

Upcoming Events

AUGUST 9 / SEPTEMBER 13

Mended Little Hearts of Phoenix monthly family support meeting in the Melvin L. Cohen Conference Center

6:30 – 8:30 p.m.

AUGUST 16 / SEPTEMBER 20 / OCTOBER 18

HCFAC Meeting

4:30 – 6:30 pm

AUGUST 16 / SEPTEMBER 20 / OCTOBER 18

HCFAC Meet and Greet in the CVICU Family Lounge (5th floor). If your child is currently inpatient, please join us for light refreshments and snacks

3:30 – 4:15 p.m.

SEPTEMBER 17

Mended Little Hearts Calendar Photography

OCTOBER 10

CPR/ First Aid Training at the Halle Heart Museum
10 a.m. – Noon

OCTOBER 18

Mended Little Hearts of Phoenix Halloween Party – Wear a costume. Enjoy food, drinks and activities in the Melvin L. Cohen Conference Center,
6:30 – 8:30 pm

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 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 first Phoenix Children's Heart Center Newsletter presented by the Heart Center Family Advisory Council. We are very excited to be able to bring you the latest events and news in the Heart Center in order to better connect with our community. I hope to see you at a local event.

Courtney Johnson, Heart Center Family Advisory Council Chair

Meeting Notes

continued...

Our Council meets monthly on the third Tuesday of every month between 4:30 and 6:30 p.m.

Meeting summaries for last four months.

March - Our guests were Dan and Margaret from the Nick and Kelly Heart Fund who spoke on the many benefits their organization provides the heart community, including but not limited to, Heart Camp and Family Day Heart Talk.

We also hosted Cindy Huie from the Adult Congenital Heart Association (ACHA) who discussed transitioning from youth to adult care for our teens. Please contact these amazing groups to find out more: Nick and Kelly Heart Fund (nickandkellyfund.org/) and ACHA (achaheart.org).

April – Our guests were from lactation support. They have a L.A.M.B. (Lactation Assistance for Mothers and Babies) team – a group of nurses committed to help any mother that wants or needs help. They were assisted by nutritionists to help us understand the balance required by our cardiac kids. Please contact the Lactation Consultants for more information at (602) 546-1937.

May-Wendell Fortenberry (Director of Care Management) spoke to us about case management and social work in the CVICU. Care management assists families from hospital to home with all the contacts, supplies and information they need. Social work helps with inpatient families to cope and care for their child. We were happy to hear these services are available. Pamphlets describing services will be available to all families staying in the CVICU over 72 hours.

June – Russ Anderson (Patient Services Consultant) came to speak with us about his new position and how he is able to support families if they need to talk about their care and any needs or concerns.

We completed a 'Cardiac Passport' for families. This passport would be a compact piece of paper that would describe your child's heart defect and other critical information that would be presented upon entry to the emergency department. More information to come.



Hosting dinner to families in the CVICU.

Save the Date

Mended Little Hearts (MLH) of Phoenix has monthly family support meetings the second Tuesday of every month from 6:30 – 8:30 p.m. in the Melvin L. Cohen Conference Center. The conference room is located in the Rosenberg Building behind the Phoenix Children's Hospital main building. Kids are always invited to do crafts and activities, and parents have a chance to win a door prize!

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!

Go to mendedlittleheartsofphx.org or like us on Facebook to get more information and added monthly events.

Check the Family Advisory Calendar for the latest events at phoenixchildrens.org/patients-visitors/during-your-stay/family-advisory-council/ heart-center.

Recent Events

In February, Family Day Heart Talk was a huge success thanks in part to all of the staff that volunteered their time, the Nick and Kelly Heart Fund for putting it all together, the Phoenix Zoo for hosting and especially the families that attended. We appreciate that our community requests continuing education to keep up on cardiology trends for their children.

In March, the 22q Symposium: Management of 22q syndrome was held. This was a free community event for families and caregivers of people with 22q deletion. It was a half day program that provided information on health issues commonly associated with 22q.

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

How to Become a Council Member

Now through November the Heart Center Family Advisory Council 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.

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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.