

In This Issue: Donate Life Month, Recruitment Updates & Much More!



HEART - to - HEART



Welcome to Volume 2 of Heart-to-Heart

Our official, quarterly e-newsletter is a partnership between the Phoenix Children's Heart Center and the Heart Center Family Advisory Council (HCFAC).

This newsletter offers the most up-to-date news from both groups.

Hospital Happenings

Heart Talk at the Zoo

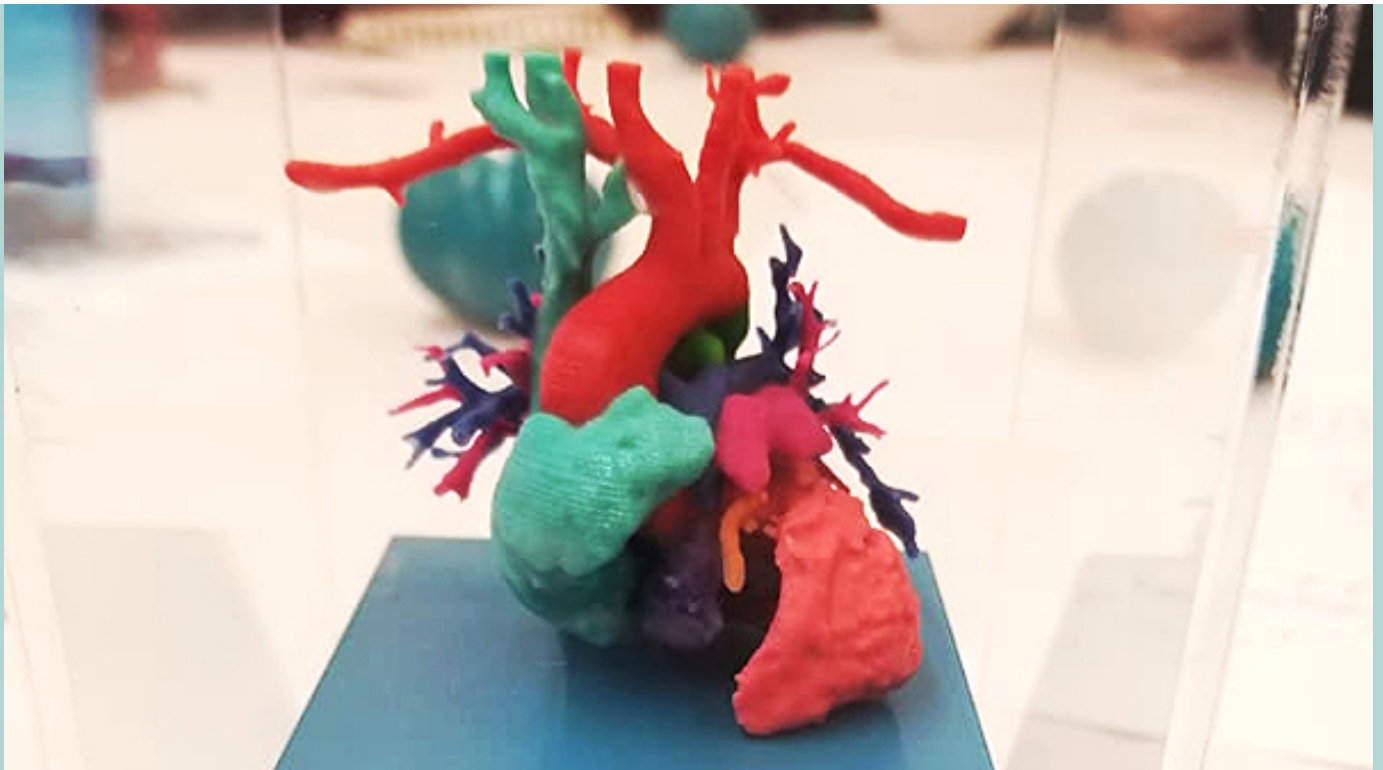
We received a lot of positive feedback from our recent Heart Talk at the Zoo day! We are working with Heart Effect on the next event and taking all your great suggestions into

consideration. Stay tuned for more developments!

Check out some of the pictures below from the 2018 event!







2018 CHOP Conference Faculty Dinner

We had a great time hosting the CHOP (Children's Hospital of Philadelphia) conference in February. Here are some photos from the event!

Top Photo (left to right): [Susan Park, NP](#); [Todd Nowlen, MD](#); Leon Goe, PhD – Executive Director, Heart Center; [Daniel A. Velez, MD](#), Chief, Cardiovascular Surgery and [Joe Graziano, MD](#), Chief, Cardiology

Bottom Photo (left to right): [Orlando Delgado, PA](#), [Ed Rhee, MD](#), [Andrew Papez, MD](#), [BJ Large, NP](#), [Stephanie Culver, NP](#), [Rob Puntel, MD](#), [Courtney Howell, NP](#)

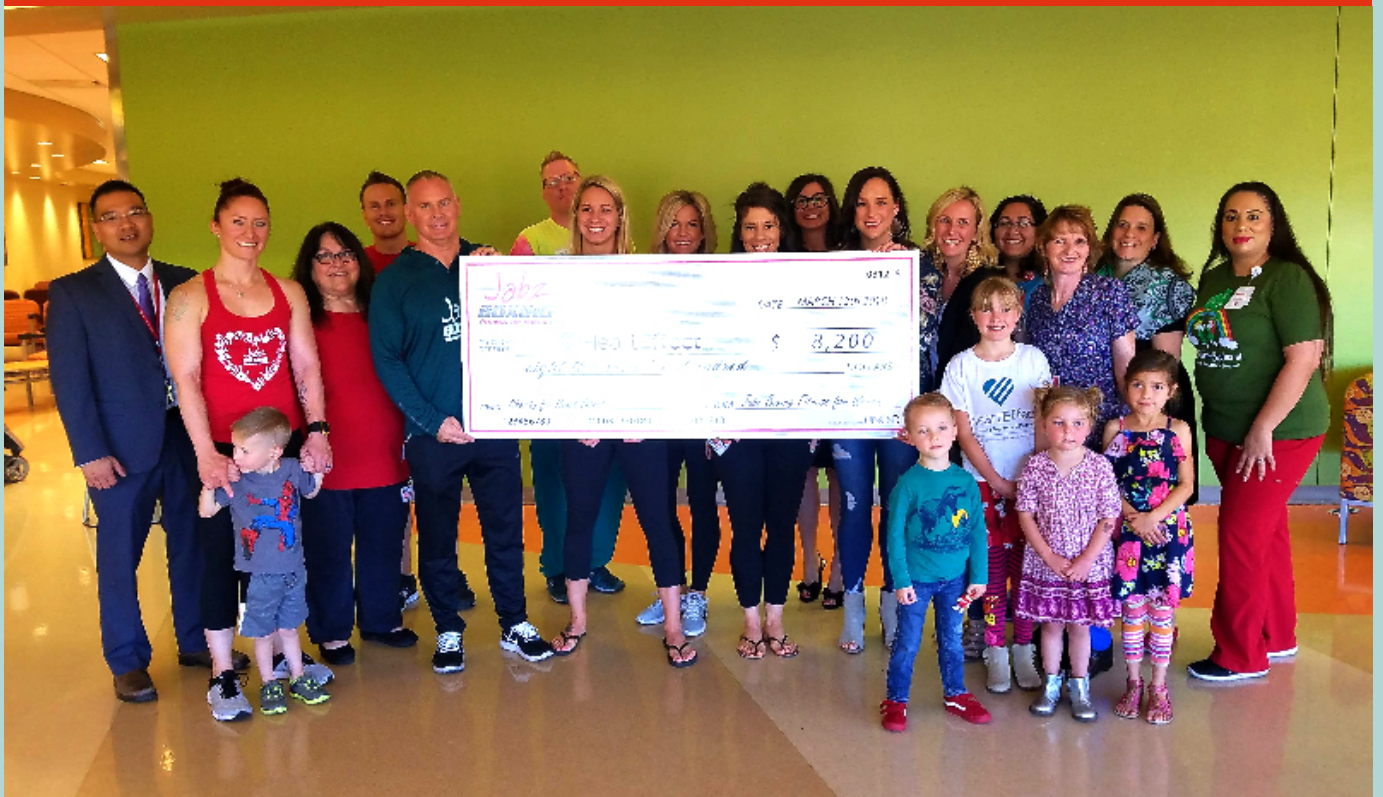


Knocking Out Heart Defects

[JABZ](#), boxing fitness for women, presented [Heart Effect](#) and Phoenix Children's Heart Center a check for \$8,200!

JABZ loves to be involved in the Arizona community and is especially passionate about helping kids. They jumped at the opportunity to host a charity class/fundraiser to benefit Phoenix Children's!

Learn more about [Heart Effect](#).



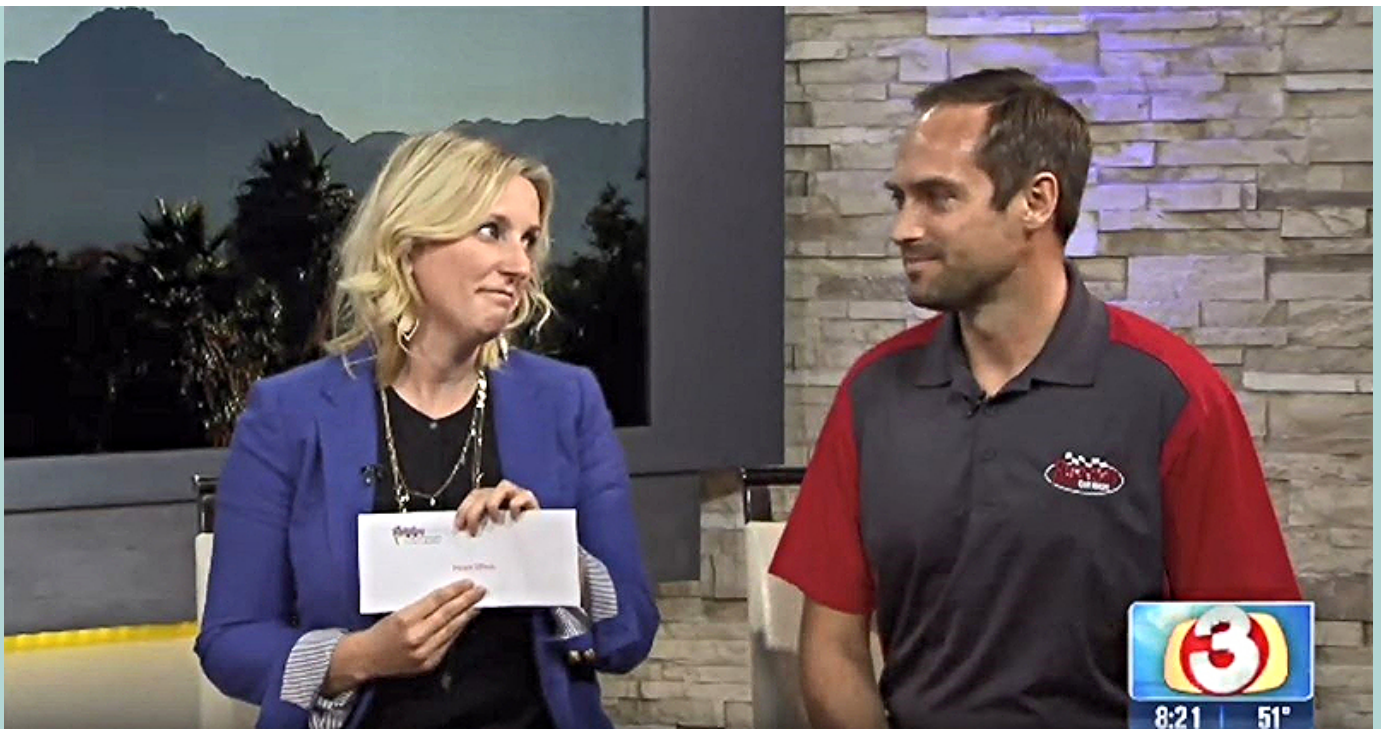
Raceway Cares

Thank you, [Raceway](#), for your generous \$10,000 donation!

"It's the obvious opportunity to do good. Saving lives clearly matters, and we want to be a company that matters," said Tim Barrett, Managing Director of Raceway.

"We exist to contribute to the flourishing of our team members and the communities in which our stores exist. Our support of [Heart Effect](#) and Phoenix Children's Hospital Heart Center allows us to do that. We wash cars, but more than that, we believe we have the privilege to lead; to lead our team members to be better, to lead our industry to be better and to lead our communities to be better. Washing cars is simply the means by which we are privileged to have this great opportunity."

Watch their heartfelt interview here: <https://youtu.be/IHaKCybFYv8>



Wedding Bells at Phoenix Children's

Amazing things are always happening at Phoenix Children's!

Phoenix Children's hosted a special wedding ceremony for the parents of a child who recently received a heart transplant and was unable to make it to his mom's wedding.

This change in venue allowed him to walk his mother down the aisle, making for a very special day!

Get our your tissues and watch the news story [here](#).



Recruitment Updates

program.

For our **Adult Congenital Program**, we are in the final stages with a high-level candidate that we are very interested in recruiting.

Finally, we have successfully recruited a **Director of Cardiac Exercise Physiology** who'll be joining us this summer from a top 10-ranked pediatric cardiac program.

Stay tuned for more details and an official announcements soon!

We received interest from more than 10 qualified **cardiac surgeons** from across the country and have extended offers to two; both of whom have signed letters of intent to join Phoenix Children's. We are excited to add these nationally recognized cardiac surgeons to our



National Donate Life Month

April was National [Donate Life Month](#)! We are proud to participate in this initiative and to help the community understand the importance of organ donation.

- In 2017, Phoenix Children's completed 14 heart transplants. This is the 6th most in the nation.
- Since the beginning of our program in 2011, to the end of 2017, we have completed 80 heart transplants.
- We are one of 54 heart transplant programs to perform *at least* one pediatric heart transplant in 2017.
- Between July 2015 to June 2017, 84.6% of Phoenix Children's patients received a transplant within one year, compared to the national rate of 53.9%.

Meet Our Talented Team

#KidsTransplantWeek Recap

Nearly 2,000 children under the age of 18 are on the U.S. organ transplant waiting list, and 25% are children between 1 to 5 years old. Due to the need for greater awareness, Transplant Families worked with Children's Cardiomyopathy Foundation, Donate Life America and several other transplant organizations to introduce the first annual **National Pediatric Transplant Week** held April 23-27.



In support of this, on Saturday, April 21st, Phoenix Children's Hospital and Transplant Families hosted a Resource Fair Keynote, **Building Resiliency Through Your Child's Transplant Journey** with speaker Dr. Brenda Aranda, Ph.D, Director, Cardiology Behavioral Medicine Cardiology Department at Phoenix Children's Hospital and Assistant Professor, Child Health University of Arizona College of Medicine. Keep an eye out for it on our social

media profiles!

Mechanical Assist Device News

It's been a busy year for the Transplant and Heart Failure team. We have reached new milestones in the mechanical Assist Device Area. Our surgical team has implanted 7

mechanical assist devices of different types throughout 2017. Of note, we have supported a child with a Berlin Heart for 9 months, longest run in the state. She is also listed for the first dual organ transplant in the history of AZ. We also implanted the first Bi-ventricular Assist Device with Berlin Hearts and the patient was bridged to transplant successfully in mid April and is recovering very well.

Phoenix Children's Hospital has the only program in the state with a Comprehensive Heart Transplant program that provides the whole range of Services including advanced Mechanical Assist Device support.



ACGME Cardiology Fellowship Update

We've moved past the first phase of approvals and onto the formal application for the program. Stay tuned for more news in the next Heart-to-Heart!



The 9th [Phoenix Fetal Cardiology Symposium](http://fetalcardio.com) is a four-day conference discussing important concepts in congenital heart disease and the most recent advances in imaging, diagnosis and management of fetal cardiac abnormalities.

This symposium has been designed for physicians including pediatric cardiologists, maternal fetal medicine specialists, obstetricians, neonatologists, radiologists, geneticists as

well as sonographers, nurses, and other paramedical colleagues and trainees.

Phoenix Children's is proud to host and provide this nationally recognized, educational conference to better patient care, right here in Arizona!



This section spotlights our Heart Center Family Advisory Council (HCFAC), a group of selected family members dedicated to improving Phoenix Children's.

2018 Heart Center Family Advisory Council

Introducing your 2018 Heart Center Family Advisory Council: (Chair) Carie Semenko, (Co-Chair) Kisori Coulson, (Secretary) David Getz, Becky Getz, Elias Bailey, Matthew Johnson, Jessica Jones, Melissa McQueen, Erica Melissa, Angel Olvera, Laurie Sang and Tricia Zimmerman.

Thank you for your time, dedication and voice!

What is HCFAC working on this year?

- They have created a communication flow chart to help families connect with the Heart Center and Phoenix Children's to answer questions, hear concerns and for those interested - an opportunity to know our staff better.
- Looking to plan an annual meeting for families to come to Phoenix Children's and hear from the Heart Center on upcoming projects, plans and more!
- Forming an Alumni Council of past Heart Center FAC members
- Continuing their work to provide feedback on the Single Ventricle Follow-up Clinic.
This is a long term goal of this group.
- Started this newsletter in January to provide updates and share hospital happenings.
- This group is always striving to grow support resources for families, parents and siblings.
- Possible planning underway for a 2019 Heart Center Reunion, where families and staff can come together for day of fun and togetherness.

What topics have we discussed this year?

- Heart Effect Chair, Stephanie Starks, came to tell us about their new '[Home for a Heart Program!](#)'
- Justin Ryan, PhD, talked about the 3-D Print Lab at Phoenix Children's and their ongoing research.
- This group would like to thank families who provided feedback on their billing experience. We shared this with Phoenix Children's, but if you would like to speak to billing directly, please call 602-933-8700.
- We hear from the Children's Cardiomyopathy Foundation and Children's Hospital of Pittsburgh of UPMC to offer a webinar focused on issues related to adherence and transition. [Register by clicking here.](#)

How can I join the FAC?

- If you would like to be considered for membership on the Heart Center Family Advisory Council, please [complete an application](#) and submit to fac@phoenixchildrens.com. The membership is made up of families who have children with a cardiac illness and have received care at Phoenix Children's.

[Learn More About HCFAC](#)

HCFAC Events & News

May 1: 'Meet and Greet' in the CVICU Family Lounge.

- First Tuesday of every month from 3:30 – 4:15 p.m.

If your child is **currently inpatient**, we welcome you to join us for free refreshments and a chance to talk

with other families. No time to talk? That's okay, feel free to grab some food to go while you tend to your heart hero.

MORE NEWS

Two HCFAC members worked on the recent patient education material released by OPTN/UNOS called "What Every Parent Needs to Know" guide. Melissa McQueen helped author/contribute to the guide and Carie Semenko contribute a quote that has been highlighted. This guide was two years in the making and the first patient education, on a national level, geared towards parents and caregivers of transplant kids. You can take a look at it [here](#).



About Heart-to-Heart

Welcome to Heart-to-Heart, the official Phoenix Children's Heart Center newsletter. Here, the Heart Center and the Heart Center Family Advisory Council will share department updates, healthcare insights, patient stories and other relevant information for parents, families and the community.

Do you have a topic suggestion or question? [Contact us!](#)

For General Heart Center Inquiries, Please Contact:

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Kim Ames, RN (CVICU Manager): kames@phoenixchildrens.com

For care related questions, please contact your provider.



Heart Center at Phoenix Children's Hospital

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