



SDHB PHEOPARACOALITION

MISSION STATEMENT

Our mission is to educate healthcare professionals and patients on the SDHB genetic germline mutation as well as its role and impact in this orphan disease, namely **Pheochromocytoma** and **Paranglioma** respectively...



OCTOBER 2017

“NEWSLETTER”

SDHB PHEOPARA COALITION

The SDHB PheoPara Coalition was formed in early 2016 and we are pleased to report that the newly established organization was up and running as of January 2017. We have formalized our legal status as well as our 501(c)(3) tax-exempt designation from the IRS, thereby enabling us to conduct fundraisers and start to support research and educational initiatives. Additionally, we have appointed our Board, established our bylaws, set up the necessary operational structure and committees, and developed a new website...

PHEOCHROMOCYTOMA / PARAGANGLIOMA

Q: Why are we focused on the SDHB gene?

A: Patients who present with an SDHB genetic germline mutation are unfortunately associated with much higher rates of malignancy. Furthermore, there are no cures for this disease and the treatments are inadequate. Today, we lack effective chemotherapeutic and radiation therapies that can give these patients hope and help them survive this orphan disease.

“SDHB related pheochromocytomas and paragangliomas are more likely to spread to distant sites, metastasize and return after they have been removed”.

2017 STRATEGIC OBJECTIVES

- To successfully launch the SDHB PheoPara Coalition as a 501(c)(3) nonprofit organization.
- To spread the word about the existence of our organization, and to fully fund, organize and staff the Coalition so that it can start to address its mission.
- To have a successful fundraiser with our Gala on April 20th, 2017 in New Jersey.
- To support at least 2 or 3 good SDHB scientific projects which will lead to a better understanding of this orphan disease and ultimately an effective treatment.
- To partner with other interested organizations and academia in this field who share a common purpose.

The second part of our mission will be to focus on supporting research which will ultimately lead to effective treatment options for the SDHB form of the disease and/or hopefully one day a cure.

RESEARCH / GRANTS

The SDHB PheoPara Coalition is active in sponsoring research to advance science in this important and underserved area...

Given that we are a new organization, our first priority has been to secure donations and funding through our planned events and now we can focus our efforts on and approve grant requests. More details regarding active projects will be shared on our website and included in future publications of this newsletter.

The SDHB PheoPara Coalition issued its first educational grant to ISP 2017, which is recognized as a premier event in this space, and was held in August in Australia.

SDHB PHEOPARA COALITION GALA

The SDHB PheoPara Coalition held its first annual gala on April 20th, 2017 at the Hilton Parsippany in Parsippany, New Jersey.



Tim Rothwell, President

Dr. Tito Fojo

Dr. Karen Adams

The event had strong support from corporate america as well as individual contributors and we are sincerely appreciative of those people who actively participated this year and made this a truly successful event.

The program included welcoming remarks from Tim Rothwell, President along with an update on the SDHB PheoPara Coalition.

This was followed by Antonio Tito Fojo, M.D.,PhD., who spoke about how research could help us think rationally about the emotional challenges of Pheochromocytoma & Paraganglioma respectively.

Last but not least came a presentation from Karen Adams who shared the perspective of a care coordinator who works with Pheochromocytoma and Paraganglioma patients daily.

We had ~250 attendees at the gala and feedback on the event has been extremely positive to date.

PRESIDENT'S MESSAGE...

Pheochromocytoma and Paraganglioma represent a significant health problem. Patients with these conditions not only face the symptoms caused by the overproduction of catecholamine's, but they also run the risk of recurrence or metastatic spread even after successful surgery for the primary tumor. This is especially true with inherited conditions such as the SDH gene mutations.

Patients with SDH genetic mutations face more challenges than those who develop sporadic pheochromocytoma or paraganglioma. Tumors are more likely to be multi-focal and are more likely to occur at a young age. For patients with SDHB mutations, the risk for recurrence or metastatic spread is much higher than for sporadic patients or for patients with other inherited forms of the disease.

At present, surgery remains the only truly effective means of managing SDHB patients. Multiple surgeries over one's lifetime is the rule rather than the exception for these patients. While progress has been made in understanding the molecular pathways involved in the development of these tumors, we still lack the critical models necessary to accelerate the development of effective systemic treatment for these tumors when they recur or spread to distant sites.

This is the reason why we created the SDHB PheoPara Coalition because we wish to focus our resources and energy on helping to find a treatment for this very rare genetic mutation. Truly effective treatments for the SDHB germline mutation are essentially nonexistent, and until recently very little research was being done in this area. Today, increasingly more researchers are working on better understanding the development of these tumors and their behavior. We hope through the Coalition to enhance this knowledge by supporting research which is focused on the SDHB component of this disease.

THE SDHB PHEOPARA COALITION “HALL OF FAME”...

Given that this was our first event as a new organization, we allocated a considerable amount of time in selecting a worthy recipient and honoree and we were so proud to award James Lee, M.D. as the recipient of the SDHB PheoPara Coalition Science Award.



Tim Rothwell & Dr. James Lee

Dr. Lee is the Chief of Endocrine Surgery at Columbia University, the Medical Director of the NY Presbyterian Hospital Endocrine Service Line, Vice Chair of New Media, and Co-Director of the Thyroid, Parathyroid and Adrenal Centers. Dr. Lee’s accomplishments and achievements are too many to share in this space, suffice to say that he is a dedicated professional who actively participates in and supports our cause and we are very appreciative of his efforts in this regard...

PAST RECIPIENTS AND HONOREES...

Awardees of The SDHB PheoPara Coaliton Science Award:

2017 – James Lee, M.D.

Recipients of The SDHB PheoPara Coalition Leadership Award:

2017 - No award given out in 2017

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THE SDHB PHEO PARA COALITION

is a 501(c)(3) not-for-profit organization...

Your contribution and support is greatly appreciated. Please click on link below to make a donation...

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