the National ME/FM Action Network.

Day One of the conference (September 22, 2011) was open to doctors, researchers, patients, support groups and members of the public, and featured a variety of workshops conducted by ME/CFS experts from across North America and around the world.

In addition to workshops, there was a full roster of speakers in the main conference hall. Some

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highlights 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 pointed to Raynaud's Phenomena (which shows impaired blood circulation in those with ME/CFS) as 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 conditions, have different clinical symptoms, she noted, adding that rates of personality disorders in ME/CFS patients - compared to the general population - are not elevated.

- 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 Basted, 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," said. Dr. Basted 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."

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Day Two Dispatch from the IACFS/ME Biennial International Conference: Translating Evidence into Practice

After a successful opening day geared towards patients and the general public, Day Two (September 23) narrowed its focus to doctors and researchers. The day got underway with discussions of on Human Gamma Retroviruses (HGRV) and their possible connection to ME/CFS. (The retrovirus known as XMRV is thought in some circles to be the culprit behind ME/CFS and fibromyalgia.)

Of particular note was a debate for and against the association of XMRV with ME/CFS.

On the "for" side was Judy Mikovits, Ph.D. (Research Director, Whittemore Peterson Institute, University of Nevada, Reno), who pointed to two studies (in 2009 and 2010) in which XMRV was successfully isolated from CFS patient blood samples.

In rebuttal, John Coffin, Ph.D. (Department of Molecular Biology and Microbiology, Tufts University, Boston), noted that the above results have yet to be reproduced elsewhere. "Indeed, XMRV is now considered by most virologists to be the consequence of a collection of artifacts originating from endogenous murine leukemia viruses prevalent in laboratory and wild mice."

Another highlight of the morning was a presentation by Harvey Moldofsky, M.D. (Professor Emeritus, Faculty of Medicine, University of Toronto), on the widespread musculoskeletal pain, fatigue, depression and disordered sleep associated with Chronic Post-SARS Syndrome. The effects of this syndrome are quite similar to those of ME/CFS and fibromyalgia. The existence of this syndrome would seem to imply the possibility that ME/CFS and fibromyalgia may themselves be the result of a viral infection.

The afternoon was marked by a lively - and at times light-hearted - debate on the necessity of "tender points" in diagnosing ME/CFS and fibromyalgia. (Testing for tender points is demanded by many insurance providers in determining the validity of long term benefit claims.) While there was technically a "for" and "against" side, neither was fully convinced of the necessity of tender points.

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Roland Staud, M.D. (Professor, University of Florida, Gainesville), 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 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."

September 24, 2011

Day 3 Dispatch from the IACFS/ME Biennial International Conference: Translating Evidence into Practice

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

Bruce Carruthers, M.D. (a medical advisor with the National ME/FM Action Network) presented the 2003 Canadian Consensus Criteria, which he co-authored, and is currently used worldwide as one of the standard definitions for ME/CFS. Dr. Carruthers said he hopes "that this case definition and its descendents will continue to emphasize both the

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clinical/epidemiological/research realms of observation and challenge all participants to integrate them into a mutual confirmation/deconfirmation process that characterizes clinical medicine, epidemiology and science in general."

Leonard Jason, Ph.D. (Professor, DePaul University, Chicago, IL) contrasted several competing case definitions, and concluded that the Fukuda (2004) 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."

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.

The IACFS/ME Awards Banquet was held in the evening, with the following awards presented:

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

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

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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

The proceedings were brought to close by Byron Hyde, M.D., who gave a speech entitled Ten Important Facts Derived from ME/CFS History and That Can Improve ME/CFS Research.

September 25, 2011

Day Four Dispatch from the IACFS/ME Biennial International Conference: Translating Evidence into Practice

The day kicked off with a session on research developments in genomics and genetics. One of many notable presentations in this session was by Lea Steele, Ph.D. (Director, Baylor Complex Illness Research Initiative, Waco, TX), who presented a paper entitled Gene-Exposure Interactions in The Etiology of Gulf War Illness: Evidence of Increased Vulnerability to Neurotoxins in Identifiable Veteran Subgroups.

Next up was a session on advances in brain and neuroendocrine functioning, including a talk on

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decreased basal ganglia activation in CFS subjects by Andrew Miller, M.D. (Director, Psychiatry and Behavioral Sciences, Emory 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 CFS/ME 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 CFS/ME.

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 CFS/ME). 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 CFS/ME patients. "We are only now emerging from a dark cloud, and that dark cloud is (the notion that CFS/ME) 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 CFS/ME. "It has contaminated and confused the literature in a harmful way."

The conference concluded a few minutes ago 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. (Earlier in his speech, he noted an overall upward trend of CFS/ME awareness amongst physicians and the general public since the IACFS/ME began its biennial conferences 20 years ago.)

For further information on the conference, including the agendas, please visit: <http://www.iacfsme.org/>

For further information on the National ME/FM Action Network, please visit: <http://www.mefmac>

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Please feel free to contact me if you have any questions or would like contact information for any of the conference speakers.

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