



Advancing Research and Clinical Care

for Children with Pulmonary Vein Stenosis

2017: Putting PVS into Focus

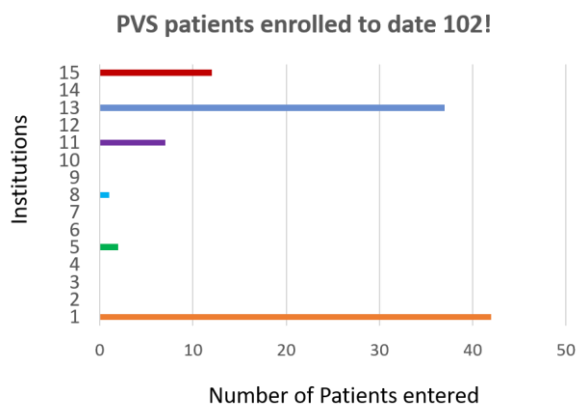
Over the past year, PVS has been highlighted at major meetings bring the disease into focus. Symposia at AHA and the Neonatal and Childhood Pulmonary Vascular Disease Meeting in San Francisco were great opportunities to bring together clinicians and researchers with an interest in PVS. Collective discussions about ways to improve disease surveillance with clinical surveillance protocols and current treatment practices has certainly helped to galvanize the community.

We look forward into continuing the momentum into 2018!

PVS Network Registry update

The PVS Network has benefited from commitment of the participating institutions through personnel and infrastructure support. Private donations and internal funding at the Hospital for Sick Children are working together to increase PVS knowledge and awareness.

The PVS registry is now open for data collection!



The majority of institutions have completed the IRB approval process and data is starting to be collected. Currently, 15 institutions have completed the onboarding, and 6 more are near completion. New patient data is being entered daily.

Remuneration will begin in the coming months.

There is still time to start the IRB process, for those still interested.

The PVS Network Website: www.pvsnetwork.org

The PVS Network website is up and running. The goal is to provide resources to parents facing a new diagnosis of PVS and to provide up to date information to clinicians regarding treatment and surveillance for children with PVS in an unbiased manner. An additional goal is to provide a centralized resource whereby current research results and clinical trials are accessible.

Send updates, research publications and patient stories to pvs.network@sickkids.ca

PVS Awareness

Increase awareness about PVS!



www.pvsnetwork.org

Through use of graphic images, we hope to increase awareness of PVS among parent and clinician communities.

We are thankful for the artistic contribution of local Biomedical Communication MSc students! Their creativity and effort were outstanding.

A new image will appear on the website every 6-8 weeks- **download it , share it ,like it on social media.**

Our first image is built around the concept 'Knowledge is Hope'

Read more at www.pvsnetwork.org/pvs-awareness.html

Meetings and Presentations: focus on PVS

AHA , Scientific Sessions
November 11-15, 2017

November 13, 2017, 10:30 - 11:45 AM
Progression of Vascular Remodeling in Pulmonary Vein Obstruction: Role of mTOR Pathway Activation and Smooth Muscle Cell Dedifferentiation

November 14, 2017, 1:30 - 2:45 PM
Patient Characteristics and Mortality in Children With Pulmonary Vein Stenosis (CHOP)

November 14, 2017, 1:30 - 2:45 PM

11th International Conference Neonatal and Childhood Pulmonary Vascular Disease
April, 2018
San Francisco

Exciting talks on Pulmonary Hypertension
PVS Debate
Update on the PVS Network registry

Research Protocols Available

Disease progression and outcomes in pulmonary vein stenosis

Retrospective clinical data collection only

Pulmonary vein stenosis: disease mechanisms and outcomes

Prospective and retrospective clinical PVS database
Option for participation in genetics/whole genome sequencing project

Contact Info and Requests for Protocols

Please feel free to send newsletter articles/ topics, upcoming talks and recent PVS publications

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Participating Institutions

Children's Hospital of Philadelphia, Cincinnati Children's Hospital, Denver Children's Hospital, Emory Children's Hospital, Stollery Children's Hospital, Hospital for Sick Children, Children's Clinics and Centers of Minnesota, Morgan Stanley Children's Hospital, Primary Children's at Utah, Nemours Children's Hospital, Seattle Children Hospital, Vanderbilt Children's Hospital, Texas Children's Hospital, Iowa Children's Hospital, Stanford Children's Hospital, Wisconsin Children's Hospital, Cleveland Clinic, Nationwide Children's Hospital and more to come.