



## Advancing Research and Clinical Care for Children with Pulmonary Vein Stenosis

### Registry Update

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The retrospective study is open and collecting patient data!

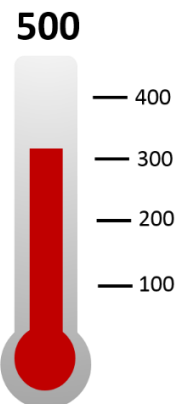
We have just over 300 patients registered in the study to date and are anticipating a total of 500 patients as the remaining institutions begin entering data.

We anticipate providing a preliminary update on the data at a meeting at AHA 2018 and anticipate closing the retrospective study data entry by December 2018.

Funding agreements will be going out shortly to help offset any costs incurred for participating in the study.

Thank you everyone for your support and collaboration!

#### PVS Registry Patients May 2018



### Institution Change

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It is business as usual at the PVS registry.

Dr. Christopher Caldarone has accepted the position as Chief of Congenital Heart Surgery at Texas Children's Hospital and Professor of Congenital Heart Surgery at Baylor College of Medicine. While we will definitely miss him at the Hospital for Sick Children, the registry will continue on at SickKids and the infrastructure will remain supported by internal and external funding.

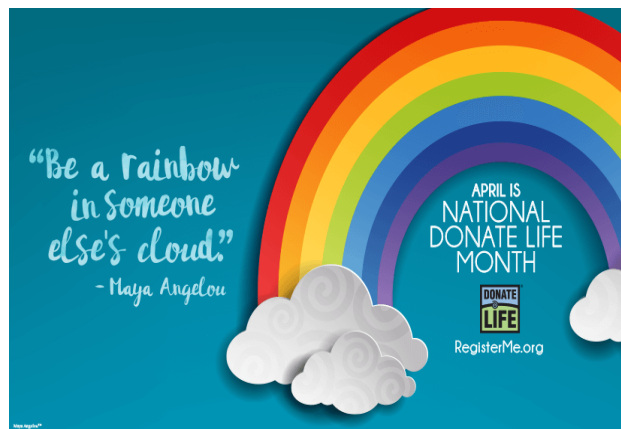
Dr. Caldarone will remain active in his role in the PVS Network here at Sickkids and we look forward to ongoing collaboration with his new role at Texas Children's Hospital

## The PVS Network Website: [www.pvsnetwork.org](http://www.pvsnetwork.org)

The website has been active for almost 1 year and we have already had over 10, 000 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 April image for 2018 highlights the role of lung transplantation and PVS  
**<http://www.pvsnetwork.org/donate-life-month.html>**



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

### **Successful T-Shirt Campaign!**

We ran a successful T-Shirt campaign for the month of March.

Proceeds will benefit PVS Network initiatives for parent education and advocacy.

Thank you for your support!



# Meetings and Presentations: Focus on PVS

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**11<sup>th</sup> 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**

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

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

**AHA Scientific Sessions**  
Nov 10-14, 2018

More info to come!

## Recently Published!

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Backes CH, Nealon E, Armstrong AK, Cua CL, Mitchell C, Krishnan U, Vanderlaan RD, Song MK, Viola N, Smith CV, McConnell PI, Rivera BK, Bridge J. Pulmonary Vein Stenosis in Infants: A Systematic Review, Meta-Analysis, and Meta-Regression. *J Pediatr*. 2018 Apr 9.

Callahan R, Kieran MW, Baird CW, Colan SD, Gauvreau K, Ireland CM, Marshall AC, Sena LM, Vargas SO, Jenkins KJ. Adjunct Targeted Biologic Inhibition Agents to Treat Aggressive Multivessel Intraluminal Pediatric Pulmonary Vein Stenosis. *J Pediatr*. 2018 Mar 23.

Kalfa D, Belli E, Bacha E, Lambert V, di Carlo D, Kostolny M, Nosal M, Horer J, Salminen J, Rubay J, Yemets I, Hazekamp M, Maruszewski B, Sarris G, Berggren H, Ebels T, Baser O, Lacour-Gayet F; European Congenital Heart Surgeons Association. Outcomes and prognostic factors for postsurgical pulmonary vein stenosis in the current era. *J Thorac Cardiovasc Surg*. 2018 Feb 23.

Tremblay C, Yoo SJ, Mertens L, Seed M, Jacques F, Slorach C, Vanderlaan R, Greenway S, Caldarone C, Coles J, Grosse-Wortmann L. Sutureless Versus Conventional Pulmonary Vein Repair: A Magnetic Resonance Pilot Study. *Ann Thorac Surg*. 2018 Apr;105(4):1248-1254

## Research Protocols Available

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### **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

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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

## Participating Institutions

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Hospital for Sick Children , Children's Hospital of Philadelphia, Cincinnati Children's Hospital, Denver Children's Hospital, Emory Children's Hospital, Stollery Children's Hospital, Children's Hospitals and Clinics of Minnesota, NY Presbyterian/ Morgan Stanley Children's Hospital, Primary Children's Medical Center at Utah, Nemours Children's Hospital, Seattle Children Hospital, Monroe Carell Jr. Children's Hospital at Vanderbilt, Texas Children's Hospital, Iowa Children's Hospital, Stanford Children's Hospital, Wisconsin Children's Hospital, Cleveland Clinic, Nationwide Children's Hospital, Boston Children's Hospital, Emory Children's Hospital, Nicklaus Children's Hospital and more to come.