

## **The Impact of Your Philanthropy**

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We remain deeply grateful for your support to help combat rheumatic heart disease (RHD), the world's most neglected disease. Nearly 40 million people suffer from RHD, which accounts for about 300,000 deaths annually, primarily among children and adolescents. RHD results from frequent, untreated strep throat infections in childhood that cause the body's immune system to repeatedly damage heart valves.

Your generosity has allowed Dr. Craig Sable, Associate Chief of Cardiology, and his team to lead efforts to eradicate RHD through global partnerships and innovative research. We present this update on the recent impact of your philanthropy with our sincere appreciation.



## Life-saving Surgeries Continue Despite COVID-19

Earlier this year, Dr. Sable and pediatric cardiovascular surgeon Dr. Pranava Sinha made final preparations for the 16th cardiovascular surgical mission trip to Uganda. The trip was part of a nearly 20-year partnership between United States medical experts and the Uganda Heart Institute (UHI) to build a sustainable heart surgery program to treat advanced RHD. The partnership provides surgical training, allows for treatment of more complex patients and increases UHI's surgical capacity.

Dr. Sable and four cardiac intensive care unit nurses arrived in Uganda on Sunday, March 8. The rest of the Children's National Hospital team, including Dr. Sinha, anesthesiologist Dr. Nina Deutsch and others, planned to arrive a few days later to prepare for eight surgeries the following week.

The world changed dramatically over the next 72 hours. COVID-19 cases in the U.S. soared from a few hundred to several thousand. Uganda, which had no confirmed cases at the time, closed its borders to U.S. citizens, making it impossible for the rest of the team to travel to Uganda. A travel ban in the U.S. threatened the return trip for the team members already in Uganda. The team faced a difficult challenge. Patients and families who had waited months or years for heart surgery were counting on these procedures.

After careful consultation with the UHI team, Dr. Sable decided that the operations for the sickest patients must continue – but with the local team providing all of the care. The UHI clinicians conducted five life-saving surgeries and shared live updates with the Children's National team virtually.

This success demonstrates the UHI team's ability to manage greater surgical capacity even when surgical missions from the U.S. resume. The partnership's goal is to complete at least 1,000 operations

each year, with local clinicians performing most of them. This capacity will mean the difference between life and death for many children and adults with RHD in Uganda and neighboring countries.

Gorreti, a 12-year-old from Kampala, had mitral valve replacement and tricuspid valve repair. Gorreti could barely walk 20 feet prior to surgery – now she has returned to school and normal activities. She made the clinicians a card that said "thank you for this gift" in Lugandan, her local Ugandan language.

## **Scalable Solutions to Save Lives**

Heart surgery is often necessary to treat children with advanced RHD, but it is not a scalable solution. The cost of an open-heart surgery in Uganda is \$5,000 to \$10,000, while treatment with penicillin for one year costs less than \$1. That's why investments in prevention strategies and research hold the best promise to eradicate RHD.

Your support enabled us to launch the GOAL trial in Gulu, Uganda in the summer of 2018. This research project is the first of its kind examining penicillin's potential to halt the progression of early-stage RHD. Penicillin has shown to be effective in treating rheumatic fever, which can lead to RHD. However, it has never been studied as an early-stage preventive strategy in children before they have any signs or symptoms.

The GOAL trial's results will help shape global priorities for RHD prevention by answering a key question – can early diagnosis with an echocardiogram combined with penicillin treatment prevent the disease from progressing, help children avoid surgery and improve outcomes?

The trial compares two groups of children ages 5–17. One group receives regular penicillin treatment, and the trial measures echocardiographic (heart ultrasound) improvement or decline. The other group does not receive penicillin. The research team screened 120,000 children to create the cohort of nearly 1,000. At two years, the trial has maintained an astounding 99 percent retention rate.

Between June and October 2020, the research team in Gulu conducted end-of-trial echocardiograms. All but four patients came in despite the COVID-19 pandemic. Dr. Sable set up a telemedicine network to seamlessly transfer the echos to Children's National. A team of experts from four continents compared these echos to the participants' enrollment echos. The team is now working on transition of patient care to the Gulu Regional Referral Hospital.

The trial results suggest that giving penicillin to children diagnosed with early-stage RHD has the potential to become the standard of care. This will essentially halt the disease in its tracks if we can implement scalable solutions in the endemic area.

We hope to return to Uganda next year for another surgery mission and look forward to sharing the GOAL trial results, which will help us answer critical questions about RHD that could save hundreds of thousands of lives. Your support is paving the way for a future without this devastating disease.

> Craig Sable, M.D. Associate Chief of Cardiology

## With Sincere Appreciation

Your generosity powers our progress to save lives and improve cardiac care for Ugandan children with RHD so they can thrive. Thank you for all the ways you support our efforts to restore hope and create stronger futures for children and families across the globe.





COVID-19 travel restrictions presented challenges, but also opportunities for creative solutions. This ride-share motorbike transported a GOAL participant to the office for their final echocardiogram.