

UPCOMING EVENTS

**SEPTEMBER 5 / OCTOBER 3 /
NOVEMBER 7**

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.

HCFAC Meeting

4:30 – 6:30 pm

**SEPTEMBER 12 / OCTOBER 10 /
NOVEMBER 14**

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

Cohen Conference Center

6:30 to 7:45 p.m.

OCTOBER 14

Mended Little Hearts of Phoenix Annual Halloween Party in the Melvin L. Cohen Conference Center

Cohen Conference Center

3:30 to 6:30 p.m.

OCTOBER 20 - 22

NPC-QIC Fall 2017 Learning Session

Some sessions will be live streamed via

Sisters by Heart Facebook site

NOVEMBER 5

Congenital Heart Walk

Tempe Diablo Stadium

Registration begins

9:00 am

Walk begins

10:00 am

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

It's hard to believe the year is more than half over - 2017 has gone by so quickly! But the Heart Center Family Advisory Council (HCFAC) has been working diligently on our goals this year. We're excited about the progress made and look forward to addressing the remaining goals in the coming months. Thank you for staying connected with us. We welcome your questions, comments and suggestions at fac@phoenixchildrens.com

Brittany Johnson, Heart Center Family Advisory Council Chair

Meeting Notes

continued...

May - We welcomed Jessica Cetro, Child Life Specialist from the CVICU. She outlined a developmental committee, which is one of the projects she is working on. They would create a way to document milestones for the inpatient children. Jessica also gathered feedback on the Beads of Courage program. We also saw progress of a procedure guide that is being developed for families in the CVICU.

June - Andrea Cabrera, from the IT department returned with continued updates regarding FollowMyHealth Patient Portal. She explained that inaccurate cancellation notifications will be disabled to minimize confusion. We were then introduced to Dr. McLaughlin, a fetal cardiologist, who showed us a learning tool she is currently working on. This tool is an Introduction Guide for Prenatally-Diagnosed Families. When completed, it will be given to families who are diagnosed prenatally, to serve as a reference during their hospital experience.

July - We received another update from Andrea Cabrera who outlined the logo update for FollowMyHealth. We welcomed Leon Goe, the new Executive Director of the Heart Center. He introduced himself and shared his vision in strategic planning for the Heart Center. And we worked on updates to the Parent-to-Parent guide for families in the CVICU.

August - Esther Munoz from Infection Prevention and Control gave a presentation on the history of visitor restrictions and she gathered feedback regarding the topic. We also heard that this HCFAC newsletter has been translated into Spanish and we brainstormed locations of new white boards for CVICU patient rooms. Andrea Cabrera continued sharing updates on FollowMyHealth and gathered feedback from users. There has been an increase in the volume of patients connected to the Patient Portal in recent months.

Save the Date

Save the date for The Congenital Heart Walk on November 5th, which is an ongoing national effort between the Adult Congenital Heart Association (ACHA) and The Children's Heart Foundation (CHF). We walk to honor and remember the millions who have been impacted by congenital heart disease (CHD). Funds raised will support the missions of both national nonprofit organizations who are uniting to fight CHD! Since 2010, CHW has raised more than \$8 million in total. Register your team today (http://events.congenitalheartwalk.org/site/TR?fr_id=1731&pg=entry).

Make sure not to miss Mended Little Hearts (MLH) of Phoenix annual Halloween Party on October 14th in the Cohen Conference Room from 3:30pm - 6:30pm, hosted by Rosita's Fine Mexican Food in Tempe.

MLH of Phoenix members are also 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.

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

Recent Events

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.

We have also done several Facebook live events. One featuring a collaborative effort with Raising Special Kids on the topic of 504's and IEPs to help your heart child be prepared for school. Check out the many resources from Raising Special Kids ranging from education plans for your heart child to how to support positive behavior (<http://m.raisingpecialkids.org/events-training>)

View our educational library 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.

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.