



Hope. The Only Antidote!

P.A.N.D.O.R.A., Inc.

Patient Alliance for Neuroendocrine-immune Disorders
Organization for Research and Advocacy

APRIL 2009

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LET'S CONNECT!



Anytime - Anywhere!
 PANDORA is announcing a novel idea that took form after many phone calls from lonely, isolated people. Let's Connect! is a new way to meet and make friends with others who have a neuroendocrine-immune disorder. They know how we feel, they know the ins and outs, they're in the same boat; so how about connecting?

Let's meet for coffee, tea, a short stroll, a movie, or a telephone chat . . . Just call 954-783-6771, leave your name, town/city, diagnosis, and phone number. PANDORA will form friendship groups with others in your vicinity. It's that easy! PANDORA, our local organization in South Florida, is here to help each of our members in any way we can. Call now!

Greetings!

As most of you know, Marly Silverman has had two very difficult months. Her mother passed away suddenly on February 20th. Because of these personal commitments and the P.A.N.D.O.R.A. work that must be done, there will be no welcome letter in this issue.

We look forward to hearing from Marly in our next newsletter.

Yvette Taylor
 Newsletter Editor

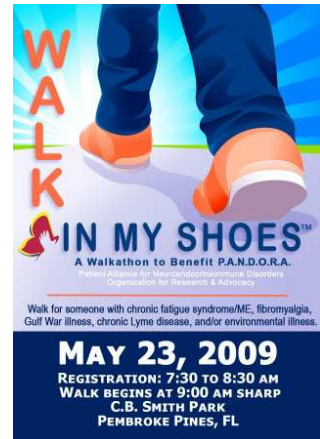
WALK IN MY SHOES™

MAY 23, 2009

7:30 a.m. to 3:00 p.m.

C. B. Smith Park
 900 N. Flamingo Rd.
 Pembroke Pines, FL 33028

Walk with P.A.N.D.O.R.A to benefit children, men, and women stricken with neuroendocrine-immune disorders, such as chronic fatigue syndrome/ME (CFS/ME), fibromyalgia (FM), Gulf War illnesses (GWI), multiple chemical sensitivities (MCS) or environmental illnesses (EI), and chronic Lyme disease (CLD). Your participation supports research that can lead to scientific breakthroughs, physician training, scholarships for individuals who have chronic illnesses, quality of life outreach programs, and advocacy initiatives. Sign up! Make a difference! Walk In My Shoes™!





Did You Know? There is Financial Help Out There!

The Patient Advocate Foundation's Co-Pay Relief Program now includes a pain fund to serve patients suffering with chronic pain. The program is open to patients who financially and medically qualify for co-payment assistance. Once approved, funds can be provided directly to the insured patients' medical and/or pharmaceutical providers. For additional information, visit www.copays.org or call 866.512.3861.



Please bring us your old cell phones, ink toners, and ink cartridges to recycle for our ongoing "Green Project." Donate to P.A.N.D.O.R.A. and help save our environment.

Support Our Walkathon Sponsors!



Registration Fees:

- Adult 5K: \$40
- Adult 1 Mile: \$25
- Young Adults & Students: \$25
- Seniors: \$25
- Children Under 12: \$10
- Guests & Adults Assisting Wheelchair Walkers: \$15
- Wheelchair (assisted by an adult): \$40

Be sure to check our website. [Click here to sign up, donate, or volunteer.](#)

May 12 is National Neuroendocrineimmune Disorder Awareness Day!

PANDORA is celebrating the whole month of May, with the walkathon being the focus of our awareness efforts. We hope that you will all participate in the walkathon in whatever capacity you can. Please check the website above to see how you can help.



[Click here to see our awareness poster.](#)

Interview With Dr. Gordon Broderick: Recipient of the *Steven Croft, MD - P.A.N.D.O.R.A. Research Grant Award*

By Marla Schwartz



Dr. Gordon Broderick has been an Associate Professor since 2006 in the Division of Pulmonary

Medicine, Department of Medicine, University of Alberta, in Edmonton. Dr. Broderick is one of those quiet geniuses

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who have joined the research community in searching for biomarkers to trace the disease progression of chronic fatigue syndrome (CFS).

The basis of Dr. Broderick's current research is to study the immune and endocrine response in adolescent patients who become ill with CFS after contracting infectious mononucleosis, which is caused by the Epstein-Barr virus. By studying patients from the time they get infectious mononucleosis to the development of CFS through the first 24 months of the illness, he hopes to identify disease progression biomarkers, including those essential for early diagnosis.



[Click here for the complete interview](#)

Dr. Kenneth Friedman Nominated for Prestigious Golden Apple Award

First year medical students at the New Jersey Medical School have nominated Dr. Ken Friedman for a 2009 Golden Apple Award for the ninth time! He won this award on two previous occasions. This award is given to a faculty member whom students feel has taught them in an outstanding manner. Usually, only three faculty members are given the award by each of the four classes of the medical school. Dr. Friedman has also been invited to lecture at the Faculty 2009 Summer Celebration and Scientific Assembly. His lecture will be "Diagnostics and Treatment of Chronic Fatigue Syndrome."

PANDORA congratulates our amazing Executive Board member!



University of Miami Department of Medicine's Annual Report 2008

In the Department of Medicine's Annual Report 2008, there is an excellent article summarizing the progress of research by directors of the Papper Laboratory of Clinical

Immunology directed by Mary Ann Fletcher, PhD, and Nancy Klimas, MD. The researchers' current efforts are to find the biological and physiological mechanisms of this complex disorder to develop effective treatments for patients. Another area of interest is a large genomics study in which scientists are analyzing the role of gene expression in patterns in the symptoms of Gulf War illness compared to CFS/ME. The report in on pages 58-60.

[Click to read the entire article](#)

Great News From the American Pain



Foundation: NATIONAL PAIN CARE POLICY ACT APPROVED BY COMMITTEE

Our voices are being heard! The U.S. House of Representative's Energy and Commerce Committee approved the National Pain Care Policy Act of 2009 (H.R. 756). The legislation has now been approved by the House and has gone to the Senate! If signed, the National Pain Care Policy Act of 2009 would combat pain by authorizing a Pain Consortium at the National Institutes of Health (NIH) to expand research on causes and treatments for pain, provide comprehensive pain care education and training for healthcare professionals, create a national public awareness campaign on pain management, and authorize an Institute of Medicine conference on pain management.

CONTACT YOUR SENATORS NOW AND URGE THEM TO VOTE FOR THIS BILL!

[TAKE ACTION NOW](#)

IACFS/ME Reno Conference Report and Summary

By Dan Moricoli,
CFSknowledgecenter.com



A report on the recent IACFS/ME Patient and Professional conferences held in Reno, NV, has been posted at the ME-CFSCommunity.com website as has a video of Dr. Anthony Komaroff's summary presentation at the professional conference.

An ME/CFS Patient Seminar to be held in South Florida is in the planning stages. We have tentative commitments from several of the world's leading ME/CFS researchers and clinicians and a highly respected motivational speaker. Before setting a date, we need an audience of at least 200 people. Please send an e-mail to me at moricoli@cfsknowledgecenter.com with the subject heading Yes, I'm Interested in the Patient Seminar. This will NOT commit you but will give us an indication of the general interest in such a program.

Please help us increase our ME-CFS Community membership by spreading the news about our community.

Making Lemonade From Lemons

By Yvette Taylor




Trying to find the good in the bad is always difficult for those who have a neuroendocrineimmune disorder. Sometimes just walking to the mailbox is a good day. It is very hard to have a positive attitude when you are figuratively tied to your bed; if you go out one day and are in bed for the next two; when you are feeling OK and go grocery shopping, only to be attacked by flying knives and having to leave the groceries; being stared at

when you use your handicap sticker and don't look sick. I have frequently told nosy strangers that I would love to give up my handicap sticker if they could take my pain away; however. that would be impossible to do, as you all so well know.

[Click here to read the whole article.](#)

Although it can be so difficult, we must try to be positive and find the great value in life. We have been given more than our share of lemons; together we can make lemonade. Please read the sidebar in which Sugar Smookler's great idea for helping each other is described: "Let's Connect!"

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