

UPCOMING EVENTS

FEBRUARY 11

Nick and Kelly Family Day Heart Talk
Phoenix Zoo
8:00 a.m. – 12:30 p.m.

FEBRUARY 21 / MARCH 21 / APRIL 18

Mended Little Hearts of Phoenix monthly family support meeting in the Melvin L. Cohen Conference Center
6:30 to 8:30 p.m.

FEBRUARY 21 / MARCH 21 / APRIL 18

HCFAC Meeting
4:30 – 6:30 pm

FEBRUARY 21 / MARCH 21 / APRIL 18

HCFAC Meet and Greet in the CVICU Family Lounge (5th floor).
If your child is currently inpatient, please join us.
3:30 – 4:15 p.m.

MARCH 4

22Q Parent Symposium
22Q Deletion Syndrome: Navigating the Journey
8:00 am to 12:00 pm

APRIL 4

Transplant Families resource fair– Enjoy food, drinks, resources and special speakers.
5:30 to 7:30 pm

MONTHLY

Young Adults with CHD support group.
Contact Becca Atherton for more information (489) 353-9381.

What is the HCFAC?

The Heart Center Family Advisory Council (HCFAC) was formed in June 2013. The council members act as a consultative and advisory resource to Phoenix Children's Hospital Heart Center leadership and staff. The council promotes the core concepts of family-centered care: dignity and respect; information sharing; participation; and collaboration.

Who are they?

The Council is comprised of 8 to 16 family members that apply, are interviewed and have membership voted upon. Each member serves a two-year term. We are always looking for new members. If you believe that you would like to give back by joining the Council, we encourage you to apply by [completing an application](#) and submitting it to fac@phoenixchildrens.com.

Meeting Notes

2016 Goals —

Family

- Understand support provided for prenatally and inpatient parents on their transition home
- Help establish a protocol for transitional care for Heart Center patients reaching adulthood
- Assist in developing committee for long term follow up of single ventricle patients

Education

- Develop Cardiac passport for heart families
- Provide education and lactation support for breastfeeding moms

Communication

- Assist in making resources available.
- Improve communications with heart community via outreach events and print communication

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Letter from our Council

Welcome to the Phoenix Children's Heart Center Newsletter presented by the Heart Center Family Advisory Council. We have set several new goals for 2017 focusing on communication, community connection, and transition/follow-up care. We're looking forward to working on these goals to make a better experience for all!

Brittany Johnson, Heart Center Family Advisory Council Chair

Meeting Notes

continued...

November - Our guest was Jason Grabham- who is the manager of integrated non-invasive cardiology. Jason runs the clinic for echos and EKGs for the heart center. This is an invaluable service that most of kids utilize on a regular basis. He has 26 years' experience in the cardiology field. There are 19 sonographers in the echo department. He believes in creating relationships with patients and families. We were grateful to get an inside peek into a department so many of us see on many of our kids' cardiac visits.

We were also privileged to welcome Dr. Karamlou and Dr. Nigro speak on possibilities for a future single ventricle clinic. PCH is one of the 8 three star programs with a 5% mortality rate.

Talked about ways that we can maximize HLHS survival at PCH and what we can do to help improve outcomes. Want to set up a Dedicated HLHS Clinic that focuses on a "one stop shop" clinic to help families.

PCH wants to use Precision-Medicine for Hypoplasts. First step is gathering data of our own patients. PCH plan is to create a formula for thriving and not just surviving of its patients.

We need a way that parents, families and the community can be plugged in. Dr. Nigro thinks that the cardiologists need to hear this need from families. His idea is to create a virtual clinic.

Dr. Nigro does think that it is important and critical to add psychological and social supports to the multi-disciplinary clinic.

December – All FAC Christmas meeting with year-end updates. CEO Robert Meyer was keynote speaker.

January - We are happy to welcome our new HCFAC members: Angel Olvera, Carie Semenko, Elias Bailey, Jessica Jones and Kisor Coulson. We are also happy to welcome returning members Brittany Johnson, Brittney Beus, Carrie Arranda, Irene Belezair, Melissa McQueen and Tricia Zimmerman. This was a meeting to review 2016 goals and form 2017 goals.

Recent Events

All the Family Advisory Councils closed out their 2016 year end with a special presentation from CEO Robert Meyer.



We are currently building an educational library of webinars for our families. You can currently learn about "Basic Cardiac Care in the CVICU" and "How Cardiac Catheterization Works and How It Can Help My Child" on the Phoenix Children's Hospital at YouTube channel

www.youtube.com/user/PhxChildrensHospital. We hope it's helpful and informative for our families and patients.

Acknowledgements

A Fond Farewell to Dr. John Nigro

How do you thank a man who has contributed so much to saving the lives of our children? There are never really enough words. We say a fond farewell to our dear surgeon and Co-Director of the Phoenix Children's Heart Center as he embarks on this new opportunity as the Director of the Heart Center at Rady Children's Hospital. The PCH Heart Family wishes Dr. Nigro and his family all the best on their new ventures!

Welcoming Dr. Daniel Velez into his new role as Division Chief of Cardiac Surgery

Over the last five years Dr. Velez has been an invaluable asset to the success and wonderful outcomes for our heart kids at Phoenix Children's Hospital. We are delighted to have the continued opportunity to work with a surgeon of Dr. Velez's talents both in the operating room and his sincere, and heartfelt spirit making every patient the top priority. Phoenix Children's Hospital is excited to welcome Dr. Velez into his new role within PCH as the Division Chief of Cardiac Surgery.

How to Become a Council Member

Now through November the Heart Center Family Advisory Council (HCFAC) will be recruiting new members. We are always looking for parents or guardians to help us strengthen our community and resources.

Please apply today by emailing fac@phoenixchildrens.com and requesting an application or by speaking with a current FAC member. We look forward to meeting you.

Questions? Comments?

If you have any questions or comments or have an event that you would like to see listed here, please contact us at fac@phoenixchildrens.com.