



## Pheo Para Alliance Launches New Patient-Focused Website

### *Site Features Extensive Patient Resources Like Regularly Updated Diagnostic and Treatment Information*

The world's largest advocacy organization for one of the most misdiagnosed neuroendocrine tumors has launched a new website featuring much-needed information on diagnosis and treatment options for pheochromocytoma (pheo) and paraganglioma (para) patients. Patient Highlights:

- Patient Support Services & Partner Organizations
- Updated Diagnostic & Treatment Information
- Glossary of Terms

The new Pheo Para Alliance website, which officially launched November 10th to coincide with NET Cancer Awareness Day, also provides ample opportunities for the entire pheo para community to get engaged and support the Alliance's global mission to advocate on behalf of its patients and spread awareness amongst medical professionals.

Coming Soon! The Alliance is also making preparations to launch a new international Doctor Tracker and Community Forum on the site where patients can share information and experiences.

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## 2019 Pheo Para International Conference June 6-8, 2018 Central New York Biotech Accelerator Syracuse, New York

Mark your calendars for June 6-8, 2019, for the Pheo Para International Conference to be held in Syracuse, NY. The conference will feature international leading experts in pheochromocytoma and paraganglioma (PPGL), including Dr. Karel Pacak from the National Institutes of Health (NIH) in Bethesda, Maryland. Dr. Pacak's work as the lead PPGL researcher at NIH has produced diagnostic and treatment information critical to patient care.

Conference participants will also hear from prominent PPGL experts from across the globe on the latest developments on diagnostics, genetics, surgical and non-surgical PPGL treatments and available patient support services. Panels of physicians and patients will be available to answer questions.

Additional PPGL featured speakers include:  
Dr. Justin Annes, Stanford University  
Dr. Gennady Bratslavsky, SUNY/Upstate Medical University  
Dr. Roderick Clifton-Bligh, The University of Sydney  
Dr. Joseph Dillon, University of Iowa  
Dr. Lauren Fishbein, University of Colorado

This will be an extraordinary opportunity to receive up-to-date information and meet and talk with other patients and caregivers.

Can't attend? The conference will be live streamed. After the event, the video will be available on the Alliance website.

Registration opens in early December. Check back to our website [www.pheopara.org](http://www.pheopara.org) for registration and event details.

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## Jeannie Lee's Story

For as long as I can remember I've always had a difficult time breathing. As a child I participated in sports, and felt that I needed to train harder...or that is was just hot. These were some of the reasons I convinced myself that I was short of breath. I continued to be an avid participant in athletics, however there would be times when I would vomit, and pass out, after pushing myself too hard. My parents would take me to the doctor regularly, and even rush me to hospital. The only diagnosis would be pleurisy. It was not until I was pregnant with my first child that a doctor diagnosed me with asthma...or at least, that was the thought. Over the years, numerous doctors tried, unsuccessfully, to treat my "asthma", but nothing seemed to work. My lungs were stressed, but structurally healthy. My pulmonologist was vexed, but she was determined to help me in any way possible.



[Read More ->](#)

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## Get involved!

There are many ways to make a difference in the Pheo Para community. One important way is to work with our government leaders to raise awareness of pheochromocytoma, paraganglioma and other rare diseases.

Pheo Para Alliance Vice-president, Stephen Furlong, PhD, recently met with U.S. Representative Bill Keating (MA 9th District) at Keating's office at the Massachusetts Maritime Academy in Buzzard's Bay. During their meeting Steve shared stories of Pheo Para patients and the common challenges they face seeking treatment for a cancer so few understand. As a result of their conversation, Steve was asked by Representative Keating to work with his office on a healthcare roundtable in Massachusetts and was also invited to participate in a patient advocacy event at MIT - two fantastic opportunities to advocate for issues important to Pheo Para patients!



You can be an advocate, too! Here are a few ways that you can make a difference:

Help strengthen the voice of our community on Capitol Hill by asking your legislator to join the Rare Disease Congressional Caucus. Our partners at Rare Disease Legislative Advocates (RDLA) make it easy with this form letter that provides you an opportunity to inform your legislator about Pheo Para. Here's the link to get started:

[http://action.everylifefoundation.org/p/dia/action3/common/public/?action\\_KEY=18785](http://action.everylifefoundation.org/p/dia/action3/common/public/?action_KEY=18785)

You can also attend Rare Disease Week on Capitol Hill, February 24-27, 2019. RDLA will bring over 500 patient advocates to Washington, D.C. for a week of events dedicated to empowering patients, families, and friends to become legislative advocates. Advocates will have an opportunity to meet with Members of Congress and learn best practices for successful advocacy.

RDLA offers travel stipends to participants to offset the cost of attending Rare Disease Week on Capitol Hill. The 2019 travel stipend application closes on December 14th, 2018. Registration for the event begins on January 3, 2019, at [rareadvocates.org/rdw](http://rareadvocates.org/rdw).

On February 27th, as part of Rare Disease Week on Capitol Hill, the NIH will host Rare Disease Day at NIH. This event aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments.

Stay tuned to the Pheo Para Alliance website [www.pheopara.org](http://www.pheopara.org) to find other ways you can make a difference for our community!

## New York NET Patient and Caregiver Education Conference

Join the Pheo Para Alliance in New York City on Saturday, December 1st at the New York NET Patient and Caregiver Education Conference. Co-sponsored by the NET Research Foundation and The Tisch Cancer Institute at Mount Sinai, this full-day educational program is designed to inform and empower neuroendocrine patients and families. Dr. Tito Fojo of Columbia University will lead a breakout session on pheochromocytoma and paraganglioma.



Breakfast and lunch are complimentary and there is no cost to attend the conference that will be held from 9:00 AM - 5:00 PM at the Westin Times Square.

Besides a pheochromocytoma and paraganglioma breakout session, there will be sessions on Understanding Clinical Trials, Interventional Radiology (IR) Procedure Basics, and Nuclear Medicine for NETs Imaging.

**Click here to register:** <https://signup.e2ma.net/signup/1882893/1773232/>

**DONATE**

Pheo Para Alliance | [info@pheopara.org](mailto:info@pheopara.org) | [www.pheopara.org](http://www.pheopara.org)

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