

CFS PHOENIX

PHOENIX RISING: A CFS/FMS NEWSLETTER	THE IACFS CONFERENCE EDITION (January 2007)
<u>Please Subscribe to PHOENIX RISING!</u>	AN INTERVIEW WITH MARLY SILVERMAN - The Founder of P.A.N.D.O.R.A., <i>The Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy</i>

By Cort Johnson

In a few years Marly Silverman has built P.A.N.D.O.R.A. into one of the most dynamic CFS patient organizations in the U.S.. P.A.N.D.O.R.A. is co-sponsoring the IACFS conference in Florida taking place from Jan 10th-14th and is organizing the big patient conference taking place on January 10th and 11th. This is the biggest CFS event we have. Phoenix Rising welcomes the opportunity to talk with Marly about her battle with CFS, her advocacy efforts and the conference.

(1) You came down with CFS/FM in 1997 and were diagnosed in 1998. What did you do before you got CFS? How did you your CFS/FM appear? Did it happen suddenly or gradually?

A: Before I was diagnosed with CFS/FM I was an Assistant Vice-President for one of the largest U.S. Banks. I represented this bank in Brazil and Portugal as an International Financial Advisor-Relationship Manager. I held licenses as a stock broker, life and health insurance and annuities, as well as was trained to sell trust and banking services and financial products. One of my tasks was to facilitate cross-selling by offering my clients all of the bank's financial products that would match or enhance their financial and life style needs. It was a very demanding job that entailed extensive travels to Brazil during the year.

In 1997, I was first bitten by (what I was told was) an African Bee in Brazil, resulting in a severe allergy reaction that could have been fatal. A month later or so I had an infection that turned into bronchitis and lingered for months. At the end of that year I was involved in a hit and run while leaving a client's office and the "flu-like symptoms" came and they have never left me. In December 1998, I was so ill, after losing so much weight... down to 99 lbs, that I was eventually forced to stop working all together. It was a very sad day for me when I realized that I had to go on disability. I needed to get better.

(2) P.A.N.D.O.R.A. has quickly grown into quite an organization; you are co-hosting the IACFS conference, advocating your Congressman/Senators and State Legislature for a Center of Excellence in Florida, you've been interviewed on news programs, you were featured in the Winter 2005 CFIDS Chronicle. What made you want to start an advocacy and support group?

Did something crystallize your desire to do so - was there an 'aha' moment for you when you decided to take this on or was this something you wanted to do early on?

A: I think my Aha moment came rather quickly, with the realization that there was no support structure of any kind for CFS/FM patients in my local area, which then lead to the realization that there was none in the whole state of Florida, which then lead me to search nationwide for "business models" that I could apply and from established leaders in our community. I remembered devouring every book, article related to neuroendocrineimmune disorders, attempting to learn as much as I could about the crucial pertinent issues.

I realized that I had to find ways to help myself and I also knew that by doing so I could probably help others too. During this process, which actually brought me extreme creativity, I began to visualize where I wanted to be one month, one year, two year and beyond as far as my health, financial situation, emotional balance, mental strength and the course I wanted to take. I decided to "follow my bliss"

(3) There aren't many homegrown patient organizations that aspire to be really active either regionally or nationally; of course there's the biggie, the CFIDS Association of America, and the NCF, the Wisconsin CFS Association, the New Jersey CFIDS Association, and probably some that I'm not aware of. Do you have any advice for people who want to start a group or just to make a difference in CFS?

A: My very first piece of advice is to write a simple business plan. Jot down what do you want to do, what are your goals, what are your expectations, an initial wish list of what you want to accomplish. It is important to be able to visualize these items. When you do, the vision becomes clear, and the mission is then almost laid out for you.

From the business plan you will then ask yourself additional questions- what kind of group do I want? For example, should it be an empowerment group where knowledge and action is the key, or should it be more of a social group, where potential friends meet, swap stories, and long term friendships are forged? Should it truly be a support group, with a professional in place directing the objectives, goals and applying for results that are more tangible? Should it truly be a grass roots advocacy group that could lead to the creation of a non profit organization?

One of the difficulties I know firsthand is that CFS/FM individuals experiencing debilitating symptoms like crushing fatigue, brain fog, and difficulty in driving specially at night and the lack of mobility can make you feel like you can't do anything. And here lies the incorrect assumption. Some members of the groups PANDORA supports don't even come to the meetings for months at a time, but they are on the phone speaking with other, they e-mail each other and somehow stay connected.

The key I believe is that depending on what kind of group you choose, diversity, respect for each other's limitation, kindness, patience and compassion are all important for any group's survival.

Simply put, the success behind the concept of making a difference does not really require leaps and bounds; it is within reach by everyone. If you as an advocate reach out to one person every day, every month or whenever you can, you are already making a difference for a whole community. The Talmud says that when you heal one person, "you repair the entire world".

(4) You've been advocating for a Center of Excellence (COE) program lead by Nancy Klimas to be based in Florida. Centers of Excellence are programs funded by the NIH. Can you tell what a COE consists of, why you are advocating for one, and how they differ from the CFS Cooperative Research Centers the NIH ran from 1990-2004?

The business model that we are trying to apply for the Florida Neuroendocrineimmune Center of Excellence is a bit different. We want the research scientific component to be multidisciplinary, i.e., immunologists, rheumatologists, neurologist, sleep disorders specialists, endocrinologists, and other disciplines that would conduct research together in synergy. But, we also want a treatment center or clinic for neuroendocrineimmune patients that provides not only medical services, but also integrative/complimentary medicine, and lastly a social service center providing information on disability, housing, transportation, employment and other crucial needs for the neuroendocrineimmune community; a one state of the art facility - one

"stop shop" for patients. Even though the NIH is shying away from the name "Center of Excellence" under their new Road Map Initiative, if one looks at the road map initiative you will note that they are now integrating their institutes' research studies in a way that promotes more collaboration internally and more efficiently in the sharing of scientific information.

Under the NIH Road Map Initiative, scientific researchers from other scientific areas not normally thought to be obliged to research CFS, FM and related illnesses are now doing very intriguing and complex research on CFS and FM. I am optimistic that it could be a tremendous boost for CFS/FM research.

Nonetheless, I also think that Request for Applications specifically for CFS or FM need to be increased and we as advocates need to continue to require them from the Dept of Health and Human Services.

(5) You got support from federal legislators for the COE, you presented a report to Michael Leavitt, the Secretary of the Department of Health and Human Services (DHHS), you met with Chief of Staff from Dr. Agwunobi's office, and you made a presentation to the Federal Advisory Committee for CFS, the CFSAC. You tried to get a statement into the latest Congressional budget regarding funding the Center but apparently failed. Can you tell where you are with the Centers of Excellence right now? How can people assist you in getting them going?

Even though we did not get what we wanted. The pressure we placed on them created results in other areas. The RFA from the NIH was a welcome step! We are very grateful to Dr. Pinn and Dr. Hannah for their leadership role in getting the RFA in place and we are very grateful too for the CAA efforts with Lobby Day.

But we still want the Florida Neuroendocrine-immune Center of Excellence. We also would like to have other Centers of Excellence in other parts of the country too. So we will continue to pursue the issue vigorously and relentlessly. We were told by the Dr. Agwunobi and other health government officials that we are on the "right track". We will persist with our grass roots legislative initiative as well supporting others throughout the country. The louder our voice becomes, the more noise we make, and so will the chances of creating long term solutions for our community. We need to energize our local, state and national advocacy movement. We all are on this together!

One way to contribute to our grass roots initiative in Florida is that if you are Floridian please go to our web site at <http://www.pandoranet.info/advocacy.html> and join on our action alert in partnership with the American Pain Foundation, who is lending us their Advocacy Tool so we can systematically contact our Florida U.S. Senators who are supporting the Appropriation Request for the Florida Neuroendocrine-immune Center of Excellence.

The next step we will take is to contact members of the appropriate Appropriations Committees that oversees budget resolutions. And when we do that, then we will ask for national support. I hope Cort that you will help us with this important task.

(6) The CFSAC has provided a valuable service in bringing CFS issues to the public and in getting federal agencies on the record but it seems to have little effect in its main mission - altering the course of CFS policies in the DHHS. In July you sent a letter to Secretary Leavitt with a laundry list of concerns regarding the DHHS's relationship with the CFSAC. These included no response to the CFSAC's recommendations for over two years, the lack of a permanent Executive Secretary for the group, and other problems that suggested that the DHHS was not empowering the Committee nor particularly interested in its recommendations. You met with the Chief of Staff for one of Secretary of Leavitt's undersecretaries, Dr.

Agwunobi. Was this meeting successful? Do you feel like the CFSAC is on a more solid footing? Or do you have a sense it is still not really being listened to?

Great questions! I was very pleased with the fact that Dr. John Agwunobi, on his presentation to the CFSAC meeting of August 24, 2006, addressed every concern I had on the letter we sent him. I believe he is genuinely interested in keeping an eye on issues relating to our community, but I am also cognizant of the fact that there are other health issues also requiring his attention and it is important to keep the pressure on DHHS officials and on our congressional leaders.

The CFSAC is doing its part, but we, as advocates...we are the ones that can put continuing pressure on DHHS to follow the CFSAC recommendations. The CFSAC can only recommend steps, share fact findings with DHHS relating to CFS. It is not their job to implement. It is up to the DHHS.

(7) Rebecca Artman, P.A.N.D.O.R.A.'s Vice President, was recently appointed to the Federal Advisory Committee for CFS, the CFSAC. What will she bring to the mix there?

Rebecca is an individual that I admire tremendously. She is one of the most outstanding patient advocates I have had the pleasure and the privilege to advocate with since the inception of P.A.N.D.O.R.A. Her input as a patient advocate will be of extremely value to the committee.

Because of her position on the CFSAC, Rebecca was informed by DHHS that she could no longer hold an administrative role in the CFS community. As a result Rebecca has resigned as Vice President and is now a Patient Advisor for the P.A.N.D.O.R.A. board. Rebecca is using experience as a patient and as an advocate to push for changes that will have immediate impact on the Patient Community. She is the chair of the Patient Care/Quality of Life subcommittee and is on the research Subcommittee. What Rebecca brings to the committee is her own voice as a patient with concerns about the availability of treatment, the social impact of the illness, and the burden on patients and their families created by CFS. Because of her own experience with the illness - difficulty finding a treating physician, loss of employment, having to move back home with her parents for financial support, and other issues common among CFS patients, Rebecca will be able to bring a patient's perspective to the committee. At the last committee meeting she commented that none of the recommendations would have a direct impact when she went back home to Jacksonville, Florida where there are few doctors who know anything about the illness let alone treat CFS. Rebecca speaks her mind quite eloquently!

THE 2007 IACFS / P.A.N.D.O.R.A INTERNATIONAL PATIENT'S CONFERENCE

(8) You and the International CFIDS Association (IACFS) are co-sponsoring the big bi-annual IACFS conference at Fort Lauderdale, Florida from January 10th to 14th, 2007. The patient's conference runs from Jan 10th -11th and the professional conference from the 12th-14th. Is this the first time a section of the conference is devoted entirely to patients?

A: No, it is not the first time. In the past the IACFS has provided with what I call a conference within a conference and laid out for patients. But in 2007 the conference will be providing an Advocacy and Leadership training program - The 2007 Advocates Extraordinaire! © and that will be a first in the history of the IACFS as well as in the history of the CFS community. It is also extremely welcome that anyone can also attend the 3 day professional conference for a very reasonable fee. In my opinion it is a gift from the IACFS to the community it represents.

We are extremely grateful to our sponsors (see list attached) that have generously contributed to the success of this program through the Sand Castles Scholarship Awards. CFS and FM patient advocates from the U.S. and abroad are being given the chance to attend the conference under a financial scholarship and are participating in the Advocacy and Leadership training. It has been a dream come true to me to witness how this whole endeavor developed and how individuals, corporations and other non profit organizations with similar mission as P.A.N.D.O.R.A.'s are supporting the IACFS in bringing one of the best conferences ever! At last count, we have 75 Advocates Extraordinaire! © attending the conference. The main goal behind the program is to excite, teach, enhance and motivate individuals, stakeholders in our community to become "agents for change". Advocates come in all shapes and forms! Diversity is very important for our advocacy community, but equally important is unity in action! The advocacy and leadership training program will empower individuals to take action with the knowledge that they are effectively making a difference short term and long term.

(9). I was astonished at how many of the heavyweights you got to participate in the patient conference. Nancy Klimas kicks off the conference, Paul Cheney gives the keynote address and in between you have David Bell, Lucinda Bateman, Kenny De Meirleir, Charles Lapp, Leonard Jason, Dharam Ablashi, Gudrun Lange and the President of the CFIDS Association of America. It seems like the prominent CFS physicians and others were really willing to lend the CFS patients a hand. I don't know if you'd see that at other medical conferences.

A: Amazing isn't? I sincerely believe these results have plenty to do with the fact that the current leadership of the IACFS and more specifically the current President, Dr. Nancy Klimas has "advocacy" deeply ingrained in her heart as a physician and researcher. It has also to do with the fact that P.A.N.D.O.R.A. is supporting the patient conference with every resource we have, including thousands of volunteer hours, financial resources, web site, newsletters, grant writing. We are very proud of our involvement and of the type of partnership with the IACFS.

(10) There are some really interesting workshops in this conference. One is called "Understanding and Living With CFS/FM: Employment For the Disabled and the Chronically III". Given how economically strapped many CFS patients are this could be worth the price of admission alone.

A: We want our community to know about the viability of future employment for CFS and FM individuals. There are many challenges but we need to start addressing these issues aggressively. We need to start a dialogue with insurance companies as well as employers. The economic impact that CFS alone brings to the national economy, as reported by the CDC is astronomical. \$9.1 billion dollars annually and this is based on the figures of 800,000 Americans suffering with CFS.

(11) I love the 'Ask the Experts" section you. It's a long session in which attendees can ask six distinguished CFS physician's questions. There's going to be some really interesting discussions going on there. Are there plans to videotape or transcribe this or any other sessions of the conference?

A: It is one of my favorite sessions too. I am awe of the caliber of the "experts" in attendance. The professional session will be transcribed by a company who will be in charge of selling the tapes. Neither the IACFS nor P.A.N.D.O.R.A. is involved in the sales of the tapes. I think it will be a good opportunity for the "economically strapped CFS/FM patients as well as the ones who are not physically able to attend the conference. I predict that in the future as technology becomes more sophisticated and less expensive that one day these conferences can be seen or heard in "real time".

(12) Included in the patient conference are several workshops on social security and disability issues. This is such an important issue. My attempts at getting disability failed and that failure has cost me greatly. Given the controversy surrounding CFS this is still a very complex issue isn't it?

A: Very much so! Disability issues will always be at the forefront of our mission because it is an issue that affects quality of life. A loss of employment is a death sentence for the disabled individual with CFS/ME/CFIDS, FM or related illnesses. It prevents individuals stricken with neuroendocrine/immune disorders from getting access to medical care, pension plans, savings & 401 K accounts, inexpensive medical, dental and life, and long term care group insurance, notwithstanding the loss of social interaction. It wreaks havoc in families here in the U. S and abroad.

(13) You'll be giving out the P.A.N.D.O.R.A. 'Sand Castle Awards' at the conference; what is a 'Sand Castle Award'?

A: The Sand Castles Award recognizes outstanding individuals that have solidly contributed to our community as well as to P.A.N.D.O.R.A.'s mission. I chose this name because I was raised in Leme (part of Copacabana Beach in Rio de Janeiro, Brazil, and I currently live in Pompano Beach. I remember how wonderful it was to create sand castles with my son in Brazil and in Florida. We watched the waves come in and we had to start all over again. I also wanted a catchy name, as well as a name that would remind folks of Florida.

I mentioned the name to John Herd in 2004 and he said he had a beautiful essay/poem that he wrote years back depicting the same theme. He graciously let us use his beautiful essay and to adapt it as well for the purpose of the award. And each year we choose special individuals for the awards. One day, we hope to add a financial component to the award to make an additional impact.

(14) You'll also be having a P.A.N.D.O.R.A. 'Box Art' Auction. What is 'Box Art'? Where do the proceeds of the auction go to?

A: The PANDORA's Box Art Auction Project has been a project in the making now for over two years. There was always something else that we need to attend to and we would end up putting the project in the back burner. So this year because of the conference being in January we saw the opportunity to announce it during the conference.

We played with the words -"PANDORA's Box" and added the "Art Auction Project." It is a fund raiser with a flair for the arts and creativity, but it also creates awareness of the plight of CFS/FM individuals. We are asking artist to donate works of art that depicts hope and or has a butterfly in the piece. We accept works of any media. During the month of May 2007 we will have hopefully sold every art piece donated to us.

During the patient conference we will have one daily door prize. A grand prize raffles of an airline ticket with a companion, donated by AirTran Airways valued at \$500 each to be used anywhere AirTran Airways flies. The raffle prize is only \$5. One lucky person will get both tickets! The U-Pick Raffle - where the purchaser of the raffle tickets can actually pick the items he wants to win, therefore increasing the odds of getting it, is also a fun way to participate and help with the fund raising events. Any taxes owed on these items are the recipient's obligation. Donations are tax deductible.

We already have disability attorneys donating one hour legal consultations, and we are asking that physicians donate one hour consultation to be raffled off too.

In addition, conferees will be pleased to know that during the professional conference the Silent Auction has some amazing items including a week stay in Hawaii, a 6 night/6 day resort stay in Orlando, Florida plus much more. Folks can donate items to the U-Pick Raffle, as well as to the Silent Auction. To donate to any of these great fun fund raisers is simple, just bring the item when you come in to the conference and specify if the donation is for the professional conference or for one of P.A.N.D.O.R.A.'s fund raising events. If not attending please contact us at contact@pandoranet.info or the IACFS office (Rick Merner) at rick@iacfs.net mention that you would like to donate to the IACFS for the silent auction and or for the raffle.

(15) There are also workshops on Sleep and CFS, Managing Pain, Quality of Life, Alternative Medicines Role in CFS treatment, Multiple Chemical Sensitivity, HHV-6, Finding a Physician for Children With CFS, Exercise and CFS, Optimizing Time with Your Doctor and several Research Update sections and others. That's a lot of stuff! Right now there are about 500 CFS patients and professionals attending the conferences. CFS patients who attend the conference get a sharp discount on the Professional Conference. Is there anything else you want to say about it?

A: Yes, they do! And what an opportunity it is to attend the professional conference too. There will be some great announcements made at the professional conference of great interest to the patient community.

- I would like to mention two other important advocacy projects we have: P.A.N.D.O.R.A.'s International Advocacy Video Contest that is now running on Youtube.com. We already have 3 great entries in the contest. I invite everyone in our community submit videos to <http://www.youtube.com/group/pandoravideocontest> and or view the current entries. We will be inviting judges to the contest soon. Videos can be uploaded for viewing on Youtube.com The contest started on Oct 11, 2006 and will end on April 30, 2007, 9:00 pm Eastern Time.

We are proud to say that we have started a whole new community on Youtube.com which is raising awareness for our cause. The purpose of the contest is to find a video that we would use for a PANDORA PSA during Awareness Month in May 2007. We are planning to show the videos currently entered and we may ask conferees to vote for their favorite one.

- The Pediatric Pennies© campaign specially created to raise awareness for pediatric issues. We are asking that conferees bring in their pennies and donate them at the conference. Proceeds will be applied towards pediatric efforts (like the one spearheaded by the Wisconsin CFS Association), research and pediatric advocacy efforts.

Good luck with the Conference!

A: Thank you Cort and I want to personally congratulate you on being an Advocate Extraordinaire! ©. Thank you for all that you do for our patient community. See you at the conference!

*Tickets are still available. Get complete information
on the patients and the professional conference by [clicking here.](#)*