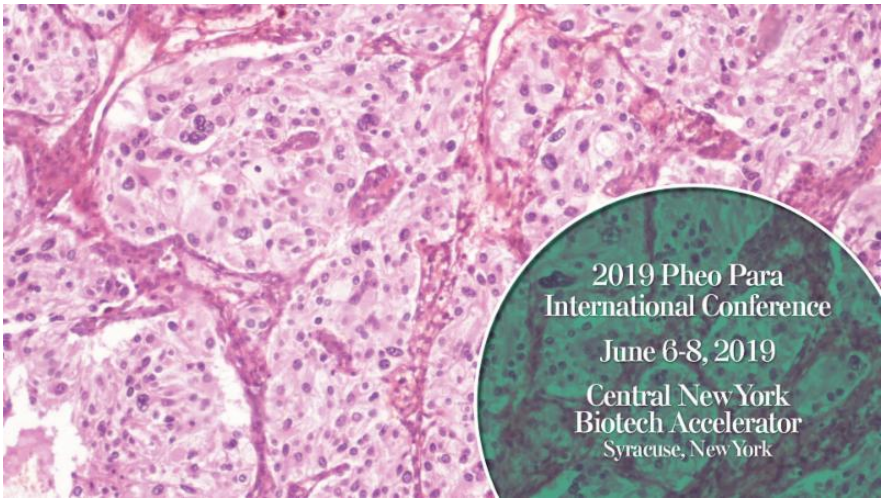
Stronger United

pheopara ALLIANCE



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

Registration is now open for the 2019 Pheo Para International Conference! This event features leading international experts in pheochromocytoma and paraganglioma.

Speakers and topics include:

- Karel Pacak, MD, PhD, DSc, NICHD, NIH: State of the Art Pheochromocytoma and Paraganglioma (PPGL) Developments
- Gennedy Bratslavsky, MD, Upstate Medical Hospital: Surgical Approaches for PPGL
- Justin Annes, MD, PhD, Stanford University, Genetic Implications For PPGL
- Bonnie Bennett, BSN RN, University of Pennsylvania: Navigating the System
- Roderick Clifton-Bligh, BSC (med) FRACP PhD FFSc, Royal North Shore Hospital, University of Sydney, Australia: PPGL Research: What's on the Horizon
- Ruban Dhaliwal, MD, MPH, Upstate Medical University: PPGL: What every Endocrinologist (and Physician) Needs to Know
- Joseph Dillon, MB, BCh, BAO, University of Iowa: Non-Surgical Approaches for PPGL

- Lauren Fishbein, MD, PhD, MTR, University of Colorado: PPGL Diagnostics
- Dr. Kaushal Nanavati, MD: Wellness For the PPGL Patient
- Dr. Shoichiro Ohta, MD PhD,Fukushima Medical University, Japan: Differences between Paragangliomas and Pheochromocytomas in malignant potential, in 80 Japanese patients
- Jonathan Riddell, MD, Upstate Medical University: Pediatric PPGL
- Jeffrey Ross, MD, Upstate Medical University: Future Opportunities of advanced PPGL results of modern genetic sequencing

Additionally, the conference will include an Expert Panel, a Patient Panel, a Caregiver Presentation, and a Friday night mixer.

For the first time, CMEs (Continuing Medical Education credits for healthcare professionals) will be offered. On Thursday evening, a Grand Rounds and Dinner will be held for healthcare professionals.

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

For more information and to register go to: www.pheopara.org/2019pheoparaconference

Pheo Para Alliance 2018 Annual Report

Board Chair's Report

2018 was a productive year for the Alliance. We finalized our merger with the Pheo Para Troopers, launched our new website, represented our community at several NET conferences, and started the process of hiring a permanent Executive Director.

In 2019 the Pheo Para Alliance will:

1. Appoint a permanent Executive Director to the Pheo Para Alliance.
2. Successfully bring the pheo/para medical and patient community together at our June International Conference in NY with live webcasts that will be archived for future viewing.
3. Launch our online Doctor Tracker for patients.
4. Expand our board to include individuals with new professional and personal insight and continue to improve our governance structure.
5. Create a long-term, comprehensive fundraising plan that will help sustain our organization's mission and further cultivate our current partnerships and donor base to help support current projects and needs.

As Board Chair, I believe in leading with full transparency and honesty. During the merger process, operating with only a handful of volunteer board members and a part-time Executive Director, the Alliance's efforts were mainly focused internally to optimize its future capabilities. Unfortunately, that drew us away from some of the patient-centered outreach at the heart of our mission. That is a no fault statement, just the reality of our situation and a process that, I believe, has made us better poised to serve our community.

With that, I want to make a formal plea to all of our current and former supporters to reengage with the Alliance. Our collective success depends on it!

Many of us have the same story when it comes to pheo/para. We were ignored for years, symptoms written off as something else, and told it could never be such a rare disease. Then we

educated ourselves, advocated for ourselves, and found the right person to listen.

The Alliance was formed to help unify that voice and those struggling with the same challenges. Our voice cannot be heard without you - the patient, the caregiver, the family member, the friend, medical professional, the company, the few that know pheo/para and will fight to make sure everyone does, too. We are too small of a disease to be fragmented and need to harness our collective experiences and passions. The Alliance is meant to bring us together, and we ask those that have been with us before, are with us now, and could be with us in the future, to unify with that in mind.

I want to publicly thank Emily Collins for her contribution to the Alliance as Board Chair (President) over the past few years and through the merger. Without her leadership, we would not be in the position of growth we are now.

With high expectations for 2019, the Alliance is poised for action. However, we need your support and engagement. Join us on social media, signup for our newsletter, join us in person this June at the International Pheo Para Conference. We would love the chance to meet and/or reconnect with as many of you as possible.

All the best,

Matthew Capogreco
Board Chair

Though many of its efforts were merger focused in 2018, the Alliance did participate in several key advocacy initiatives. Click here to read more...

Rare Disease Day
February 28, 2019

February is a big month in the rare disease community with highlights including Rare Disease Day and Rare Disease Week on Capitol Hill.

Rare Disease Day, February 28, 2019
Rare Disease Day is the international advocacy day to bring widespread recognition of rare diseases as a global health challenge. This year's theme, "Bridging Health and Social Care", emphasizes the need to bridge gaps in the coordination between medical, social and support services to help tackle challenges faced by people living with a rare diseases and their families. Internationally, the #ShowYourRare social media campaign encourages people to paint their faces to "show their rare" for Rare Disease Day. In the United States, the zebra is the official symbol of rare diseases and people are being encouraged to "Show Your Stripes". Whether you choose to Show Your Rare or Show Your Stripes, get involved! To see how you can participate and "Show Your Stripes" visit: https://rarediseases.org/rare-disease-day/

Rare Disease Week on Capitol Hill, February 24-28, 2019
Sponsored by the Rare Disease Legislative Advocates (RDLA), Rare Disease Week on Capitol Hill brings together members of the rare disease community from across the United States to be educated on federal legislative issues, meet other advocates, and share their stories with legislators. Open to patients, caregivers, patient advocates and patient advocacy organizations, activities include a Legislative Conference, scheduled meetings with members of the House and Senate on Capitol Hill, a Rare Disease Congressional Caucus Briefing, and Rare Disease Day at the NIH. These activities are free but require registration. For more information or to register go to: https://rareadvocates.org/rdw/

Rare Disease Day at the NIH, February 28, 2019
Rare Disease Day at the NIH is sponsored by the National Center for Advancing Translational Sciences (NCATS) with aims of:

- Raising awareness of rare diseases and the people they affect
- Raising awareness of NIH research collaborations underway to address scientific challenges and to advance new treatments.

This event is free to the public, but registration is required. For more information, visit https://events-support.com/events/Rare_Disease_Day/page/1947

2019 Bay Area NET Patient Education Conference

Hosted by UCSF and NorCal CarciNET, the 2019 Bay Area NET Patient Conference had over 300 attendees from across California. Live streamed, the conference began with Dr. Emily Bergsland of UCSF reviewing NET Basics: Types of NETS, Common Treatments, and What You Should Know about Your Tumor. PPGL-specific information discussed by Dr. Bergsland included:

- Between 35 and 40 percent of PPGL patients have germline mutations
- 19 genes are linked to PPGL
- ALL PPGL patients should see a genetic counselor
- Patients should be seen by a Multidisciplinary NET team that includes an endocrinologist, a nuclear medicine specialist, surgeons and anesthesiologists with expertise in PPGL, and a genetic counselor

Also stressed by Dr. Bergsland was ways for patients to facilitate care when they have multiple providers across multiple centers including:

- Maintaining copies of scans/reports
- Maintaining copies of lab results
- Keeping a diary of symptoms
- Keeping a list of the names of all of providers and their contact information

The Keynote Speaker, Dr. Sonia Lupien from the University of Montreal, discussed Stress and Cancer: From Science to Personal Perspective. The fact that the body's stress response is handled by the adrenal system has special implications for the PPGL community. Dr. Lupien discussed one opportunity for controlling the stress response by taking advantage of social support, including groups like the Pheo Para Alliance's Community Forum to receive "virtual empathy."

A special lunch breakout and discussion, led by Dr. Justin Annes (Stanford University) and Dr. Chienying Liu (UCSF), included opportunities for patients and family members to get information specific to pheochromocytoma and paraganglioma. Eleven patients and family members were in attendance. Questions asked included the relationship between PPGL and GIST, guidelines for testing children who have tested positive for a mutation, and the possible influence of a ketogenic diet on PPGL.

Points made by Drs. Annes and Liu included:

- Though a PPGL patient may be "cured", it is always important to have continued follow up
- There is no link showing a connection between a ketogenic diet and a cure for PPGL
- In the future, there needs to be further research to determine whether or not current standards of care are appropriate

- The importance of all patients diagnosed with PPGL discussing genetic testing with their healthcare providers
- There is currently a PRRT (Peptide Receptor Radionuclide Therapy) trial going on at the NIH involving Lu-177-DOTATATE as a therapy for inoperable PPGL. The hope is that this trial will be expanded to multiple centers by the end of this year.

Besides the opportunity to learn from these PPGL experts, the Conference provided an opportunity for patients and family members to meet other members of the PPGL community and learn about advocacy and educational opportunities provided by the Pheo Para Alliance.

Image courtesy of NET Research Foundation.

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Pheo Para Alliance | info@pheopara.org | www.pheopara.org

STAY CONNECTED:

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