

UPCOMING EVENTS

NOVEMBER 6 –

- Congenital Heart Walk
- Tempe Diablo Stadium
- 7:30 – 11:30 a.m.

NOVEMBER 8 –

- Mended Little Hearts of Phoenix Monthly Family Support Meeting
- Melvin L. Cohen Conf. Center
- 6:30 – 8:30 p.m.

NOVEMBER 15 / JANUARY 17 –

- HCFAC Meeting
- PCH, 2nd Floor, Conf. Room 22110
- 4:30 – 6:30 p.m.

NOVEMBER 15 / JANUARY 17 –

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

DECEMBER 7 –

- Heart Transplant Holiday Party
- Heart Center Lobby (2nd floor)
- Enjoy food, drinks and activities
- 6:30 – 8:30 p.m.

DECEMBER 10 –

- Mended Little Hearts Annual Holiday Party
- Atherton Residence
- 1:00 – 4:00 p.m.

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 prenatal 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

July – Our guests were the Fetal Program team which includes Dr. Lindblade, Lynn Litwinowich, RN and Shelley Akey, NP.

The Fetal Program team explained the current process to help newly diagnosed cardiac families. Initially they meet with families to explain the diagnosis and answer any initial questions. Then they develop a management strategy with these cardiac families. Families are offered a tour of the CVICU and eventually speak with their surgeon as part of the management plan. Social services are available if requested as a psychological support to the family during this time.

You can get more information about this program at their website at: <http://www.phoenixchildrens.org/medical-specialties/fetal>.

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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 are very excited to be able to bring you the latest events and news in the Phoenix Children's Heart Center in order to better connect our community. I hope to see you at a local event.

Courtney Johnson, Heart Center Family Advisory Council Chair

Meeting Notes

continued...

August – We invited Co-Director of the Phoenix Children’s Heart Center, Dr. Mitch Cohen (pictured on right) to present the *Heart Center Annual Report*. Every year this report is published to share rates and clinical outcomes of our heart center and compare them to other centers around the country. This publication is sent to local pediatricians and cardiologists around the country. If you would like to see this comprehensive guide for yourself, it is available electronically from the Phoenix Children’s Heart Center page at <http://heart.phoenixchildrens.org/newsletters-and-annual-reports>.

September – Our guest was LovelIAM founder Daradee Murray. Her organization raises money for the Nick and Kelly Heart Fund to help send our cardiac kids to camp, and to host Family Day at the Zoo. You can find more information on their website at <http://www.loveiam.org>.

October – Our guest was Dr. Tabitha Moe (pictured on right) who spoke on transition from pediatric to adult congenital cardiac care. She shared some resources that will be incredibly helpful for families about to make this change in care. These resources can be found at <https://iheartchange.org/> and <https://www.achaheart.org/> (website for the Adult Congenital Heart Association).



Mitchell Cohen, MD



Hosting dinner for families in CVICU.



Tabitha Moe, MD

Save the Date

Holiday parties are coming soon! Please save the date for the 5th Annual Heart Transplant Holiday Party on Wednesday, December 7. RSVP to Susan Park at (602) 933-0270. Also save the date for the Mended Little Hearts Annual Christmas party on December 10 from 1:00 – 4:00 p.m., hosted by the Atherton’s.

Mended Little Hearts 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. Mended Little Hearts of Phoenix members are invited on 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 are being hosted by Becca Atherton. You must be over 18 and no longer a camper with Nick and Kelly to attend. 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.

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.

Recent Events

We received a generous donation from Mad Greens and Corleone’s to help feed our families with an amazing dinner in the CVICU for a night.



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 YouTube channel at 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.

To sign up to receive this e-newsletter, send an email to fac@phoenixchildrens.com