



Advancing Research and Clinical Care for Children with Pulmonary Vein Stenosis

Pulmonary Vein Stenosis Network Symposium: March 5, 2020!

The 2nd Biannual Pulmonary Vein Stenosis (PVS) Network Symposium will be held on Thursday March 5th in conjunction with the **13th International Conference on Neonatal and Childhood Pulmonary Vascular Disease** in San Francisco on the **March 5-7, 2020**.

The PVS Network Symposium will bring together experts in the field to highlight current understanding of PVS, explore gaps in clinical knowledge and guide the development of consensus for practice strategies. We are looking forward to great multidisciplinary discussions!

Please tell your colleagues and trainees!

Overview of the agenda March 5th, 2020

Session 1: Pulmonary Vein Stenosis in the Ex-Premature Infant

Session 2: Surveillance and Medical Treatment of PVS

Session 3: Catheter Based Interventions

Session 4: Surgical Approaches

Registration and Agenda Link: <https://www.ucsfcmecme.com/2020/MPD20002/info.html>

2020 PVS Network Workshop

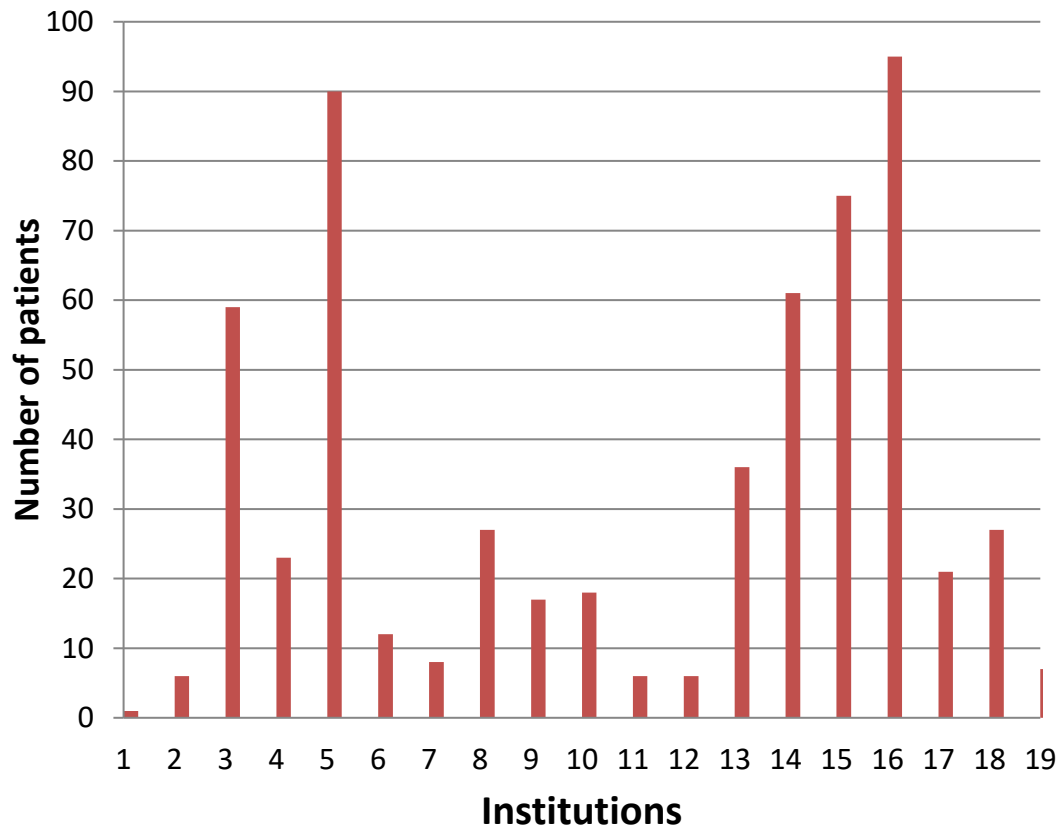
A PVS Network Workshop will be held for PVS Network members to help have focus discussions building on the momentum of the PVS Symposium. The workshop and dinner will be held on Thursday March 5th, 2020 at 7pm. It will be a great night of socializing and productivity!

We will identify knowledge gaps and priorities from the PVS Network Symposium sessions and focus discussions around clinical surveillance protocols, PVS teams, and catheter and surgical options. A survey will be sent at the end of the symposium allowing participants to sign up for various PVS Network working groups to help move clinical priorities forward.

More details regarding the workshop will come in a separate email!

The PVS Network 2020 Registry Update

The retrospective registry is closed to new patients and is in the data verification phase. We have **over 640 patients** registered! Thank you to everyone who has contributed. We are always thankful to the Warren Family for their donation and making this possible!



Meet Crystal Tran!

Crystal is the PVS Network Research Coordinator who has been a tremendous help with data extraction and general administration of the REDCap database.

She can be reached at crystal.tran@sickkids.ca



Upcoming Meetings and Presentations:

13th Neonatal and Childhood Pulmonary Vascular Disease, San Francisco, March 5-7, 2020

<https://www.ucsfcmecme.com/2020/MPD20002/info.html>

PVS Network Symposium March 5

SCAI Scientific Session, Atlanta, May 13-16, 2020

Children's Healthcare of Atlanta - Pulmonary Vein Stenosis Symposium, Atlanta, October 8-9, 2020

PVS session May 16 8:00am

PVS Symposium Oct 8-9

Recently Published!

Barrera CA, Saul D, Rapp JB, Smith CL, White AM, Biko DM, Otero HJ. Diagnostic performance of CT angiography to detect pulmonary vein stenosis in children. *Int J Cardiovasc Imaging*. 2020 Jan;36(1):141-147.

Callahan R, Esch JJ, Wang G, Ireland CM, Gauvreau K, Jenkins KJ. Systemic Sirolimus to Prevent In-Stent Stenosis in Pediatric Pulmonary Vein Stenosis. *Pediatr Cardiol*. 2019 Nov 12.

Vanderlaan RD, Honjo O. Commentary: It takes a village: changing the trajectory of pulmonary vein stenosis outcomes. *J Thorac Cardiovasc Surg*. 2019 Oct 3. pii: S0022-5223(19)32113-0.

Rosenblum JM, Altin HF, Gillespie SE, Bauser-Heaton H, Kanter KA, Sinha R, Cory M, Alsoufi B. Management outcomes of primary pulmonary vein stenosis. *J Thorac Cardiovasc Surg*. 2019 Sep 25. pii: S0022-5223(19)31910-5.

van Duin RWB, Stam K, Uitterdijk A, Bartelds B, Danser AHJ, Reiss IKM, Duncker DJ, Merkus D. Intervening with the Nitric Oxide Pathway to Alleviate Pulmonary Hypertension in Pulmonary Vein Stenosis. *J Clin Med*. 2019 Aug 12;8(8). pii: E1204.

Kurita Y, Baba K, Kondo M, Eitoku T, Kasahara S, Iwasaki T, Ohtsuki S, Tsukahara H. Clinical outcomes after the endovascular treatments of pulmonary vein stenosis in patients with congenital heart disease. *Cardiol Young*. 2019 Aug;29(8):1057-1065.

Khan A, Qureshi AM, Justino H. Comparison of drug eluting versus bare metal stents for pulmonary vein stenosis in childhood. *Catheter Cardiovasc Interv*. 2019 Aug 1;94(2):233-242.

Nasr VG, Callahan R, Wichner Z, Odegard KC, DiNardo JA. Intraluminal Pulmonary Vein Stenosis in Children: A "New" Lesion. *Anesth Analg*. 2019 Jul;129(1):27-40.

Alsoufi B. Cracking the Mystery of Pulmonary Vein Stenosis. Semin Thorac Cardiovasc Surg. 2019 Summer;31(2):274-276.

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. 2019 Summer;31(2):266-273.

Kirkpatrick EC, Mitchell ME, Thilly WG, Hidestrand P, Tomita-Mitchell A, Hidestrand M, Gostjeva EV. Metakaryotic cells linked to pediatric pulmonary vein stenosis. Cardiovasc Pathol. 2019 Mar - Apr;39:51-53.

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, Texas Children's Hospital, Denver Children's Hospital, Children's Hospital of Philadelphia, Cincinnati 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, Iowa 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.