

The International Congenital Heart Leadership Summit, 2017

The inaugural International Congenital Heart Leadership Summit (www.ichls.org) was held in Barcelona July 16-21, 2017, in conjunction with the World Congress of Pediatric and Congenital Cardiac Surgery (WCPCCS). The Summit, which included 37 delegates representing 22 countries from six continents, focussed on the health and wellbeing of congenital heart disease (CHD) and rheumatic heart disease (RHD) patients through patient and family-led group actions. The invitation-only event brought together leaders of CHD/RHD groups from around the world to learn, share, and build collaboration to promote better outcomes for CHD/RHD patients. The program combined formal sessions targeted to a professional audience and highly interactive information and training sessions exclusively for the attending community patient and family leaders.

The Summit had two components: training sessions for the attending leaders with the goal of learning from each other and identifying strategies for collaboration. The family group leaders shared information on best practices in providing advocacy, education, and support services for their home regions. Topics included global perspectives on quality of life; end of life: what do patients want and need; and creating a human rights statement for congenital/rheumatic heart disease. The second component was the WCPCCS's general program that was open to all congress attendees. Here, three formal sessions covered the issues of quality of life, global disparities, and the power of the patient-provider partnerships.

The Summit was the first time ever that patient and family groups from around the world, gathered to discuss these important issues. As well, health care providers shared experiences on how to partner with patient and family groups to strengthen the quality, access, and sustainability of the care they provide. One of the key focus areas discussed was the urgency to offer comprehensive and quality pediatric and lifetime care to all children affected by heart disease.

The Summit culminated in the formation of the Global Alliance for Rheumatic and Congenital Hearts (www.global-arch.org), a body that will represent CHDF/RHD patient and family groups, with the aim to

collaborate for better lifelong outcomes for children and adults with heart disease. The organization is being led by committed and passionate group of CHD/RHD patient and family organization leaders and healthcare professionals.

ICHLS founding members: Amy Verstappen (U.S.), Vikas Desai (India), Rob Lutter (NZ), Disty Pearson (U.S.), Shelagh Ross (Canada); Egidia Rugwizangoga (Rwanda), Noémi D. de Stoutz (Switzerland), Bistra Zheleva (U.S.), Annabel Lavielle (U.S.), and David Kasnic (U.S.)