



Advancing Research and Clinical Care for Children with Pulmonary Vein Stenosis

PVS Network Symposium: Save the Date!

The PVS Network Symposium will be held in conjunction with the **13th Neonatal and Childhood Pulmonary Vascular Disease** in San Francisco in the **Spring of 2020**.

We will have a one day symposium focused on PVS and highlighting all the great clinical care and research done by those in the PVS field. We will bring together experts to discuss strategies for surgical and catheter based interventions and discuss surveillance strategies.

This will also be an exciting time to build on the momentum and infrastructure of the retrospective registry and plan future prospective studies that will address existing knowledge gaps.

Goals of the Spring 2020 PVS Network Symposium

- Encourage multidisciplinary discussions focused on PVS management
- Highlight and debate strategies for PVS interventions
- Highlight and debate strategies for surveillance for disease recurrence
- Encourage discussion with pulmonary hypertension, neonatology and pulmonologists colleagues at the 13th Neonatal and Childhood Pulmonary Vascular Disease
- Establish priority prospective studies for the PVS Network

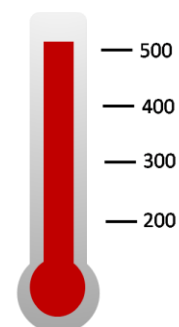
2019 Registry Update : 500!

The PVS Network Registry will wrap up in the fall of 2019.

We are busy abstracting data and verifying data

Thank you for everyone's dedication and collaboration

PVS Registry Patients March 2019



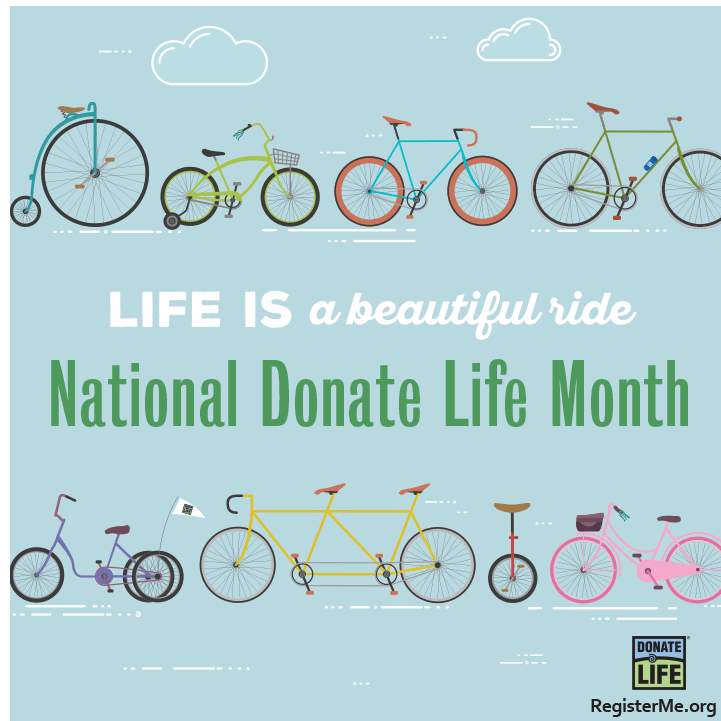
The PVS Network Website: www.pvsnetwork.org

The website has been active for almost 2 years! 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.

April is National Donate Life Month

Life is a beautiful ride

For the 2019 National Donate Life Month theme, Donate Life America was inspired by bicycles and the phrase “Life is a beautiful ride.” Like the donation and transplantation journey, a bicycle serves as a symbol of progress, renewal and the moving circle of life.



More at <https://www.donatelife.net/ndlm/>

Upcoming Meetings and Presentations:

PULMONARY VEIN SURGERY SESSION

Moderators: Christopher A. Caldarone /Glen Van Arsdell

Catheter-Based Intervention for Pulmonary Vein Stenosis
Ryan Callahan, Boston Children's Hospital

Surgical Video: Repair of Primary Pulmonary Vein Stenosis
(Premie)

Eric N. Feins, Boston Children's Hospital

AATS

May 4, 2019

11:15 AM - 12:30 PM

Scimitar Syndrome Repair Using the In Situ Pericardium
Rerouting Technique

Ignacio et al. Madrid, Spain

Decision Making and “How I Do It” for Scimitar Syndrome
Vladamiro L. Vida

Younger Age at Operation Is Associated with
Reinterventions Following the Warden Procedure

Ziyad M. et al. 1Texas Children's Hospital, Houston,

AHA Scientific Sessions

Nov, 2019

More info to come

Recently Published!

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. *SeminThoracCardiovasc 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 ThoracCardiovasc Surg.* 2018 Jul;156(1):278-286.

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 and biomarker projects

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

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.