

## PHOENIX RISING SPECIAL EDITION

### A Layman's Guide to the

### The 2007 P.A.N.D.O.R.A. International IACFS Patient Conference

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### Part I: Politics, Advocacy and the Media / Dr. Teitlebaum and D-ribose / The Ask The Experts Section

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The patient conference was an overwhelming success. It has always been a kind of poor sister to the professional conference but this time with its strong program and top-notch speakers the patient conference was a success in and of itself. According to people who'd been to the patient conferences in the past the attendance for this one was double or triple that of the preceding conference. The credit for this success must go to Marly Silverman, Rebecca Artmann and the rest of the P.A.N.D.O.R.A. volunteers. You can access an excellent interview with Marly by [clicking here](#).

One of the most encouraging aspects of both IACFS conferences was the availability of the participants. Virtually everyone I talked to, from officials at the National Institutes of Health (NIH) to the Centers of Disease Control (CDC) to the CFIDS Association of America (CAA) to the CFS researchers and physicians present willingly gave their time to discuss CFS issues. Gratifyingly they almost all appeared to be impressive, highly competent individuals.

Of course, not all was positive - there were ups and downs in both the patient and professional conferences and these will be reported. These overviews are liberally supplemented by my inputs; i.e. they include information not given in the talks.

**POLITICS AND ADVOCACY** - The patient conference started off, appropriately, with perhaps the most important issue facing CFS patients - the politics and advocacy of CFS. What the federal government does or not does not do regarding CFS has enormous implications for CFS research, disability and treatment. Kimberly McCleary the President and CEO of the CFIDS Association of America (CAA) underscored this point in her talk.

#### *Kimberly McCleary -President and CEO of the CFIDS Association of America - Empowerment Within the CFS Community*

Kimberly McCleary very dramatically demonstrated the importance federal dollars play in CFS research by showing a chart that overlaid the CFIDS Association of America (CAA) contributions to CFS research with those of the federal government. While the CAA has at times been able to marshal as much as \$450,000 for CFS research even at its peak it's spending is dwarfed by federal funding rates that are from 10 to 30 times higher. There is no simply no substitute for effective advocacy at the federal level. First we take quick look at the agencies involved in CFS research.

**The NIH** - The subject of CFS research and the NIH is a complex one that will be covered in a future paper. Suffice it to say, though, that the CFS program at the NIH is a matter of concern. While the two officials in charge of CFS research at the NIH, Vivian Pinn and Eleanor Hanna, were able to get the institutes to sign off a special grant (an RFA) that supplied funding for five

major new CFS research projects there are no new programs in the works and the outlay on CFS research is still at near record lows. (The RFA funded seven grants, five of which were focused directly on CFS.). The RFA notwithstanding, the NIH has been approving about 1 or 2 new CFS grants a year for the past four years. The Office for Research into Women's Health (ORWH) did get the services of Dr. Hanna when it took over the CFS research program in 2001 but it hasn't received any new funds for CFS initiatives and had to raid its other programs to get the \$2 million dollars it needed to cofund the 2003 neuroimmune grant initiative (RFA).

Later in the Professional Conference, Pat Fero, the founder of one of the oldest CFS support groups, the Wisconsin CFIDS Association, presented data indicating numerous abnormalities regarding CFS research funding including significant over reporting of CFS funding and including non-CFS projects under CFS research.

In the last five years the ORWH has dramatically changed the focus on CFS in the NIH and is now interested in funding only multi-dimensional studies that attempt to explain CFS in a mechanistic fashion. It is unclear whether the CFS research community, never exactly robust, has managed to adjust to the ORWH's new focus. Dr. Hanna and others assert that they are willing to fund more studies than they have but that researcher input to the agency is low and generally does not meet the criteria for multi-dimensionality and innovation they have set. Every time Dr. Hanna took the mike at the conference she pressed CFS researchers to submit these kinds of studies.

When I asked her and Dr. Pinn about funding programs such as Centers of Excellence or Research Centers that could jumpstart CFS research they invariably responded by stating that the best research opportunities for CFS researchers lay in attempting to get CFS patients involved in basic science studies. When I asked Dr. Pinn whether studying CFS at the NIH was viewed as a kind of researcher suicide she demurred but again stated the opportunity now was to get CFS research studies shoehorned under other research projects. *Ironically it appears that Dr. Theoharides took just that approach when he got a project on a subject (anti-depressants) - of little interest in CFS - and with a focus - a hyperactive HPA axis - opposite to that found in CFS - approved as a CFS grant in the Neuroimmune RFA!* Dr. Pinn's assertion that 'CFS' does not have to be in the title of a study that nevertheless includes CFS patients, while undoubtedly useful, still underscores the negative environment CFS research finds itself.

I asked Kimberly McCleary if the over reporting of CFS research funding at the NIH involved a situation similar to that which occurred at the CDC some years ago. The GAO investigation of that incident resulted in the CDC's commitment to payback funds it stated it had spent on CFS research but had not and a period of independent oversight that has just ended. She replied that the two situations were different; the CDC incident involved lying to Congress about funds specifically appropriated for CFS research. The NIH, on the other hand, is under no legal obligation to fund a specific amount of money on CFS.

The NIH itself is in a time of great transition as it is reorganized under the Roadmap Initiative. The Office in which the CFS research program is located, the Office for Research into Women's Health (ORWH), is a small Office located whose budget (@ \$40 million dollars) pales in contrast to the billion dollar plus budgets of some of the institutes. Dr Pinn, the leader of the ORWH, explained that an NIH reorganization bill that was unexpectedly passed in the last hours of the last Congress gave the NIH six-eight months to determine how the Offices will be altered. She listed a range of options that could occur from outright elimination of the ORWH to establishment of a new oversight committee that controlled her budget. Until this issue is resolved there will be no new programs for CFS.

There is some opportunity here, however. The Roadmap Initiative proposes that the NIH focus more on multidisciplinary initiatives - a focus the ORWH has been employing with CFS for the

past five years. The Trans-NIH group that is now the focus of CFS research efforts at the NIH is a model that the NIH could employ in the future.

Thus there is the possibility that the CFS research program could, given its present direction, take advantage of the huge changes taking place in this immense institution. On the other hand one wonders if it also could be swallowed up or further sidelined without much afterthought. Although Dr. Pinn and Dr. Hanna both were knowledgeable about CFS and appeared committed to producing a successful CFS research program at the NIH the CFS research program there has clearly not enjoyed the support of the upper level NIH officials.

On a more positive note the CFS SEP - the review committee that has been perceived to be a thorn in CFS researchers sides by some advocates - will undergo changes as Dr. Hoffeld, a lightning rod for criticism over the past five years, will be retiring in the near future.

**The CDC** - Two major events will effect future CFS research at the CDC; the 'payback funds' resulting from the 2000 GAO Investigation are being exhausted, and the CDC is also being reorganized. I spoke to several CDC researchers at the conference. One said enthusiasm within the CFS research team was high but that the whistleblower incident and the GAO investigation in the late 1990's was a huge embarrassment to the agency and that resentment towards both Dr. Reeves and the CFS research program still lingers.

Dr. Reeve's program has been extremely innovative in its efforts to meld genomics, proteomics, laboratory measures and clinical data. The CFS research program has become a kind of showcase for this next step in medical research technology and this, in itself, may help insulate it. On the other hand not all are in agreement with this new approach. Without new funding the CDC program will certainly decline; one researcher spoke of possible cuts of 60%. The future of the CFS research program at the CDC like that of the NIH is in flux.

Both the NIH and CDC appear to be in similar circumstances; while the individuals directly involved in CFS research in both institutions appear to be committed to the success of their programs but it is not at all clear that that commitment is shared by those around them. Indeed, Dr. Agwunobi, the Asst. Secretary of Health, was refreshingly direct when he told the CFSAC that *'You still have to convince the institutions of the importance of this fight'*. Convincing the powers that be in the Department of Health and Human Services that CFS research is important may be the greatest task facing the CFS movement in the U.S. The success or failure of that enterprise will most likely affect every CFS patient. How to achieve this task is the question to which we now turn.

### ***Tom Sheridan, Legislative Advocate for the CFIDS Association of America (CAA) Legislatively Speaking***

Tom Sheridan, the legislative advocate for the CFIDS Association of America (CAA), gave an hour long talk on the state of CFS advocacy in Washington. *Unfortunately I was lost on the road during his talk. I was, however, able to get an overview of his talk from another CFS patient and talked to Tom afterwards.* .

**Making a Difference** - CFS patients may not be able to directly sway the views of NIH or CDC officials but they can dramatically alter how they will act. Tom talked about a CFS patient who got to know a low ranking California legislator in the early nineties who, when he became part of the Appropriations Committee, substantially increased funding into CFS. We can look back and see a dramatic spike in funding that was essentially the result of one CFS patient's effort to make a difference. Another moment of serendipity occurred in the early 1990's when CFS advocates were able to get language recognizing CFS into the NIH Reauthorization Act that gave CFS research a foothold in the NIH for the next 15 years.

Given this it was heartening to hear Tom Sheridan say that he believed that scientific and political support for CFS was building up to the critical mass at which real progress may be made. Several factors suggest he is correct; the CAA has been able to build up increasing Congressional support, the good publicity created by the recent CDC media event accompanying the Pharmacogenomic studies and by the ongoing CAA media campaign has resulted in a mostly positive media environment. The administration changeover at the last election creates new possibilities as new individuals take over important committees. We have seen how one individual may make a difference in this area. It is important that CFS patients make their lawmakers familiar with CFS issues. This is where we can get the most bang for our buck; where it is possible for one input to multiply a thousand fold.

In fact a recent success story dramatically illustrates how effective advocacy can be. The Whittemore's in Nevada have been able to parlay their considerable legislative influence into convincing the state of Nevada to sponsor the first state funded CFS Research Center. This Center will combine research, education efforts with graduate students and physicians and treatment. I was able to talk to Anne briefly at the conference and she indicated her strong commitment, in particular, to build a treatment center for CFS patients. Kimberly McCleary hope that a successful Reno Center will help build a case for a Center of Excellence program at the NIH.

The Whittemore's daughter came down with CFS some years ago and languished until she entered into an Ampligen treatment program. We're very lucky to have in the Whittemore's a couple that is willing to commit both considerable financial resources and time and energy into realizing this project. Anne indicated that a website for the Center will be opening soon. Phoenix Rising will following the progress of this exciting project closely.

I was able to grab Tom and Kimberly Cleary and ask them some questions. Since the termination of the Cooperative CFS Research Centers in 2001 CFS advocates have been trying to get the NIH to open Centers of Excellence that would combine CFS treatment and research. Doing so was an important part of the recommendations that the CFSAC, the federal advisory group for the NIH, submitted to the Director of Health and Human Services. P.A.N.D.O.R.A has been advocating for a Center in Florida lead by Nancy Klimas.

When I asked Tom about the fight to create a Center he explained that the way to get the Centers established was to generate enough heat on the right officials. These Centers, which cost somewhere about a \$1,000,000 a year are not expensive relative to other medical research projects. If legislators generate enough heat on NIH officials they could make them happen simply to get them off their desk. We don't have that kind of heat yet. This is one reason why it is important that CFS patients become aware of who their representatives in Congress are and what they are responsible for, and make them aware of our needs.

The possibility that CFS advocacy may be nearing some sort of critical mass doesn't mean CFS is in for good times; indeed failure is a real danger. If the progress generated during these periods does not pan out a movement can collapse in on itself. Tom spoke of these times as a 'make or break' period. Therefore we turn to the next set of talks - those designed to support CFS patients in making a difference with their advocacy.

**Support Our Advocacy Organizations** -Although a least a million people in the U.S. have CFS the world of CFS advocacy is not a large one. The largest CFIDS Association in the U.S., and the only one that is an effective advocate at the federal level, the CAA, has only about 8,000 members, a mere fraction of those effected. Despite its prominence within the CFS community and the many activities it is involved in, the CAA is not a large organization; Kimberly McCleary told me there have been times the CAA has been forced to choose between focusing on the CDC and the NIH. Its staff numbers twelve several of whom are engaged in administrative duties.

The CAA has a grassroots advocacy program patients can join and every year it produces a Lobby Day in Washington, D. C. ([click here](#)). The federal advisory committee for CFS, the CFSAC, meets regularly during the year. It is important that CFS patients participate in these meetings in order to demonstrate their support for CFS research. Patient participation has fallen near zero lately however. The CFSAC website has a great deal of information on the federal issues in CFS. ([click here](#)).

The CAA is the big guy on the block and has at times been a lightning rod for criticism from CFS patients disappointed at the rate of progress in their illness. About 10 years ago, for instance, I had problems with the makeup of the Chronicle and quit - something I now realize was remarkably short-sighted. This is the only CFS organization able to influence the government at the federal level - we need them to be as vital and engaged an organization as possible. I have just rejoined and will join our other major national CFS organization, the IACFS, shortly ([click](#)).

It is important to empower our local CFS support groups as well or even, if one is not available to create one. A group of strong local groups working on regional and national issues can have a strong impact on the future of CFS. In our interview with Marly Silverman she laid out an overview of the process she went through in creating P.A.N.D.O.R.A. ([click here](#)). P.A.N.D.O.R.A has not been on the scene for long but it is already engaged in a variety of important issues. The limitations CFS places on one need not prevent someone from engaging in effective advocacy. Marly explained that groups of CFS patients doing what they can, even if in individually small amounts, can combine to make a large impact.

### *Media Panel: How to Convey your Advocacy Message to the Media*

**Moderator: Marly C. Silverman, Panel: Martin Kramer, Ron St. John, Marla Schwartz & Diane Mohoreanu**

#### **Martin Kramer - Media Training 201**

Another way to build CFS support is through the media. Tip O'Neil once said that all politics is local and the much the same is true for the media. National television is the ultimate media event - in one swoop a single interview on a morning news program will reach tens of millions of viewers but such coverage is very rare. All stories start somewhere, though, and this makes local sources such as community newspapers very important. Everyday employees at the media outlets comb through hundreds of community newspapers looking for stories.

Diane Mohoreanu recommended that CFS patients identify reporters who write health related stories and pitch them with stories. If you do get in touch with a reporter it's very helpful to become a source for them and give reporters websites, phone numbers etc. that can help them with their story. If you can get in as a source you have a chance of really making a difference. Familiarity in the media breeds familiarity; reporters like to get a good source and stick with them and this can result in a CFS patient becoming a kind of guide for an entire region. Marly Silverman appears to have achieved this in the Miami/Fort Lauderdale region where she's now been interviewed on the radio and TV. This, of course, takes time. When I asked her how she got to this point she noted it took several years before her efforts really began to bear fruit.

If you are interviewed there are some things to remember; it's important to speak in personal terms. When news outlets do a piece on CFS they will often want to talk to patients, researchers, physicians, etc. The CFS patient's job in this case is to provide some personal emotional resonance not to give an overview of the state of CFS research or advocacy. If you're lucky enough to get a television interview look the interviewer in the eye and communicate what it's personally like to have CFS. Don't use big words or jargon. Do not comment beyond your expertise - instead refer reporters to people with the appropriate expertise. Never go 'off

the record' with a reporter - there is no such thing. Do not answer yes or no questions - these can be traps designed to skew a discussion in a certain direction. Do not step over hostile or inaccurate comments - if something inaccurate shows up in a question then take care of that before answering the question.

One participant in the session said she had been asked by a television host to dumb down her answers (she refused) and asked what she should have done. Our presenter said she should have dumbed her answers down - opportunities on network television are few and far between.

How Not to Build Media Support - stated that CFS patients in emotional turmoil or who are severely effected by their illness may not portray CFS in a good light. I talked about this extensively later with a reporter who has CFS. She noted that CFS patients, unfortunately, still sometimes have to fight the perception that not only are they malingerers but that they are 'hysterical' or unbalanced. Because of this they have the extra burden of appearing calm and rational even while they may be seething inside at the lack of governmental or medical support for their illness.

She related an incident that occurred when a CBS reporter contacted a national CFS organization regarding a CFS story that was, ironically, designed to portray CFS in a positive light. The CFS representative took offense at something the reporter said and ending up posting the reporters private cell phone number on the organizations website. Some of the ensuing phone calls actually physically threatened the reporter. She said this is the kind of bizarre story that makes the rounds at conferences and can damage CFS's credibility for years.

***Jacob Teitelbaum, MD: Understanding and living with CFS/FM. Effective treatment of CFS and Fibromyalgia - including new research on D-Ribose***

Unfortunately I did not attend Dr. Teitlebaum's talk on using CORvalen's D-ribose supplement in CFS but I did talk to a Corvalen representative at the conference. D-ribose, which is derived from glucose, is an important structural component of many of the components (DNA, RNA, ATP, FADH, coenzyme-A, and NADH) the mitochondria in our cells need to keep them well supplied with energy. CORvalen's D-ribose has been shown to increase diastolic functioning, physical functioning overall, exercise tolerance and quality of life in congestive heart failure patients. It has also been used to restore energy levels after intense exercise.

Each patient in Dr. Teitlebaum's study took one scoop (5 g) of CORvalen three times a day with food or liquids. The CORvalen representative recommended that CFS patients take the normal dose for a month or so and then cut back to two scoops a day if they wished. It often takes several weeks for CFS patients to determine if its working. He reported that Dr. Cheney began using CORvalen in the middle of 2006.

Why does CORvalen assist diastolic functioning? Because, as Dr. Cheney pointed out at the conference, it takes more energy to relax the heart than to contract it. The CORvalen representative indicated that this applies to the other muscles as well and that the stiffened contracted muscles found after exercise in many CFS and FM patients could be due to energy depletion.

He said that CORvalen, like other CFS treatments, will not cure CFS but it could very well be beneficial. He was giving out samples and I took one and experienced a substantial energy boost. (I respond quickly and well to most supplements). You can read more about CORvalen in the last issue of Phoenix Rising ([click here](#)) and visit the CORvalen website at <http://www.corvalen.com/index.php>

## ASK THE EXPERTS SECTION

Moderator: **Nancy Klimas, MD**, Panel: IACFS Board of Directors: **David S. Bell, MD, Lucinda Bateman, MD, Kenny De Meirleir, MD, PhD, Patricia Fennell, MSW, CSW-R, Fred Friedberg, PhD & Charles W. Lappe, MD**

In this session CFS patients got the opportunity to ask CFS experts questions.

*What are the chances for full recovery? Does it matter how long you've been ill?*

Dr. Lappe stated that its best to get to patients early but that he's had 5, 10, 15 and even patients who've had CFS for 22 years become well - there's always hope for recovery.

*What supplements/treatments do you find most effective?*

Dr. Lappe started this talk off and others added to it. He noted that none of these are a cure for CFS. What they do is improve your health. He recommended

B-12 (3000 mcgs/twice a week) -  
DHEA (quantity unknown) - but said 40-60% of CFS patients showed improvement  
NADH (quantity unknown) - NADH is a current favorite  
COQ10 (100 mgs./day) - about 35% of CFS patients respond  
Magnesium w/malate - good for CFS and FM  
Lysine - orally  
Acetylcarnitine (1000-1500 mgs. 2x's/day)

Dr. Bateman added  
Vitamin D  
Omega 3 fatty acids

Dr. De Meirleir added  
Lipoceutical glutathione

Dr Evengard added  
Probiotics

*How effective is human growth hormone?*

Dr. Lappe stated that he always checks the sex hormones and has had some success with estrogen if its low but not so much with testosterone. He said that two studies have shown modest improvement with HGH but that it was very expensive and because it can contribute to cancer the FDA very tightly regulates who can and cannot use it. Essentially he seemed to feel that it was hard to get, it was very expensive (\$1500) and that while it may work it wasn't really worth the effort. He felt that secretagogues that are said to stimulate growth hormone were too weak to be effective.

*How important is inactivity a factor in maintaining or contributing to CFS in those who cannot get around?*

Dr. Friedman - there are no hard statistics for this but he felt that only maybe 1 in 4 patients were really inactivity enough for inactivity to be a maintaining factor.

Dr. Lappe said he used the adage 'If you rest you rust'. He said he thought CFS patients were like cement trucks, that as long as truck keeps going the cement can flow but once it stops they really start to hurt. *This does not mean that Lappe advocates continually exercising. Part of the reason that catching CFS early is helpful, I believe, is the physician's ability to initiate appropriate rest periods. I've spoken to a Lappe patient; Lappe does advocate pacing and being attentive to ones body and allowing for rest but he also believes that too much rest can be harmful.*

Dr. Fennell - brought all the pieces together when she stated that particularly during the onset period or during periods of crisis there is a very definite ceiling that CFS patients traverse at their peril. She said that during other periods there is a definite floor as well and that CFS patients should be as active as their floor and ceiling allow. *Dr. Fennell's book deals extensively with the different stages of CFS- she was one of the most dynamic speakers in the conference.*

*Cognitive Behavior Therapy (CBT) is a hot button topic in CFS. What role, if any, does CBT play in CFS treatment?*

Friedberg - Ten ago he said he would have said none, now he feels it does - not as a cure - but as an aid. He noted that CBT is not used just CFS, it is used in heart disease and diabetes and should be useful in virtually any chronic disease.

Dr. Fennell - again referred to the different stages that CFS patients go through and felt that CBT is probably useful in some and not in others.

*How important is thyroid disorder in this disease?* This kicked off a big discussion.

Dr. Lappe - said that the idea that because CFS have low basal temperatures they have 'Wilson's Syndrome' was not only inaccurate but dangerous. The low temperatures in CFS are not due to thyroid problems but to hypothalamic problems.

Dr. De Meirleir - stated that an RNase L fragment appears to block the activity of the thyroid receptor and this could lead CFS patients to be hypothyroid without have low thyroid levels. He laid out several indices that could be checked to determine if this was so.

Dr. Klimas - noted that prescribing thyroid in CFS was quite controversial. Dr. Bateman weighed in by stating that unless there were signs of overt thyroid deficiency that she did not prescribe thyroid. Dr. De Meirleir ended the discussion with the idea of pulsing the thyroid medication if it was used to avoid possible injury.

*Some researchers believe that CFS is one of a spectrum of diseases that include fibromyalgia, Gulf War Syndrome, irritable bowel syndrome, multiple chemical syndrome and others. Do you believe this to be true?*

Dr. Bateman - finds a great deal of similarities between these patients and finds they intergrade with each other greatly. It sounded like clinically they appeared to be different subsets of one general disorder.



