phace syndrome™ community

2018 Annual Report

Building COMMUNITY

Raising AWARENESS

Sharing MEDICAL ADVANCEMENTS

Supporting RESEARCH

Someday all doctors will know about PHACE Syndrome & every child with PHACE will receive the best care possible!

What is PHACE Syndrome?...

PHACE Syndrome is the uncommon association between large infantile hemangiomas, usually of the face, and birth defects of the brain, heart, eyes, skin and/or arteries. It is an acronym that stands for the medical names of the parts of the body it often impacts:

Posterior fossa abnormalities and other structural brain abnormalities.

hemangioma(s) that are typically large and located on the skin of the head and neck area.

arterial anomalies of the head (brain) and neck. These can be arteries that are too narrow (stenotic) or dilated (aneurysmal) or the lack of normal blood vessels in the head and neck.

Cardiac defects, with the most common being coartation (narrowing) or the aorta or other aortic abnormities.

eye anomalies not caused by the growth of the hemangioma such as problems with the optic nerve.

Sometimes an "S" is added to PHACE making the acronym PHACES; with the "S" standing for "Sternal defects" and/or "Supraumbilical raphe".

phace syndrome community™

www.phacesyndromecommunity.org

The PHACE Syndrome Community (PSC) is the only organization of its kind in the United States advocating on behalf of individuals and their families who have PHACE Syndrome.

It is estimated that over 50 children are born each year in the United States with PHACE. There are over 1000 known cases of PHACE Syndrome to date, but the cause still remains unknown.

Together, we can advance PHACE Syndrome medical research to find the cause!

Dear PHACE Families & Friends,

We are so grateful for your generous support of the PHACE Syndrome Community (PSC)!

With your support, the PSC was able to offer a community of support to over 500 individuals with PHACE Syndrome. We also brought together over 40 families at our bi-annual conference for cutting edge disease education and family support.

I first became aware of the PSC almost six months after my daughter was diagnosed. The PSC was still in its early years and because of the assistance it needed, I wanted to use my organizational and communication skills as well as compassion to make the PSC the go-to place for all PHACE related questions.

My personal mission is to help further the PSC by strengthening the relationships within the medical community, while instilling core values and reaching out to families who may feel their lives unraveling when their child is first diagnosed.

Our goal for 2019 is to continue to add talented,eager volunteers to our already passionate and motivated team in order to expand our work further.

With Deep Gratitude,

Jerri Lauffer
PSC Board President

Board of Directors

Jerri Lauffer - President
Michael Kotyk - Vice President
Lawrence Baylis - Treasurer
Paul Butera - Secretary
Jill Salas - Past President
Mary Alice Kaspar
Jen Meints
Steven Russakoff
Dr. Dawn Siegel

Medical Advisory Board

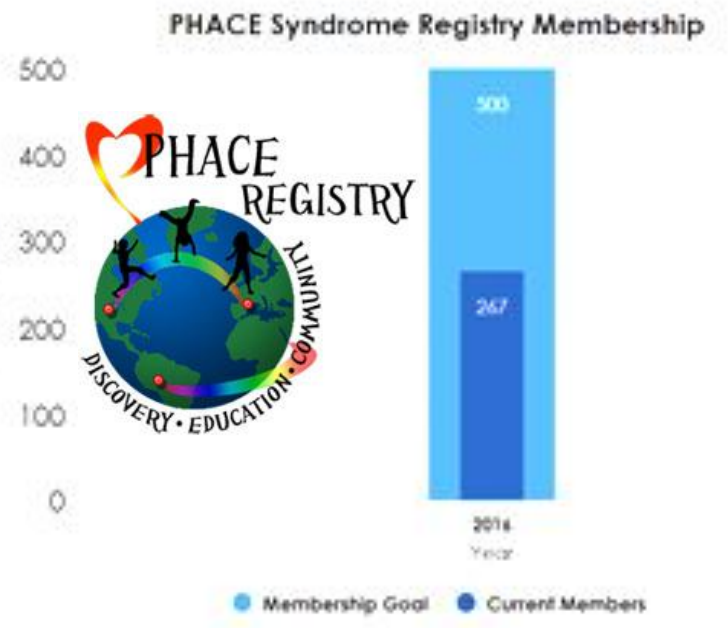
Beth Drolet, MD
Darren Orbach, MD, PhD
Geoffrey Heyer, MD
Maria Garzon, MD
Dawn Siegel, MD
Christopher P. Hess, MD, PhD
Ilona J. Frieden, MD
Elena Pope, MSc, FRCPC
Denise Adams, MD

Partnerships to Advance Research

In 2018, Dr. Dawn Siegel and Dr. Beth Drolet were awarded two research grants via the Gabrielle Miller, Kids First Research Program to submit samples for DNA sequencing.

Over 100

PHACE Syndrome families participated!



In 2012, Dr. Siegel and Dr. Denise Metry joined their individual PHACE research programs into a single centralized database to help find answers for this disease. Children's Hospital of Wisconsin is now the central location for the **PHACE Syndrome Registry Project.**

Children's Hospital of Wisconsin

2018 Highlights

550 PHACE Syndrome Community members

140 Conference Attendees

2018 Best of Atlanta Award in Local Business

7200 reached in Awareness Week

Hired first Executive Director

220 Race for PHACE runners

320 Registry Participants

2018 SUPPORTERS

Children's Healthcare of Atlanta

Culhane Meadows PLLC

Children's Hospital of Wisconsin

Maria C. Garzon, MD
Co-Director, Vascular Anomalies Group
Columbia University Medical Center, NY
NY-Presbyterian,
Morgan Stanley Children's Hospital

Pierre Fabre

THRIVENT FINANCIAL®

Boston Children's Hospital
Until every child is well™

CVS Health®

Conference Impact

Our Bi-Annual Family Conference provides meaningful connection and education to PHACE Families.

"The conference means I can finally fit in somewhere and be surrounded by people who understand me."

"From meeting families who have walked the most similar life to my own, who have fought similar medical battles I've fought, this was the coolest event I've ever been a part of! ***I'll be coming back every year!"***

BUDGET

PSC's $60,000* operating budget is focused on:

- Raising awareness about PHACE Syndrome at Race for PHACE, online, and through mailers and local events.
- Supporting research with Registry referrals and participation in projects to find the cause.
- Building community and sharing medical advancements through our bi-annual family conference.

*2018 operating budget estimated and rounded at year-end.

Over 70 ¢ of every dollar supports PHACE families!

$12,000+ RAISED ONLINE!

Thank you for celebrating with us!

Through all your efforts to celebrate online on behalf of the PSC and to share our information to raise awareness and dollars for PHACE, you helped us have a record breaking year!

Generous Friends

$1000+
Lawrence & Adriane Baylis
M J Chase
Karina & Peter Copen
Dr. Maria Garzon & Mark Vassallo
Michael & Erin Kotyk
Jason & Jerri Lauffer
Kristen Lauffer
OTB Bikeworks Inc.
Stephen & Kim Verska

$500+
Rachel Friedman
Mary Alice Kaspar
Jude Lauffer
Martin Maloney
Monteverde's Inc.
Rajesh Nishtala
Cathy Reed
Dr. David & Ina Russakoff
Linda Sweeney

$250+
Paul and Erin Butera
Michael Fletcher
Desiree John
Robin Maggs
Timothy Maynard
Dianne Murray
Heather Ranck
Scott Schreurs
Karen Steigerwald
David Tetrick
Maurice Zadeh

Up to $250

Thank you everyone!

PHACE Syndrome Community, Inc.

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phace syndrome community™

We appreciate your support!