



To the CCRC Community,

First and foremost, we hope you are all safe and well. In this unique and challenging time, we are constantly reminded of the importance of family, friends and community. The CCRC has always been a tight knit community of friends, families and colleagues who share a common goal: improving the lives of children with congenital heart disease. It is therefore especially disappointing to miss out on the camaraderie, friendship, and teambuilding that come from our in-person meetings. COVID-19 has forced us to maintain our community in novel ways - through Zoom conferences, frequent conversations, and frequent check-ins.

Nevertheless, we have not let changes in our current climate adversely impact our work and drive to deliver, through clinical research, the best treatments and outcomes for our patients. In 2019, the CCRC grew to include more sites, adding essential team members and renowned surgical partners. We continue to analyze data and disseminate new studies comparing outcomes for infants with cyanotic heart disease, presenting new insights on factors associated with somatic growth, as well as understanding the burden of reintervention following palliation of cyanotic heart disease.

Significantly, in 2020 the CCRC is completing studies on a large multicenter cohort of neonates with symptomatic tetralogy of Fallot. This study, internally termed "Infants with Tetralogy of Fallot (iTOF)," was a finalist for top clinical science at the American Heart Association Scientific Sessions in Philadelphia in November 2019. The iTOF primary manuscript has recently been submitted for publication. We are very proud of the scope and quality of this project and the 10+ ancillary studies in progress that it has spurred. Several of the ancillary studies have already been presented (virtually) at major academic meetings this year.

If 2020 has taught us nothing else, it has forced each of us to prioritize our meaningful relationships, impactful work, and efforts to improve the lives of those around us. We are proud that the CCRC embodies all of these priorities.



Christopher Petit, MD
CCRC President

Bryan Goldstein, MD
CCRC Vice President

Conference Highlights

Fall 2019

The primary focus for the October 2019 meeting was completion of the iTOF Study. This study, led by Dr. Bryan Goldstein, would be presented a month later at the AHA Scientific Sessions in Philadelphia. This was the first CCRC study to take advantage of our expanded membership - we included patients from 9 centers - and our surgical leaders took on an important role in this study. Dr. Shiraz Maskatia suggested further studies to understand the impact of fetal diagnosis of TOF on outcomes.



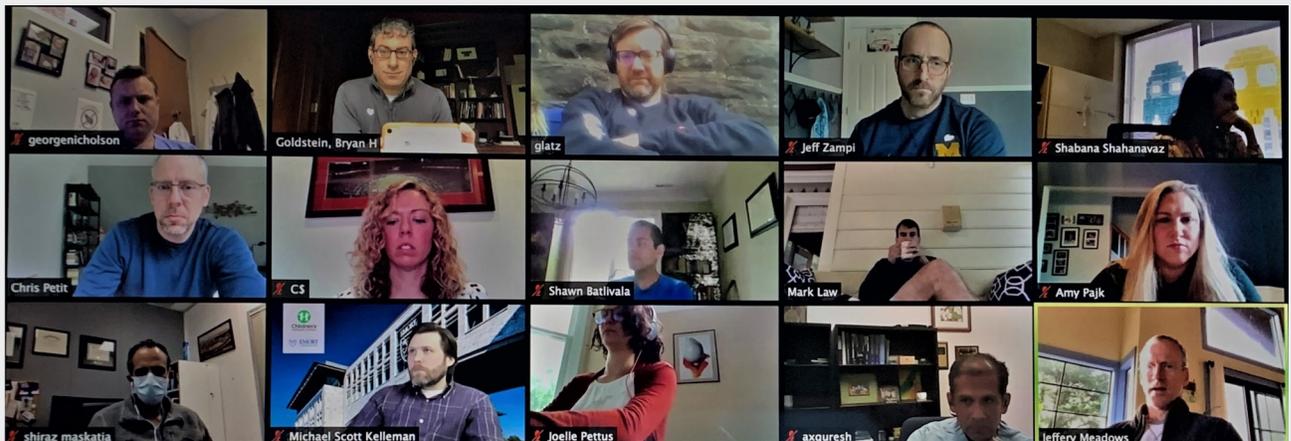
With completion of the primary iTOF study, the CCRC investigators began to expand the focus. The group reviewed 13 separate proposals for additional iTOF studies focusing on a variety of topics such as outcomes for low birthweight neonates, the impact of small branch pulmonary arteries, late outcomes of the population including need for late reintervention, predictors of radiation exposure and late neurodevelopmental outcomes in the iTOF population.

Even with a packed schedule, the group was able to fit in a little fun with a very early group “fun run” and our evening outing with another delicious Atlanta food truck, healthy competitive cornhole and casual conversations with community members, family and friends.

Spring 2020

In a year of many firsts, the CCRC hosted its 10th meeting — virtually! While we missed the in-person interactions, dinners and usual festivities (including the standard bowling domination of Andy Glatz), we adapted and remain as productive as ever! Several ancillary TOF studies were prepared for presentation at a variety of cardiology, cardiac surgery, and general pediatric meetings including: SCAI, AATS, ACC and PAS.

The group invited various colleagues interested in participating in ancillary studies, grant proposals or registry approaches to participate virtually. We want to thank everyone who joined us and contributed to another productive meeting.



Presentations



Dr. Goldstein presented The Comparison of Management Strategies for the Neonate with Symptomatic TOF Study at AHA's 2019 Scientific Sessions, November 2019

Dr. Mark Law presented "Impact of Physiologic Palliation Strategy on Outcomes in the Symptomatic Neonate with Tetralogy of Fallot" virtually at the American College of Cardiology in March of 2020.

Dr. Athar Qureshi presented "Comparison of Management Strategies for the Neonate with Symptomatic Tetralogy of Fallot and Weight Less than 2.5kg: Insights from the CCRC" at the American Association of Thoracic Surgeons (AATS) in April of 2020.

Dr. Shabana Shahanavaz presented "Outcomes following Balloon Pulmonary Valvuloplasty in Symptomatic Neonates with Tetralogy of Fallot - Results from the CCRC" at the Society for Cardiovascular Angiography and Interventions (SCAI) in May of 2020.

Dr. George Nicholson presented "Impact of Neonatal Management Strategy on Feeding and Somatic Growth in Infants with Symptomatic Tetralogy of Fallot: Results from the CCRC" at the Pediatric Academic Society (PAS) in July of 2020.

CCRC Participating Sites



Our Community Shines

Dr. Bryan Goldstein and Amy Pajk of the CCRC, along with their families, participated in A Heart Like Ava's 6th Annual 5K Walk/Run in November 2019.

The foundation has been a long time supporter of the CCRC and continues to support CHD research in honor of their angel Ava Mae. Celebrating and raising funds for CHD research with families like the Lasseters always warm our hearts and make for a great Saturday! We are deeply grateful to Bre, Brandon and all our Heart Families.



This year, Will and Kaitlin Hammill (pictured here with Dr. Chris Pettit and their daughter Kennedy) committed to substantial ongoing and future support of the CCRC.

We collectively give our sincerest gratitude to the Hammill family for their continued support, parental insight and participation in CCRC efforts! We honestly couldn't do all that we do without you.



Jeannie Hancock, a heart family warrior, donated proceeds from a recent ribbon sale to the CCRC. Thanks for considering the CCRC and we hope to partake next year!

CCRC Team Showcase



Dr. Jennifer Romano of Michigan Medicine Congenital Heart Center joined the CCRC as a surgical liaison in Fall 2019. We are fortunate to have her insight, expertise and perspective on the CCRC:

“The CCRC is incredibly supportive of one another and shares a common goal of advancing care for patients.”

“From watching the CCRC, I’ve seen what an intelligent, gifted group of individuals this is in terms of research design, statistical analyses and overall collaboration. The group continues to generate significant, timely questions and raise key issues in the interventional space that are a bit more on the cutting edge. The intention isn’t about increasing case numbers or sample sizes, it’s the initiative and ability to consider the outcomes and internal and external perspectives to critically evaluate a dataset that makes the CCRC’s work the highest level of research possible.

It’s significant that the group analyzes questions from every possible angle and really parses out the data available to make the most of any dataset. The CCRC is willing to take the time to provide quality work and seek outside perspectives to gain new insights that can help lead to tremendous impact in the pediatric cardiology field.

One of the group’s greatest strengths is its practice of encouraging and facilitating open dialogue and truly listening to others. Getting centers together that have different philosophies, approaches and strengths and weaknesses and learning from each other can create significant changes in care.

By including surgical representation, the CCRC successfully capitalized on the unique quality of pediatric cardiology that both specialties are truly invested in determining the best outcomes for the patients and families. These connections allow for the opportunity to make better educated conclusions as a care team and to counsel families to make the best decision possible for the patient.”

We’re happy to announce the addition of the Children’s Hospital of Pittsburgh to the CCRC. We look forward to new connections, collaborations and growth.

UPMC | **CHILDREN’S
HOSPITAL OF PITTSBURGH**

- Petit et al.** (2016). Relation of aortic valve morphologic characteristics to aortic valve insufficiency and residual stenosis in children with congenital aortic stenosis undergoing balloon valvuloplasty. *American Journal of Cardiology*.
- Gao et al.** (2016) Aortic valve morphology correlates with left ventricular systolic function and outcome in children with congenital aortic stenosis prior to balloon aortic valvuloplasty. *Journal of Invasive Cardiology*.
- Petit et al.** (2017) Outcomes after decompression of the right ventricle in infants with pulmonary atresia with intact ventricular septum are associated with degree of tricuspid regurgitation: Results from the CCRC. *Circulation: Cardiovascular Interventions*.
- Glatz et al.** (2018). Comparison between patent ductus arteriosus stent and modified Blalock-Taussig Shunt as palliation for infants with ductal-dependent pulmonary blood flow. *Circulation*.
- Maskatia et al.** (2018). Echocardiographic parameters associated with biventricular circulation and right ventricular growth following right ventricular decompression in patients with pulmonary atresia and intact ventricular septum. *Congenital Heart Disease*.
- Petit et al.** (2018). Technical factors are associated with complications and repeat intervention in neonates undergoing transcatheter right ventricular decompression for pulmonary atresia and intact ventricular septum. *Cardiology in the Young*.
- Bauser-Heaton et al.** (2019). Use of novel “Flip Technique” aids in percutaneous carotid artery approach in neonates. *JACC Cardiovascular Interventions*.
- Goldstein et al.** (2019) Differences in cost of care by palliation strategy for infants with ductal-dependent pulmonary blood flow analysis of data from the CCRC study of patent ductus arteriosus stent and modified Blalock-Taussig shunt. *Circulation: Cardiovascular Interventions*.
- Meadows et al.** (2019). Comparison of outcomes at time of superior cavopulmonary connection between single ventricle patients with ductal-dependent pulmonary blood flow Initially Palliated with Either Blalock-Taussig Shunt or ductus arteriosus stent. *Circulation: Cardiovascular Interventions*.
- Petit et al.** (2019). Comprehensive comparative outcomes in children with congenital heart disease: The rationale for the CCRC. *Congenital Heart Disease*.
- Qureshi et al.** (2019). Classification scheme for ductal morphology in cyanotic patients with ductal dependent pulmonary blood flow and association with outcomes of patent ductus arteriosus stenting. *Catheterization Cardiovascular Interventions*.
- Bauser-Heaton et al.** (2020). Use of carotid and axillary artery approach for stenting the patent ductus arteriosus in infants with ductal-dependent pulmonary blood flow. *Catheterization Cardiovascular Interventions*.
- Nicholson et al.** (2020). Impact of palliation strategy on interstage feeding and somatic growth for infants with ductal-dependent pulmonary blood flow: Results from the CCRC. *Journal of the American Heart Association*.



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The CCRC Team



Final Message

Connect with us!

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Be on the lookout for some rebranding and don't forget to ask about our next virtual happy hour!

We look forward to another productive virtual meeting this Fall with tentative plans to reconvene in person in Atlanta next May. In the meantime, the group moves forward with big project ideas underway—both internal and with our collaborative partners.

As a whole, we are engaged, invested and navigating next steps to transition to a registry format that will allow us to capture longitudinal outcomes in important congenital heart disease. The change in our work reflects the profound need of the entire CHD field to track outcomes, to generate meaningful benchmarks, and to determine when innovations are an improvement over contemporary therapy. Watch for news on further development of CCRC 2.0!

The CCRC remains focused on the needs of its community, patients and families. We are working more closely in 2020 on the establishment of an Advisory Board comprised of parents, patients, and the CHD community at-large. Please reach out if you would like more information, have an interest in collaborating with us or have questions on donations and ways to get involved.

CCRC Orange Cocktail

SPRITZ VENEZIANO

2 oz Prosecco
1 1/4 oz Aperol
Splash of Soda water

TEQUILA SUNRISE

3 oz Orange juice
1 1/2 oz Tequila
1/2 oz Grenadine

FUZZY NAVEL

3 oz Orange Juice
3 oz Peach Schnnapes

BLUE MOON & ORANGE

Pretty self explanatory here!



Cheers and until next time!

- The CCRC