



PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS  
**P-A-N-D-O-R-A**  
ORGANIZATION FOR RESEARCH AND ADVOCACY inc.



## P.A.N.D.O.R.A.'s & Lifelyme™ Newsletter

NEWS FROM  
PANDORA  
October 2010

### Speaking for You

October will end up being a very active month for P-A-N-D-O-R-A advocacy. David Adonailo, General Counsel for P-A-N-D-O-R-A, Inc., will be speaking at the fall [Chronic Fatigue Syndrome Advisory Committee](#) meeting in Washington D.C. on October 13 or 14. Be sure and listen to the livestream testimony as you will notice a different tone this year.

Soon after the meeting, Tina Tidmore, P-A-N-D-O-R-A Media and Communications Director, and Marla Silverman will be attending the New Jersey Chronic Fatigue Syndrome Association Conference. We look forward to promoting collaboration with others to improve the quality of life for people with CFS/ME.

Of course, we will send you a report.

### Nominate P-A-N-D-O-R-A

With such great success in the Chase Community Giving project, we feel that we can work together and do more. So....

### Let's Do it Again!

[American Express](#) is offering \$200,000 to five different charities every three months. People vote for their favorite charities once a week. The next three-month round of voting starts on Jan. 1, 2011, but they are accepting nominations for that period now. To be eligible, a non-profit organization must be nominated by many people, meet the American Express requirements and be approved by the TakePart Advisory Board.

- being operationally stable
- Having a presence across the United States
- Having a clear and meaningful mission
- Having a broad support base
- Serving diverse audiences

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### JOIN US

facebook

# MEMBERS PROJECT<sup>®</sup>

FROM AMERICAN EXPRESS AND TAKEPART



To read complete information on the American Express Project, go [here](#).

**We can't pass up a chance at \$200,000.**

Go [here](#) to fill out the nomination form.

Be sure and enter the full name: Patient Alliance for NeuroEndocrinImmune Disorders Organization for Research and Advocacy, Inc. For step-by-step instructions and a specific suggestion for the comments window, go [here](#).

After nominating P-A-N-D-O-R-A, we encourage you to do the same for other patient organizations.

## Ryan Positive for XMRV

We know many have been concerned with the heart-wrenching situation of ME/CFS patient Ryan Baldwin, who was forcibly removed from his loving parents but was reunited with them last year.



Baldwin, now 18 and finishing his high school education through correspondence, announced his XMRV status in an article in the local newspaper.

Lisa Baldwin, Ryan's mother, is quoted as saying they consider this to be hopeful news as they think treatments may be coming soon.

See more of the interview with the Baldwin family concerning this development [here](#).

## Ryde for Lyme

The Lanford Foundation is coordinating with some Florida college students for a bicycle ride on October 16-17. The route will go from Gainesville to Tallahassee, Florida through the state's Nature Coast.

Patients across the nation can help by joining the [facebook group](#) and getting corporate sponsors. If any patients are able, they may sponsor a ride.

Money will also be generated through the entrance fee and advertising.



## Agent for Change

[Marly's Blog](#)



## Mitch Pagerey Racing for P.A.N.D.O.R.A. & NEI Center



Mitch Pagerey in car #89 with P.A.N.D.O.R.A. & NEI Center logos



[Click here to see more photos of Mitch](#)

The proceeds will go to help a young woman with Lyme disease who has struggled to pay for adequate health care. She has been sick for two years and has a job. But at one point, she was so sick she was airlifted to the Mayo Clinic in Jacksonville, Florida.

Patients can be sponsors and offer donations to go directly to helping this woman. Go [here](#) for more information.

## Musum Takes the Silver Medal

When he was awarded the silver medal, NEI Center(™) project chairman Veny Musum said, "I was moved to tears." He competed in the September New Jersey Senior Olympics 800 meter track event.

Musum, a Lyme Disease patient, sported the NEI Center logo as he ran past the crowds, cameras and news reporters.

We are glad to share this great accomplishment as Musum continues to improve in conquering his illness. He said he pushed through the "wall" during the race because he wanted to give hope to so many others.

We share this hope that good research, such as that planned for the NEI Center(™), will bring improved quality of life to other NeuroEndocrineImmune patients.



## P.A.N.D.O.R.A. on the Radio

Dr. Nancy Klimas, well-known ME/CFS researcher, and two other P.A.N.D.O.R.A. members were interviewed on a South Florida radio program with Ron St. John as the host. If you missed the interesting conversation about XMRV and a call for Congress to fund research, then you missed it.

Thankfully, you can still listen through the link [here](#). Look toward the bottom of the page for the program labeled "9/19/2010 11 p.m."

## Petition to U.S. Secretary of Health

## Ryan is Home



The Baldwin family still needs your help. Click on the image to join the ["Bringing Ryan Home"](#) Facebook Cause Page

## Don't Dump It! Donate It!



Click here for more info

P.A.N.D.O.R.A. is going "Green"!

Donate your old cell phones, ink toners and ink cartridges and proceeds will benefit P.A.N.D.O.R.A.

## In Memoriam

[P.A.N.D.O.R.A. NEI in Memoriam](#)



Click on image to join the Facebook Fans Page

## WATCH US

By popular demand, we have set up a "sister" petition on Change.org asking US Secretary of Health & Human Services, [Kathleen Sebelius](#), to meet with P-A-N-D-O-R-A concerning funding for the NEI Center™. We were surprised to find people signing the petition within minutes of our posting it. If you have not signed the petition we have on Facebook and are not on Facebook, then please sign this other petition [here](#).



**NOTE:** if you have already signed the petition on Facebook, please do not sign this sister petition. This sister petition is for those who do not use Facebook.

As of Sept. 27, the Facebook petition had 1,671 signatures. [Sign the Facebook petition here...](#)

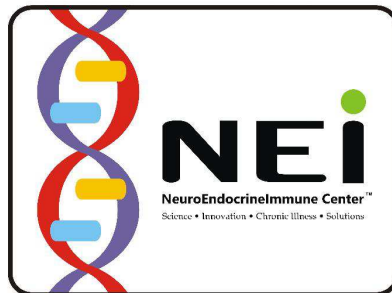


## NEI Center: Our mission statement

The NeuroEndocrineImmune (NEI) Center™ is a community patient-driven grass roots project of P.A.N.D.O.R.A, in partnership with the Lanford Foundation-Lifelyme, Inc.

It is the first research center to incorporate biomedical engineering scientific and clinical research, and integrating patient computer aided disease diagnosis and treatment (CADDT) specifically designed for multi-system illnesses and complex diseases.

To read the entire mission statement and for more information, go to [P.A.N.D.O.R.A.'s Facebook Cause Page](#) for the NeuroEndocrineImmune (NEI) Center™.



JOIN US



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and donate to  
P.A.N.D.O.R.A

NEI Center

[Contact Information](#)

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Become an agent for change join  
our mailing list below

Join Our Mailing List!

## P.A.N.D.O.R.A.'s Mission

To be one strong voice for  
many© . . .

- Creating and Raising Community Awareness
- Advocating for Quality of Life Issues
- Providing Support and Educational Resources
- Establishing Partnerships in our worldwide community
- Supporting Scientific Research
- Encouraging

	<p>Empowerment groups</p> <ul style="list-style-type: none"><li>• Organizing Educational Medical &amp; Patient Conferences</li></ul> <p>These goals will assist patients with neuroendocrineimmune disorders and their families in leading productive and fulfilling lives.</p> <p>Built on Hope * Strong on Advocacy Finding a Cure through Research</p> <p><b>1 Voice - 1 Community - 1 Cause™</b></p>
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