



Bergen ME/ CFS-FM Support Group Newsletter

NJCFSA Annual Conference

As you know, the October meeting was cancelled since the regular meeting day (October 17th) coincided with the NJCFSA conference.

The conference was a big success. Approximately 150 people heard presentations by four renowned speakers. Dr. Judy Mikovits of the Whittemore Peterson Institute shared information about the XMRV virus discovery – which was published just one year ago. Her data included the latest updates. Dr. Susan Levine is a perennial favorite who, this year reported on the previous week's proceedings of the CFS Advisory Committee (CFSAC) – the federal advisory committee. Dr. James Oleske spoke of his position on the CFSAC as well as his work with children with CFS at a time when there were few doing this. Disability attorney, Barbara Comerford explained some of the means to successfully obtaining disability benefits and pitfalls that may be encountered along the way.

NOW AVAILABLE!

NJCFSA October 17, 2010 Conference on DVD

Host: Kenneth Friedman, PhD

Moderator: Malcolm Schwartz, MD

Speakers: Judy Mikovits, PhD
James Oleske, MD, MPH
Susan Levine, MD
Barbara Comerford, Esq.

\$20 – includes S&H

Very limited number of Conference Handouts (including presentation PowerPoints) available for an additional \$5.00

Send check payable to: NJCFSA

Mail to: NJCFSA

PO Box 447

Florham Park, NJ 07932

Also available at NJCFSA Library - NJCFSA members only (S&H \$3.50 for the 3 disk set)
Standard library rules apply.

Medicare Part D

Medicare Part D



Come and Learn about
The Medicare Prescription Benefit
Sheila Brogan will be presenting information on the Medicare Part D
program on

Tuesday, November 9, 2010 at 1 PM
At the Northwest Senior Center
46-50 Center Street
Midland Park, NJ 07432
Call 201-445-5690 to register for the workshop

- ❖ Learn about Medicare Part D
- ❖ Understand about Medicare Part D costs - premiums, deductibles, co-pays, coverage gap
- ❖ Learn how to evaluate the different plans using the Medicare web site

Assistance with evaluating and enrolling in a Medicare Part D plan is available on Tuesdays and Wednesdays. Call Sheila Brogan at 201- 447-5695 for more information.

Book Review

By Pat Fero - Pat Fero is the leader of the Wisconsin Chronic Fatigue Syndrome Association (WCFSA). Pat highly recommends this book.

The Sound of a Wild Snail Eating

By Elisabeth Tova Bailey

The Sound of a Wild Snail Eating is the perfect book for me. The heft and print size are exactly

right. It's not too large and heavy, it is not very long, and the print is very readable. The title causes me to ask the questions: If the snail is wild then who hears it eating? Is that even possible? Why write about a snail eating anyway?

The reviews say the book is “beautiful and moving and funny and sweet and wise and profound.” Did you know that Elisabeth Tova Bailey’s book has just been named to the top ten books of 2010 in Science & Technology by the American Library Association's Book List Editors? Elisabeth wrote *The Sound of a Wild Snail Eating* for us . . . for those with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. It is a book written about "being" . . . about observing . . . and about escaping the confines of illness.

Elisabeth is bed bound, moved from her farmhouse to a studio apartment where she has caretakers. A friend sets a small pot filled with violets dug up from the woods beside her bed and says “I found a snail in the woods. I brought it back and it’s right here beneath the violets.” Elisabeth wonders why she would enjoy a snail and what on earth would she do with it? She is unable to get out of bed to return the snail outdoors. Yet, now she is responsible for this tiny living thing. The thought overwhelms her.

WHY? You know the answer. People with incapacitating ME and CFS can barely take care of themselves let alone another living creature. We are confined by illness and the challenges it brings are always with us.

Elisabeth writes on page 5: “When the body is rendered useless, the mind still runs like a bloodhound along well worn trails of neurons, tracking the echoing questions; the confused family of *whys*, *whats*, and *whens*, and their impossibly distant kin *how*.... Sometimes my mind went blank and listless; at other times it was flooded with storms of thought, unspeakable sadness, and intolerable loss.

I am hooked on this book. I understand what the author is feeling and I want to know more. What about the wild snail?

On page 6: “It was all I could do to get through each moment, and each moment felt like an endless hour, yet days slipped silently passed. Time unused and only endured, still vanished, as if time itself is starving, and each day is swallowed whole, leaving no crumbs, no memory, no trace at all.

Do you feel what she means? Our sense of seconds, hours, days, weeks, months and years change once this devastating illness has hold of us. What about the wild snail?

Chapter 2 is called Discovery. Elisabeth watches the snail. It is alive and moving slowly. On successive mornings, she sees small square holes in scraps of paper, postcards, and envelopes that had been propped against the lamp on the bed table. Thinking that the snail might need some other food, she places withered flowers at the base of the pot. The snail moves to eat. “The sound was of someone very small munching celery continuously...the tiny, intimate sound of the snail’s eating gave me a distinct feeling of companionship and shared space.”

Early on Elisabeth discovers that the snail can move a distance in her bedroom before returning to the flowerpot in the morning. What if someone stepped on its delicate brown shell? Caretakers

find a glass terrarium and landscape it with moss, leaves and bits of native plants. Elisabeth reads that snails like to eat mushrooms and a portabella is placed in the “little green kingdom.”

There you have it. Elisabeth cannot get out of bed, but over months she has so many questions about the snail that she lives those questions.

Chapters weave Elisabeth's limits and lack of “functional capacity” with the phenomenal abilities and quiet habits of a snail. Snails live in small colonies, yet they each live very hermit-like lives. “I knew there were other people homebound from illness or injury, scattered here and there throughout rural towns and cities in the world. And as I lay here, I felt a connection to all of them. We too were a colony of hermits.”

Elisabeth Tova Bailey, an observer of Gastropods, read so many books and articles on snails, that she has become somewhat of an expert. On another level, Elisabeth is an expert on living with this devastating illness. It took her four years to write **The Sound of a Wild Snail Eating**.

I am still thinking about Elisabeth’s observations. This is a good read—realistic—but also inspiring. The book can help educate your family members, your doctor, and your friends about the reality of living with ME or CFS.

Please help spread the word, go to your bookstore, go online, or request *The Sound of a Wild Snail Eating* at your local library.

Next Meeting

Due to the NJCFSA conference there will be November 21st. 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: Nancy Visocki at ngv.njcfssa@verizon.net, Judy Machacek at judymachacek@msn.com, Pat LaRosa at pcl.njcfssa@gmail.net 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 decide 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.*