



THE AGA KHAN UNIVERSITY



CONGENITAL HEART DISEASE FUND, PAKISTAN REPORT 2017

In Pakistan, more than 60,000 babies are born with congenital heart disease (CHD) each year. There are over thirty-five types of CHD, with a range of abnormalities in the heart; including incomplete, abnormal or missing parts, as well as leaky valves and holes in the chamber partitions of the heart. Symptoms of CHD include irregular breathing and immature growth, and children with this condition appear smaller compared to others their age due to weakness. Some forms of CHD cause drastic health complications and need to be treated immediately after birth.

CHD can generally be detected during a mother's pregnancy, and with cardiac procedures or surgery, 85 per cent of patients can survive until adulthood to live normal lives. However, in developing countries like Pakistan, over 60 per cent of the children with CHD are unable to make it past their first few years due to poor diagnosis and a lack of tertiary health care institutions. Pakistan has one of the highest prevalence rates of CHD in the world, yet it only has four hospitals that can perform surgeries on patients with CHD.

CHD patients need to be diagnosed early to survive, and because the awareness of this disease is very low in Pakistan, many children with CHD die undiagnosed. Moreover, even when patients are diagnosed, most families cannot afford the cost of CHD surgeries and procedures for their children.

Recognising this gap, AKUH, through its Mending Kids' Hearts campaign, has been creating awareness and raising funds for CHD patients who cannot afford the cost of care. In 2017, Rs 85 million was disbursed to 342 needy patients with CHD through the Congenital Heart Disease Fund.

AKUH is dedicated to paediatric care in Pakistan, and has been expanding its capacity as well as improving the quality of care provided to CHD patients. This year, AKUH has treated a total of 675 patients with CHD through cardiac procedures and surgeries.

The number of patients treated at AKUH grows every year. In 2017, the Hospital added two paediatric cardiac surgeons to its team, enabling it to double the number of CHD surgeries and procedures conducted between 2016 and 2017; moving it one step closer to the goal of conducting over 1,000 surgeries per year by 2020.

A MIRACLE CHILD

Asiya and Naseer tried for seventeen years to have children and had given up all hope. Somehow, a year and a half ago, Asiya learned that she was pregnant and she could not believe her luck.

She gave birth to a baby boy, Haroon. His birth felt like a miracle and a test, because as soon as he was born, the doctors broke a devastating piece of news. It was found that he had some abnormality, and they learned that Haroon had congenital heart disease. It was hard to fathom how after all their struggle to have children, they were tested further with a child that they could lose; who would not survive if he was not treated immediately.

Asiya and Naseer were afraid that the cost of treatment would be unaffordable to them but they refused to give up. After trying several hospitals and almost losing hope, they came to the Aga Khan University Hospital (AKUH), where they found comprehensive care for their son. At AKUH, Haroon was found eligible for patient welfare, and the cost of treatment was reduced significantly. Their child was admitted for over two months, and was treated successfully through a heart catheterisation procedure.

Asiya is relieved that she was able to find hope for her son, and today, Haroon is a normal and healthy baby. She is the strongest advocate for the Patient Welfare Programme at AKUH, she says, *"After coming to AKUH, my thinking has changed completely; over here every human life is valued. I urge everyone to seek help here. They are very cooperative and supportive, they know the value of your life."*

