



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

### 2019 Registry Update

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The retrospective study is still open and we are collecting patient data!

We have just over 400 patients registered in the study to date and are anticipating a total of 500 patients as the remaining institutions begin entering data.

We anticipate closing the retrospective study data entry by March 2019.

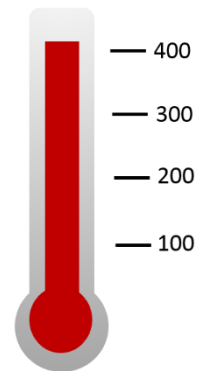
We will be verifying data entry and will contact research coordinators as we clean the data.

Thank you everyone for your support and collaboration!

#### PVS Registry Patients

Jan 2019

500



### PVS symposium

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We will be organizing a PVS mini-symposium for **Spring 2020**.

The symposium will be held in conjunction with the **13<sup>th</sup> Neonatal and Childhood Pulmonary Vascular Disease** in San Francisco.

We look forward to an exciting program that will highlight the work of the PVS community.

More info to come!

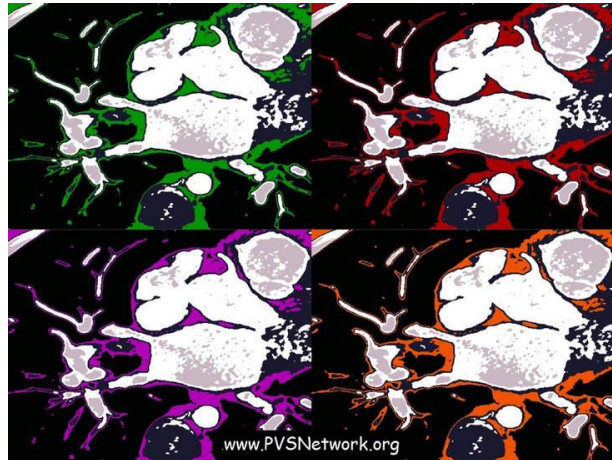
## The PVS Network Website: [www.pvsnetwork.org](http://www.pvsnetwork.org)

The website has been active for almost 1.5 year and with over 18, 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.

We recently posted a survey to obtain feedback about parent initiatives and updates for the website. Lots of great feedback and suggestions! We will be implementing suggestions over the next coming months once the survey closes.

### **Website activities to date:**

- Parent educational resources and illustrations
- Successful T shirt Campaign- Over \$ 1,400 raised towards parent advocacy and initiatives ( T shirts are still available using the link on the website)
- Successful social media awareness campaign - Over 8 images shared through social media



### **New initiatives 2019!**

- **Talking with the Experts**
  - We will be conducting video interviews on PVS relevant topics with experts across the country and posting them on the website
- **Faces of PVS Campaign**
  - This will be a new awareness campaign that highlights the PVS community

## Upcoming Meetings and Presentations:

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**12<sup>th</sup> Annual Neonatal and Childhood Pulmonary Vascular Disease**  
March 7-9, 2019

PH and premature lung disease focus

**AATS**  
May, 2019

More info to come

**AHA Scientific Sessions**  
Nov, 2019

More info to come

## Recently Published!

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DiLorenzo MP, Santo A, Rome JJ, Zhang H, Faerber JA, Mercer-Rosa L, Hopper RK. Pulmonary Vein Stenosis: Outcomes in Children with Congenital Heart Disease and Prematurity. *Semin Thorac Cardiovasc Surg.* 2018 Sep 29.

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 Jul;198:29-35

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 Jul;156(1):278-286.

## 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

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## 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.