



Advancing Research and Clinical Care for Children with Pulmonary Vein Stenosis

2018: What is your Resolution?

The New Year always brings with it a realigning of priorities, redefining goals and commitments to new endeavors.

In 2018, we challenge you to think about how your institution can improve clinical care through the development of protocols for PVS imaging or contribute to research that will improve outcomes for children with PVS.

This year, the PVS Network will work together to :

- Complete the retrospective study data collection. This will help us understand treatment practices, surveillance protocols and contemporary outcomes across more than 15 institutions.
- We will continue to highlight pulmonary vein stenosis through our awareness campaign.
- We are working to expand the genetics study and are grateful to the new institutions who have committed to contributing samples over the coming year.
- Plan a PVS symposium to share tough clinical cases, research updates, develop consensus guideline writing groups and nurture new collaborations.

The PVS Network Website: www.pvsnetwork.org

The website has been active for just 9 months and we have already had over 6000 unique visitors. Our hope is that we are able to provide a non-biased resource for parents caring for a child with PVS and to create a sense of community to help foster collaboration.

The PVS awareness campaign is a modest initial step towards increasing awareness and fostering a sense of community.

Our new image for 2018 is out! <http://www.pvsnetwork.org/resolution.html>

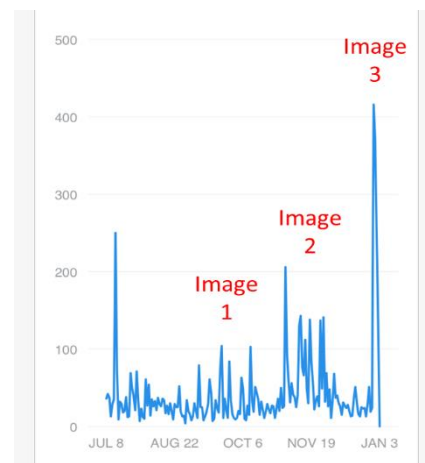


Download it, Share it and Like it on social media!!

Every Click Counts!

Thank you to everyone taking time to distribute the images.

With each image release, we are getting more views and spreading PVS awareness!



Participating Institutions

Remuneration packages will be distributed shortly. Initial invoices will offset some of the costs needed to set up the study at each institution. We will provide further remuneration once we have final institutional enrollment numbers. More to come!

Thank you to the generous financial support of our donors and the commitment of each PVS registry team at the individual institutions!

Meetings and Presentations: Focus on PVS

**11th Annual Neonatal and Childhood
Pulmonary Vascular Disease
April 18-21, 2018**

Saturday April 21, 12:00

Pro and Con debate for PVS management!

May 1, 2:00-5:30 session

**AATS
April 28-May 2, 2018**

High waitlist mortality in transplantation for pulmonary venous disease: an analysis of the UNOS pediatric thoracic transplantation database

Please send abstracts, presentations to highlight PVS research in newsletter and website!

Recently Published!

Altit G, Lee HC, Hintz S, Tacy TA, Feinstein JA, Bhombal S. Practices surrounding pulmonary hypertension and bronchopulmonary dysplasia amongst neonatologists caring for premature infants. *J Perinatol.* 2017 Dec 12. doi: 10.1038/s41372-017-0025-3.

Goldberg JF, Jensen CL, Krishnamurthy R, Varghese NP, Justino H. Pulmonary vein stenosis with collateralization via esophageal varices: Long-term follow-up after successful treatment with drug-eluting stent. *Congenit Heart Dis.* 2017 Sep 18. doi: 10.1111/chd.12537

Cory MJ, Ooi YK, Kelleman MS, Vincent RN, Kim DW, Petit CJ. Reintervention Is Associated With Improved Survival in Pediatric Patients With Pulmonary Vein Stenosis. *JACC Cardiovasc Interv.* 2017 Sep 11;10(17):1788-1798. doi: 10.1016/j.jcin.2017.05.052. Epub 2017 Aug 16.

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

Rachel Vanderlaan MD, PhD
Pulmonary Vein Stenosis Research Program
Hospital for Sick Children, Toronto