



## **Bergen ME/ CFS-FM Support Group Newsletter**

### **Meeting**

Meeting attendance seems to be growing each month. At this recent meeting, a capacity crowd gathered to mingle and listen to guest speaker Cynthia Mulder, NP (nurse practitioner) of The Pain Management and Wellness Center at Englewood Hospital and Medical Center (EHMC.)

Some thoughts from her presentation

Why patients turn to a Pain Management Center:

- Physician does not understand patient's illness
- Physician is too busy to listen
- Treats patients symptoms rather than the whole patient
- Didn't know what to do for patient, so referral was made
- Was uncomfortable with ordering the pain meds long term.

What causes a bad patient/doctor relationship?

- Constant talker – Patient does not get to tell story
- Note taker – does not make eye contact
- Finish your sentences
- Auto Pilot – looks like he/she is listening but mind is far off

The average doctor allows patient to speak for 18 seconds after patient begins to speak. This results in:

- Patient deprived chance to tell story
- Patients often withhold reason for visit until the end or until subsequent visit
- Doctors steer conversation back to their familiar medical ground
- Patient may not be properly diagnosed because they did not have opportunity to relay all symptoms.

Good approach to discussing symptoms, such as pain

- Tell me about your pain. This can be done in 3-5 minutes

Goals of Patient with ME/CFS/FM

- Obtain a proper diagnosis
- Alleviate or decrease symptoms
- Develop a partnership with physician

Top reasons patients may not express symptoms to doctor

- Fear of being seen as a complainer
- Belief that healthcare provider knows what symptoms patient has and all that can be done is being done
- Fear of the meaning of symptoms
- Fear of loss of control
- Fear of being disabled with a disease

What happens when not treated

- Additional medical complications
- Depression or anxiety
- Decreased sensitization

- Relationship or career issues develop
- Limited mobility
- Decreased involvement in activities
- Insomnia
- Interference with activities of daily living
- Increased healthcare costs

#### Patient Centered approach to care

- Comprehensive assessment
- What is patient's understanding about symptoms and diagnosis?
- What are other contributing factors?
- What does patient believe will help make symptoms better?
- What treatment best fits patient's belief system

#### Patient Education

- Best way to treat disease is to understand the disease
- Educate the patient and the family
- Develop therapeutic relationships
- Service to life is the original meaning of medicine
- The best healthcare providers empower patients to meaning in their lives

#### Solutions

- Treat the whole patient – not just symptoms. It is an integrative model.
- Use a variety of treatment modalities: diet, nutrition, exercise, etc.

#### Ideal Doctor

- Listens, caring, humanistic, accepts patients are very knowledgeable
- Respects patient's beliefs
- Is available – makes most of the visit
- Promotes self care
- Keeps current
- Is not afraid to say, "I don't know, but I will help you find out.
- Understands that the greatest teachers are patients they listen to.

#### And VERY important is Patient Attitude

- If you look for the bad, you will find it. If you look for the good, you will find it.

As was discussed at recent meetings, there are things you can do in order to get a proper diagnosis, receive treatment for symptoms and to develop a relationship with your healthcare provider.

- Have your symptoms or things you need to discuss written down and give the paper to the doctor. He can gauge the time that can be spent on a topic but knows all the things you need to address. Keep your story concise. While you may have a lot to tell, time is also a factor. Keep the details complete but brief, so as not to lose the doctor's attention.
- Take notes or have another person with you to remember details.

### **Kudos for Marissa**

In the January issue of this newsletter, we printed a letter from NJCFSA Youth Trustee, Marissa Newell in which she asked for your help with her annual gift auction. Marissa will be going to college next year and we would like to help make her final auction her biggest one to date.

**Sponsored by Marissa Newell & V.F.W. Post 2639**

**Saturday May 8, 2010**

Location: V.F.W. Post 2639 1515 Corlies Avenue, Neptune, NJ 07753

Doors Open: 6:30 pm - Drawing: 7:30 pm - Often a sold-out event.

Admission: \$10.00 at door

**\*ADULTS ONLY\***

### **All proceeds go to the NJCFSA**

Admission includes 1 sheet of regular basket tickets, coffee, tea and cookies.  
Additional tickets and larger basket tickets available at an additional cost

❖If you would like to make a monetary contribution, please send your donation payable to the NJCFSA with the notation “**Marissa’s Auction.**” PO Box 447, Florham Park, NJ 07932.

### **Awareness Month**

May is ME/CFS/FM Awareness Month and specifically May 12<sup>th</sup> is set aside as Awareness Day. It is hoped that everyone will try to do something to increase awareness. You could send information, such as the Information Sheet for Family Friends and Caregivers that was included in the March issue of this newsletter. You might send a note of thanks to the people in your life who “get it” and are supportive of you. Make a copy of an article on ME/CFS to share with people who do not understand this neuroendocrine immune dysfunction. There are also many ideas on the major ME/CFS websites.

### **Awareness Month- part 2**

Renowned CFS Pioneer, David Bell has shared his thoughts for this year.

David S. Bell MD, FAAP  
Lyndonville, NY 14098  
May 1, 2010

To my friends with ME/CFS, I would like to put out a personal appeal for funds to be sent to the Whittemore-Peterson Institute (WPI) in order to speed up the progress of the current research.

Here is my reading of a very complex situation. Medical authorities, educational institutions, governmental agencies, and most practicing physicians have disrespected and minimized CFS in just about every way possible, from creating an insulting name for the illness to advising extreme caution in treatment, except cognitive behavioral treatments.

It is easy to dismiss my remarks to follow by saying that I am biased. And it is true, I am very biased and for twenty-five years I have quietly sat on the sidelines believing that science will win out and true progress will be made. I am beginning to think this has been a great mistake. The profession I love has failed miserably.

In 1985 an outbreak of CFS hit Lyndonville NY and affected 210 persons, 60 of whom were children. The official response from the CDC and the New York Health Department was that this was mass hysteria. No one talked with a single patient.

In 1990 I worked with Dr. Elaine DeFreitas and Dr. Paul Cheney and a retrovirus was found and the material published. A second paper had been accepted by PNAS and contained a photograph of C-type retroviral particles from a tissue culture of spinal fluid of one of the children in the Lyndonville outbreak. This paper was suddenly pulled and not published after a couple of flawed negative papers. A complete description of these troubled times is in Osler's Web by Hilary Johnson. The funding for our studies was pulled and all work on this abruptly stopped.

I think the same tactics are being employed to hamper the current work on XMRV by the WPI. The WPI is a private organization and, as I understand it, no federal grants or funding has been forthcoming. There have been three negative PCR-only studies, which have established only that CFS cannot be

superficially studied. At this time no study that has attempted to replicate the WPI study has been heard from. Many CFS research organizations have declared publicly that "XMRV is a dead issue." Nothing is farther from the truth.

I cannot predict the future, but my fear is that the current political and scientific organizations who do not want to see retroviral involvement will attempt to stifle studies on XMRV in CFS. Huge amounts of money are spent on studies on cognitive therapy, and studies proving that CFS is heterogeneous (you can argue that polio is heterogeneous). We have not heard from the CDC, other than the inappropriate comment that this was not likely to turn out to be anything, made right after the Science paper publication in October 2009.

We are now eight months later and not a peep. Maybe they are finding XMRV and want to be very careful. Maybe they haven't looked and are assuming that this heretical idea will blow away. Eight months? And the Band Played On.

It is possible that thirty other labs are finding XMRV in CFS or that no one else in the world is even looking for it. Science requires that labs do not disclose their findings prior to publication and I agree with this rule. But, is the WPI going to be isolated by the scientific community and wither away because of lack of funding? Is XMRV going to become more of the compost of CFS research?

But, there is an alternative. We cannot wait ten years for science to grind out its conclusions. Every person in the world who believes that CFS is important should send \$10 to the WPI. I plan to send \$10 today. It may not be much, but it is a start. There may be 10 million persons in the world with CFS. Let's see, that's...I need a calculator. May 12 is our day.

Let's do this. After 25 years of work in this field I do not have much, but I have my integrity. I feel that WPI has made an important discovery, and I feel they are an ethical organization; they are not padding their pockets. But I also have my fears. And the greatest fear of all is that their discovery may not be appropriately followed up. For the 9,999,999 other people out there, who think CFS is both real and important, send \$10 to:

Whittemore Peterson Institute  
6600 N. Wingfield Parkway  
Sparks, NV 89436

Thank you.  
David S. Bell MD, FAAP

## **Coming Event**

### **Physicians Lunch & Learn**

Designed for physicians – open to the public

Thursday **May 27<sup>th</sup>** 11:00 AM – 1:00 PM

Co-sponsored by Englewood Hospital and Medical Center, NJCFSA & the Bergen Support Group

Held at Englewood Hospital and Medical Center (EHMC)

Conference Rooms A & B

Space is limited - **RSVP required**

1-866-980-EHMC Register for "Chronic Fatigue Syndrome/Fibromyalgia event"

Lunch & Free parking included.

## **Program**

-Self Care: J. Gudin, MD; S Ross, MD; C. Mulder, NP – The Pain Management and Wellness Center  
-Stress Management: J. Taw, MD, MPH; The Center for Integrative Healing  
The EHMC participants are well-versed in Fibromyalgia.  
-ME/CFS information will be presented by Lorraine Steefel, RN, DNP. Also present will be Nancy McGrory Richardson of Hemispherx, as well as members of the NJCFSA Board of Trustees and leaders of the Bergen Support Group.

### **Next Meeting**

The next meeting will be held on Sunday May 16th. Agenda and Hot Topic: to be announced.

This newsletter is intended for CFS & FM patients in the area of this support group. The purpose is to share information and support. If you have questions about meetings please contact: Pat LaRosa at [pcl.njcfsa@gmail.net](mailto:pcl.njcfsa@gmail.net), Nancy Visocki at [ngv.njcfsa@verizon.net](mailto:ngv.njcfsa@verizon.net), Judy Machacek at [judymachacek@msn.com](mailto:judymachacek@msn.com) or leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.

***WEATHER or Emergency*** – *In the event of bad weather, or other emergency, we encourage you to check your email before leaving for Englewood. If it has been decided that a meeting will be canceled, an email will be sent via the yahoogroups list. The Hospital will also be notified of the cancellation. The email posting also applies to a cancellation of the First Wednesday of the Month luncheon which is an informal gathering, an opportunity for people to meet and chat with other members.*