

UPCOMING EVENTS

MAY 2 / JUNE 6 / JULY 11

HCFAC Meeting
4:30 – 6:30 pm

MAY 2 / JUNE 6 / JULY 11

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.

MAY 4

Heterotaxy Awareness Day

MAY 6 - 12

Nurses Week

MAY 15 / JUNE 13 / JULY 11

Mended Little Hearts of Phoenix monthly family support meeting in the Melvin L. Cohen Conference Center
6:30 to 8:00 p.m.

MAY 16

Heart Effect - Information session: The next step towards patient empowerment
Heart Center Lobby
6:00 to 8:00 p.m.

JULY 24 – 28

Nick and Kelly Heart Fund Camp
Camp Friendly Pines in Prescott, AZ

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

2017 Goals —

Communication

- Develop a parent guide for common procedures in CVICU.
- Translate all newsletters to Spanish.
- Community education of state resources.
- Continue Web education.

Community Connection

- Expand the Meet & Greet including bedside and 9th floor.
- Create a committee to obtain and serve monthly dinner donations for inpatient families.
- Collaborate with community partners, especially for event information.

Transition/Follow-up Care

- Address community billing concerns.
- Address community portal concerns.
- Transition to adult care protocol
 - Develop a survey for families to get input on concerns and needs of this group of patients to help the hospital develop this protocol with multiple other institutions.
- Develop a committee for Single Ventricle Long Term Follow Up.

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Letter from our Council

So glad you picked up Heart Center News! In this edition, you'll find our Heart Center Family Advisory (HCFAC) goals for 2017. We've already started working on some of them and are thrilled about the progress. If you have any comments, questions, or suggestions, feel free to email us at fac@phoenixchildrens.com. We love to hear from you!

Brittany Johnson, Heart Center Family Advisory Council Chair

Meeting Notes

continued...

February - This was our second council meeting. We were able to finalize our 2017 goals. They are listed on the other side of this page.

We also talked about what the top things that impacted our stay while we were inpatient.

March – We welcomed Andrea Cabrera from the IT department to help explain and take feedback for Phoenix Children’s patient portal called Follow my Health.

FollowMyHealth™ is PCH’s Patient Portal to manage your child’s personal medical records with 24/7 secure online access from any computer, smartphone or tablet. Kids ages 13 and above can also access their own health records and use all of the tools available in FollowMyHealth.

You can get more information on access through the website <http://www.phoenixchildrens.org/patient-s-visitors/during-your-stay/electronic-health-records-patient-portal>

We also had our first Facebook live Heart talk this month featuring 504 and IEP planning for heart kids. You can watch this at your convenience on the Phoenix Children’s Hospital Facebook site under *Complex kids and education*.

April – Our guest was Tom Wright, Manager of Pharmacy Operations.

We were also pleased to welcome back Dr. Tara Karamlou to discuss updates to recent research being conducted.

Heart Effect Chair, Stephanie Starks and Co-Chair Erica Endicott were also our guests. They shared their mission of supporting the lifesaving work, research and technology of the Phoenix Children’s Heart Center and Cardiac 3D Print Lab.

They came to share a project they are working on with the PCHA who is creating a public portal to promote transparency and patient empowerment. Please watch the Facebook live under *Making Heart Families Their Own Best Advocates* at your convenience.

Recent Events

We were thrilled to be a part of Heart Talk at the Zoo hosted by the Nick and Kelly Children’s Heart Fund.



We are currently building an educational library of webinars for our families. You can currently learn about *3D Print Lab, Basic Cardiac Care in the CVICU, How Cardiac Catheterization Works and How It Can Help My Child* and many other topics.

View these 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.

Save the Date

Heart Effect would cordially like to invite you to join them for *Information session: The next step towards patient empowerment* as we discuss the life-changing research being done at Phoenix Children's Hospital with special guests from the Pediatric Congenital Heart Association and Thoracic Surgeon and Research Scientist from Phoenix Children's, Dr. Tara Karamlou. Refreshments and hors d'oeuvres will be served along with the opportunity to meet with members of Heart Effect. Please register with Event Brite (<https://www.eventbrite.com/e/heart-effect-information-session-tickets-34341967750>).

Nick and Kelly Heart Fund is holding camp exclusively for heart kids in Arizona. Registration for our Heart Camp is now open and can be found at CampDoc (<https://app.campdoc.com/#!/home/auth/email>). Heart Camp is scheduled for July 24-28, 2017 and takes place at Camp Friendly Pines in Prescott, AZ.

Mended Little Hearts (MLH) of Phoenix has monthly family support meetings the second Tuesday of every month from 6:30 - 8:00 p.m. in the Melvin L. Cohen Conference Center.

MLH of Phoenix members are invited the second Saturday of every month to visit The Halle Heart Children's Museum in Tempe and receive free admission!

Young adults with CHD group is being hosted by Becca Atherton. You must be over 18 and no longer a camper with Nick and Kelly to attend. Please RSVP at 480-353-9381 with Becca.

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.