



Hope. The Only Antidote!

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

Patient Alliance for Neuroendocrine Immune Disorders
Organization for Research and Advocacy

P.A.N.D.O.R.A. - Patient Alliance for
Neuroendocrine Immune Disorders
Organization for Research and Advocacy,
Inc. Newsletter

SUMMER

2009



Summer Newsletter

In This Issue

[Dinner & a Movie at Gilberts 17th St. Grill to Raise Funds for PANDORA](#)

[PANDORA Sponsors ME-CFS Community Seminar](#)

[PANDORA Invited to SUPERNOVA party in Ft. Lauderdale](#)

[Annual Garage Sale Brings Attention in Ft. Lauderdale & Raises Funds](#)

[We Love You, Emily!](#)

[Meet Cynthia Colabella & Learn About Ehlers-Danlos Syndrome](#)

[Meet Our New Writer Contributor Paula Hayward: "Deliberately Choosing Joy"](#)

[We Appreciate Our Volunteers Extraordinaire!](#)

[The NeuroEndocrineImmune \(NEI\) Center Is in Progress & a Fundraiser in New York](#)

[News From Me-CFSCommunity](#)

[Fibromyalgia Center Celebrates Anniversary](#)

[Upcoming Meetings](#)

FROM THE EDITOR: OUR

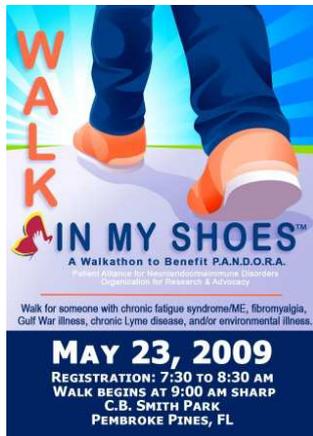
PANDORA IS NOW ON

WONDERFUL FUNDRAISERS AND A VERY BUSY SUMMER FOR P.A.N.D.O.R.A.

by Yvette Taylor

I hope that you read about the Florida Health Expo in the May newsletter. Since then, we have had several events to celebrate

NEUROENDOCRINE IMMUNE DISORDERS AWARENESS and raise much needed funds.



Despite torrential rains, the [Walk in My Shoes\(TM\)](#) walkathon went on as planned. There was even a brief respite from the deluge as our walkers went on their trail. My niece and nephew walked for me and enjoyed the company of [Karen Sacks](#), a Board Member of PANDORA. Way to go Karen! It did start raining again

right before the walkers got back, but we were in a party shelter to enjoy the rest of the event. With music from a DJ ([PARTY TRAIN](#)) in the background, we had a great lunch and a fun raffle session. I won a \$25 gas card, which I ended up giving to my son who was driving on vapors and was two days away from his paycheck. I was so happy that my surrogate walkers (i.e., my family won a California Kitchen gift card and a \$100 day at a spa)! They bought loads of raffle tickets, and I was really glad they walked in my shoes.

Our gross proceeds totalled \$8,979. We had plenty of inkind donations (\$2,933), which helped offset the expenses we incurred. This nice chunk of money is helping PANDORA to continue with its nationwide efforts to establish the NeuroEndocrineImmune Center in the state of New Jersey, with satellites in several locations in the U.S. to start.

Dinner & a Movie at Gilbert's 17th Street Grill



eBay has an option, Giving Works, a program that allows charities to list items for auction or sale on their website. We recently had a very successful auction. [eBay Giving Works](#) allows their clients to list items for sale on our charity online store--[pandoraonlinestore](#)--with 10 to 100% of the sales proceeds going to PANDORA. It means that anyone who has an account with eBay can list their articles directly on our onlinestore page and direct the percentage donation to us automatically. When the item is sold, the merchant get his or her money, and PANDORA get its portion. It is a simple and wonderful way for us to raise funds and for a merchant to move merchandise while contributing to a good cause.

If you don't want to list the item directly to our page, but still wish to donate an item for sale, please e-mail us:

contact@pandoranet.info

Before, during, and after our **DINNER & A MOVIE** at [Gilbert's 17th Street Grill](#), we had an auction through eBay and raised over **\$2,550!** Auction items were a humidor, Monte Cristo cigars, Catalina Hotel weekend, PANDORA starter bracelet, PRADA clutch, beaded shawl & bag, perfume by CHLOE & MARC JACOBS, and our #1 auction item: a telephone consultation with **Dr. Nancy Klimas**, a leading local, national, and international specialist in chronic fatigue syndrome (CFS-ME).

If you know of a company or merchant who has items they sell through eBay, suggest that they consider participating in the eBay Giving Works program; eBay provides incentives to merchants for joining this special program.



If your support or empowerment group wants to help PANDORA raise funds for our ongoing efforts and educational programs, we would be more than happy to put it on eBay on your behalf. You will be acknowledged with our sincere gratitude.



GILBERT'S 17TH STREET GRILL
PRESENTS

DINNER & a MOVIE

Pre-Release Screening of the Documentary *Invisible*
A Fund Raising Dinner To Benefit P.A.N.D.O.R.A.

June 8, 2009, 5:30 pm - 8:00 pm
Gilbert's 17th Street Grill
1821 Cordova Rd., Fort Lauderdale, FL 33316
(954) 768-8990 www.gilberts17thstgrill.com
Cash Beer & Wine Bar Minimum Suggested Donation: \$25
Co-sponsored by Relief Response®

Your donation supports research and advocacy to improve the quality of life for individuals with chronic fatigue syndrome, fibromyalgia, Gulf War syndrome, multiple chemical sensitivity, and persistent Lyme disease.

RSVP to ssmookler@pandoraneet.info or 954-783-6771

SPECIAL GUEST APPEARANCE
BY NANCY KLIMAS, M.D.

RAFFLE SALES & A DOOR PRIZE



Patient Alliance for NeuroendocrineImmune Disorders
Organization for Research & Advocacy, Inc.
www.pandoraneet.info

Dinner & a movie followed 2 weeks later on June 8th at [Gilbert's 17th Street Grill](#), that was closed to the public. The restaurant was filled to capacity with 45 PANDORA members plus their families and friends, who enjoyed healthy and delicious food. PANDORA raised a whopping total of \$3,727, which includes the auction items (see detail on the right side) and \$2,970 in in-kind donations! [Beth Gilbert](#), whose parents own the restaurant, has CFS-ME and shared her story with us. [Dr. Nancy Klimas](#) spoke after we saw the excellent documentary [Invisible](#), which was produced by the Vermont CFIDS association. We were all thrilled when Dr. Klimas offered an hour telephone consultation to go with our other items on eBay (see article **PANDORA NOW ON EBAY** on the right side of this newsletter).

PANDORA Sponsors ME-CFSCOMMUNITY.COM SEMINAR ON JUNE 13, 14

By Yvette Taylor

PANDORA sponsored the ME-CFS Community seminars on June 13th & 14th by raffling off a one-of-a-kind bracelet designed by [Lori Lawhead](#), [Walk In My Shoes](#) t-shirts, and goodie bags filled with massage gift certificates, the movie "[Invisible](#)," and lots of information about CFS & ME!

DELIBERATELY CHOOSING JOY

by Paula Hayward



One way I Rise UP, particularly on challenging days, is by Deliberately Choosing Joy.

I'm usually able to see the Good in all things and situations. But, some days are just better than others. Yesterday was a big medical day. You know the drill . . . pick ups at pharmacies, co-pays (or lack of them), and long waits on hold with insurance companies seeking explanations of medical benefits.

At day's end, I was a bit forlorn...

[Click here to read full article.](#)

A VERY BIG THANK YOU TO OUR SUMMER VOLUNTEERS:

Jilly Serota, Mary Ann Parker, a Gulf War veteran, Mary Ann's daughters, **Georgina** and **Stefania Ferrara** and **Pam Roth** gave a gift of time and worked in the PANDORA office.



If you would like to volunteer the gift of time, please call our helpline: **954.783.6771**. If you cannot leave your house, there are still many things you can do from home.

The NeuroEndocrineImmune (NEI) Center (tm) is in progress! Save the Date September 13, 2009, for a special fundraising Golf Tournament in Buffalo, New York, hosted by the Communications Workers of America LOCAL 1122 in Western New York, a benefit for our strategic partner the Lanford Foundation-Lifelyme, Inc.

The [CFS Knowledge Center](#) presented "**Breaking Free of the Confines of Chronic Illness,**" a program of Hope, Healing, and Happiness, founded by Dan Moricoli. They held a seminar in WPB on Saturday and Miami on Sunday. Dr. Klimas spoke at both sessions, which is always a treat. Check out [ME-CFS Community.com](#) for stories, wellness, support, and resource groups.

[Fern Silver](#), a motivational speaker from New York, was terrific. Her emphasis was finding joy in life despite our challenges. We really had fun. My new dance partner was Karen Sacks, a hard-working board member. I haven't spoken to her since the event to find out whether she had to "pay the piper" too. I was in bed for three days, but it was worth it!

PANDORA INVITED TO THE SUPERNOVA PARTY IN FORT LAUDERDALE



On July 31, New Board Member [Beth Gilbert](#) and Stephen & Marly Silverman attended the **SUPERNOVA Party at La Playa/Shooters** on the Intercoastal waterway in Fort Lauderdale. We were able to create awareness to our cause by raffling off a couple of Walk In My Shoes (tm) t-shirts and a fibromyalgia educational video. Thanks to Wes "Shakezy" Williams and Wil Gellin for this special invitation.

PANDORA's Annual Yard Sale Brings Local Attention to NeuroEndocrineImmune Disorders!



[Last year on our October 2008 Newsletter we announced a strategic partnership with the Lanford Foundation-LifeLyme, Inc.](#) The partnership is geared towards the establishment of the NeuroEndocrineImmune Center (tm), headquartered in Newark, New Jersey, with satellite partnerships nationwide and, eventually, worldwide.

We have been working tirelessly to make this dream a reality. A state-of-the-art facility, where scientific and clinical research, patient care, and social services all in one building specifically designed for patients with neuroendocrineimmune disorders.

Current fundraising efforts for this endeavor include a golf tournament in Buffalo, New York, at the [Chestnut Hill Country Club, Darien Center](#), hosted by the Communications Workers of America LOCAL 1122 in Western New York. One of their members suffers with CFS-ME and Lyme disease. We are grateful to **John Mudie, Executive Vice-President**, Communications Workers of America, Local 1122 for organizing this fundraiser event that will place us closer to a dream come true--the **NEI Center in New Jersey**.

We are now looking for individuals who would like to participate in these efforts as [Advocates Extraordinaire \(tm\)](#). Please read the letter we posted on [ME-CFScommunity.com](#) and [send us an e-mail](#).

In our next newsletter, we will share the on-going efforts and their results. We are engaging state legislators in New Jersey to support our efforts. We now have a standing resolution in the New Jersey Senate to encourage the establishment of the NEI Center (tm).

The New Jersey state assembly already approved their own resolution supporting the NEI Center!

Stay tuned! The best is yet to come!

**News From ME-CFS
Community.com**

On August 8th, we had a very successful **FIRST ANNUAL YARD SALE**. Despite the heat and high humidity that even for Floridians was hard to endure, we were able to pull off a great sale, earning \$684.50 (including the sales from the lemonade stand --see article below). Special thanks to the neighbors on Beacon Street, who contributed to the event that started as a neighborly conversation and developed into a fundraiser for PANDORA. A heartfelt thank you to all who contributed, including our special volunteers and board members: Suely Campos, Teresa Reid, Janet & Emily Roy, Sugar Smookler, Ed Reid, and Yvette Taylor.

Special thanks to Marly's neighbors Cheryl and Matt Prchal & Janet and Dan Roy.

We LOVE YOU, EMILY!



During our yard sale, a very special young lady had an idea about how to help PANDORA and her neighbor Marla Silverman. **Emily Roy**, who is 7 years old, decided to set up a lemonade stand. She also baked the most delicious sugar cookies. In addition she also donated some of her toys to the yard sale (pictures below). Her enthusiasm and great sale techniques resulted in her proudly giving PANDORA \$34.50! We

Help us create and pick ME/CFS phrases for use on button, mugs, and bracelets. Submit a phrase or phrases and earn \$50 for each one we use.

Please vote on our story contest finalists. The person who receives the most votes will win \$250; the runner-up, \$100. ME-CFS Community.com is grateful for our sponsor: Dr. Herbert Hyman, a physician who is now volunteering in a public clinic in West Palm Beach, for donating the prize money. You can see his column at ME-CFScommunity.com [by clicking here](#). Post questions about CFS, and he will respond as soon as possible.

Fibromyalgia Center in Fullerton, CA, Celebrates Second Anniversary

Dreams can come true! Located at California State University, Fullerton, the Fibromyalgia Research and Education Center opened in May 2007. Although not a treatment center, it is an environment in which research is conducted and training for professionals and students is provided. The Center supports a web-based training program, in conjunction with the National Fibromyalgia Association, for healthcare providers on the assessment and management of fibro.

PANDORA congratulates them on their 2nd anniversary and wishes them continuing success!

Please save your empty ink cartridges, copy toners, and old cell phones for PANDORA. This program is in partnership with Dade Recycling and allows us to make money, depending on the type of the material donated. Call us at 954-783-671, and we will direct you to the nearest drop off location.



Fall Meeting Schedule

were all touched by her loving gesture. Good luck in second grade, Emily, and thanks for your wonderful gift!

Here is another picture of Emily Roy next to the toys she donated to PANDORA for the yard sale. She also helped to sell them too when a young customer needed help. Emily learned about neuroendocrineimmune disorders, and she is looking forward to volunteering on another PANDORA project, perhaps as our youngest Advocate Extraordinaire, highlighting the [PEDIATRIC PENNIES CAMPAIGN\(TM\)](#)



Meet Cynthia Colabella and Learn About Ehlers-Danlos Syndrome



by Marla Schwartz

What is Ehlers-Danlos syndrome (EDS)? On the Ehlers-Danlos National Foundation (EDNF) www.ednf.org EDS is defined as a heterogeneous group of heritable connective tissue disorders, characterized by particular (joint) hypermobility, skin extensibility, and tissue fragility. There are six major types of EDS, which are classified



We will resume our normal office hours and open our HELP line to 3 times a week after Labor Day.

On **September 3rd**, **Marly Silverman** will be attending [The CFS/FM Empowerment Group at Memorial Hospital West in Pembroke Pines](#)

On **September 8th** [The Ft. Lauderdale/Pompano Beach Neuroendocrineimmune Disorders Empowerment Group](#) will have its "Back to Fall" meeting at Spectra Care in Ft. Lauderdale.

[Click here for Empowerment Groups Web Page to see the details about these upcoming meetings and others in Florida and beyond.](#)

NEWSLETTER STAFF

[MARLY SILVERMAN](#)

Publisher

[YVETTE TAYLOR](#)

Editor and Staff Writer

[MARLA SCHWARTZ](#)

Staff Writer

[PAULA HAYWARD](#)

Staff Writer

[SUGAR SMOOKLER](#)

Administrative Assistant



according to their manifestations of signs and symptoms, many of which are similar to neuroendocrine disorders. . . . Once thought to be a rare condition of the connective tissue, EDS is now believed to affect 1 in every 5,000 people.

Now meet a fellow PANDORA member, **Cynthia Colabella**, who has EDS. She is a very active member in PANDORA'S Advocate Extraordinaire program. So how did her involvement in PANDORA begin?

"Two years ago in 2007, I attended the [PANDORA's Advocate Extraordinaire](#) training program at the [THE 8TH IACFS International Conference on CFS and related illnesses](#) held in Ft. Lauderdale via a recommendation from my friend Charlotte, who is on the Board of Directors for ENDF," Cindy explained. "With EDS the scale can range from day to day and patient to patient; there is no rhyme or reason to it, even the weather affects us all in an adverse way."

[Click here to read her story.](#)

Email Marketing by

