



Advocacy at the Eighth World Congress of Pediatric Cardiology and Cardiac Surgery

Original Article

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Abstract

The *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* (WCPCCS) will be held in Washington DC, USA, from Saturday, 26 August, 2023 to Friday, 1 September, 2023, inclusive. The *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* will be the largest and most comprehensive scientific meeting dedicated to paediatric and congenital cardiac care ever held. At the time of the writing of this manuscript, *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* has 5,037 registered attendees (and rising) from 117 countries, a truly diverse and international faculty of over 925 individuals from 89 countries, over 2,000 individual abstracts and poster presenters from 101 countries, and a Best Abstract Competition featuring 153 oral abstracts from 34 countries. For information about the *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*, please visit the following website: [www.WCPCCS2023.org]. The purpose of this manuscript is to review the activities related to global health and advocacy that will occur at the *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*.

Acknowledging the need for urgent change, we wanted to take the opportunity to bring a common voice to the global community and issue the *Washington DC WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases*. A copy of this *Washington DC WCPCCS Call to Action* is provided in the Appendix of this manuscript. This *Washington DC WCPCCS Call to Action* is an initiative aimed at increasing awareness of the global burden, promoting the development of sustainable care systems, and improving access to high quality and equitable healthcare for children with heart disease as well as adults with congenital heart disease worldwide.

Background

The *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* (WCPCCS) will be held in Washington DC, USA, from Saturday, 26 August, 2023 to Friday, 1 September, 2023, inclusive. The *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* will be the largest and most comprehensive scientific meeting dedicated to paediatric and congenital cardiac care ever held. At the time of the writing of this manuscript, *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* has the following demographics:

- 5,037 registered attendees (and rising) from 117 countries,
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For information about the *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*, please visit the following website: [www.WCPCCS2023.org]. The purpose of this manuscript is to review the activities related to global health and advocacy that will occur at the *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*, an extremely important quadrennial gathering of the global paediatric and congenital cardiac community.¹⁻⁴

The World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) Organizing Committee (Jeffrey P. Jacobs, MD, FACS, FACC, FCCP, Gil Wernovsky, MD, Mitchell I. Cohen, MD, David S. Cooper, MD, and Kathryn M. Dodds, RN, MSN, CRNP-AC) recognised that the World Congress is an incredible opportunity to collectively bring more attention to the global inequities in access to quality care for paediatric and congenital cardiac patients. Advocating for patients with paediatric heart disease and congenital heart disease can help increase awareness about these conditions, promote early detection and treatment, and improve the lives of those impacted by these diseases. Furthermore, professional advocacy is the responsibility of all who are dedicated to paediatric and congenital cardiac care; such advocacy will ensure that healthcare professionals have the necessary resources to deliver consistent excellent care for our patients and their families.^{5,6} Similarly, professional advocacy will ensure that we have the necessary resources to make life better for our patients and their families.^{5,6} The Organizing Committee of the *Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* has made advocacy for our patients a top priority of World Congress.

Paediatric heart disease and congenital heart disease do not discriminate. Sadly, survival is dependent to a large extent on where one is born, and the available medical and surgical resources for treatment in that area.

Congenital cardiac malformations are the most common types of birth defects. Congenital heart disease is present in approximately 10 out of every 1000 live births.⁷ Before the introduction of current diagnostic modalities (including echocardiography), the estimated incidence of congenital heart disease ranged from 5 to 8 per 1000 live births. With improved diagnostic modalities, many more patients with milder forms of congenital heart disease can now be identified so that contemporary estimates of the incidence of congenital heart disease around the world range from 8 to 12 per 1000 live births.⁸⁻¹⁰ However, the burden is much higher in countries with higher birth rates; and unfortunately, these countries also tend to have the lowest per capita income and highest levels of poverty, making congenital heart disease an overwhelming health, economic, and social challenge to address.

An estimated 1.35 million babies are born each year with congenital heart disease worldwide.¹¹ As published in 2020 by The Global Burden of Diseases, Injuries, and Risk Factors Study (GBD 2017 Congenital Heart Disease Collaborators: Meghan S Zimmerman, Alison Grace Carswell Smith, Craig A Sable, and colleagues)¹¹: “The relative importance of congenital heart disease as a cause of child mortality is rapidly increasing, as evidenced by the increase in the proportion of deaths due to congenital heart disease from 1990 to 2017, for all but the high socio-demographic index (SDI) quintile.”¹¹ The fact that the proportion of deaths due to congenital heart disease is not declining in many low-income and middle-income countries is the fundamental reason for our call for action. Many of these children do not receive timely diagnosis or treatment, leading to significant and unnecessary morbidity and mortality. Every year, over 260,000 people die from congenital heart disease globally. In high-income countries,

medical and surgical advances have increased childhood survival from 10% in 1950 to roughly 97% by 2017, and 70% of individuals with even the most complex heart defects are now living into adulthood.^{12–14} Today, 70% of the deaths associated with congenital heart disease globally occur in infants, and 85% of those deaths occur in low-income and middle-income countries.¹¹ In most low-income and middle-income countries, up to 90% of those born with congenital heart disease do not have access to necessary cardiac care¹⁵; therefore, these low-income and middle-income countries continue to suffer the high levels of death and disability that high-income countries overcame more than 50 years ago. Congenital heart disease is a leading cause of mortality in neonates and children in low-income and middle-income countries, and for those who survive, it is often a life-limiting condition. *Therefore, we urgently need to assure more resources globally to neonates, infants, children, and the surviving adults with congenital heart disease.*

This challenge is not limited to patients with congenital heart disease. In addition to congenital heart disease, other cardiac conditions are acquired in childhood and contribute significantly to the burden of paediatric heart disease and congenital heart disease (e.g., rheumatic heart disease, myocarditis, cardiomyopathy, Kawasaki disease, endocarditis, hypertension, and many other acquired cardiac and vascular diseases); all of these acquired cardiac conditions have less favourable prognoses in low-income and middle-income countries. Importantly, rheumatic heart disease, a preventable non-communicable disease, is the most common acquired heart disease among children and young adults in Africa, impacting 1.5–3% of school-aged children. More than 10% of impacted individuals die within 12 months of diagnosis. Rheumatic heart disease also accounts for a substantial proportion of maternal mortality and significant economic burden. It is a fact that rheumatic heart disease is endemic in many low-income and middle-income countries and is considered the most common cause of acquired heart disease in children and young adults, impacting over 38 million individuals worldwide. Rheumatic heart disease is largely preventable, and the global community needs to be involved in controlling this devastating disease in every country.^{16,17}

These gross inequities in the health status and mortality of people with paediatric heart disease and congenital heart disease, particularly in low- and middle-income countries, are politically, socially, and economically unacceptable, and therefore of concern to all countries. Long-term investment into the lifelong well-being of neonates, infants, children, and adults should be a guiding value for investments in health, and a key priority for all. To achieve the newborn mortality targets of the 2030 Global Agenda for Sustainable Development (and Sustainable Development Goal 3), we must address mortality from congenital heart disease, which represents over 1/3 of the burden of birth defects worldwide.¹⁸

The Washington DC WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases

Acknowledging the need for urgent change, we wanted to take the opportunity to bring a common voice to the global community and issue the *Washington DC WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases* (Figure 1 and Figure 2). A copy of this *Washington DC WCPCCS Call to Action* is provided in **Appendix 1** of this manuscript. This *Washington DC WCPCCS Call to Action* is an initiative aimed at increasing awareness of the global burden, promoting the

We recommend to governments, multilateral organizations (the World Health Organization, the United Nations Children's Fund, the World Bank and others), funders, professional societies, research and teaching institutions, civil society, and the private sector, the following key actions and 2030 Goals:



Figure 1. The Washington DC WCPCCS Call to Action calls for several key actions: (1) increase capacity to care for people with pediatric and congenital heart diseases, (2) build the pediatric and congenital cardiac workforce, (3) finance pediatric and congenital cardiac care, and (4) close the data gap.



8th World Congress of
Pediatric Cardiology
and Cardiac Surgery
AUGUST 27 – SEPTEMBER 1, 2023
WASHINGTON D.C.



Endorse the WASHINGTON, D.C. CALL TO ACTION
ON ADDRESSING THE GLOBAL BURDEN
OF PEDIATRIC AND CONGENITAL HEART DISEASES



bit.ly/3KeUoif

Figure 2. The QR code for the Washington DC WCPCCS Call to Action.

Table 1. Global Health and Advocacy Village at the Eighth World Congress of Pediatric Cardiology and Cardiac Surgery

Count	Organisation name	Country
1	International Quality Improvement Collaborative (IQIC) for Congenital Heart Disease	GLOBAL
2	The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD)	GLOBAL
3	World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS)	GLOBAL
4	World Society for Pediatric and Congenital Heart Surgery (WSPCHS)	GLOBAL
5	World University for Pediatric and Congenital Heart Surgery (WUPCHS)	GLOBAL
6	Hospital del Niño Ovidio Aliaga. La Paz	Bolivia
7	Amigos do Coração Goiás	Brazil
8	Circulo do Coracao de Pernambuco	Brazil
9	Association Child's Heart	Bulgaria
10	Global Alliance for Rheumatic and Congenital Hearts	Canada
11	Global Cardiac Surgery Initiative	Canada
12	Fundación Corazones Luchadores	Chile
13	Fundación Cardioinfantil	Colombia
14	A Big Heart To A Small Heart	Croatia
15	Sydänlapset ja -aikuiset ry - The Finnish Association for Heart Children and Adults	Finland
16	La Chaîne de l'Espoir	France
17	Fundacion Aldo Castaneda	Guatemala
18	Neistinn, Children's Heart Foundation in Iceland	Iceland
19	Congenital Heart Defects Protective Mission	India
20	AICCA ETS	Italy
21	Mission Bambini	Italy
22	Chain of Hope Jamaica	Jamaica
23	Kenya Mended Hearts	Kenya
24	Brave Heart (Lebanon)	Lebanon
25	CHD Malaysia	Malaysia
26	IJN Support Group	Malaysia
27	Beating Hearts Malta	Malta
28	ADANEC	México
29	Ayuda a Corazon de Niño AC	México
30	KARDIAS AC	México
31	Los Cabos Children's Foundation	México
32	Brave Little Hearts Namibia	Namibia
33	RHD is not disability/Namibian Rheumatic and Congenital Hearts	NAMIBIA
34	Connecting Hearts to End Heartbreak - CHEER Hearts	Nepal
35	HM Habib Cardiac Endowment Fund	Pakistan
36	Pakistan Children's Heart Foundation	Pakistan
37	Amigos de Corazon	Perú
38	Heart Warriors of the Philippines	Philippines
39	Philippine Rheumatic Fever and Rheumatic Heart Disease Foundation, Inc.	Philippines
40	Rheumatic Heart Disease Philippines	Philippines
41	Children's Heart Foundation	Poland
42	Brave Little Hearts SA	South Africa
43	Fundacion Menudos Corazones	Spain

(Continued)

Table 1. (Continued)

Count	Organisation name	Country
44	Hjärtebarnsfonden	Sweden
45	Cuore Matto	Switzerland
46	World Heart Federation	Switzerland
47	The Cardiac Children Foundation of Thailand	Thailand
48	FAAYO Hearts	Uganda
49	Samaritan's Purse Children's Heart Project	Uganda
50	Uganda Heart Institute RHD	Uganda
51	Amosov National Institute of Cardiovascular Surgery	Ukraine
52	Ukrainian Association for Cardiovascular Surgeons	Ukraine
53	Chain of Hope	United Kingdom
54	Children's Heart Federation	United Kingdom
55	European Congenital Heart Disease Organisation	United Kingdom
56	Somerville Heart Foundation	United Kingdom
57	Adult Congenital Heart Association	United States of America
58	Anthony Bates Foundation	United States of America
59	Camp Odayin	United States of America
60	Cardiac Kids Foundation of Florida	United States of America
61	CardioStart International	United States of America
62	Children's HeartLink	United States of America
63	Conquering CHD	United States of America
64	Edwards Lifesciences and Edwards Lifesciences Foundation	United States of America
65	Family Heart Foundation	United States of America
66	Gift of Life International	United States of America
67	Haiti Cardiac Alliance	United States of America
68	Heart Care International, Inc.	United States of America
69	Heart to Heart Global Cardiac Care	United States of America
70	Hearts of Joy International	United States of America
71	Hearts Unite the Globe	United States of America
72	Hypertrophic Cardiomyopathy Association	United States of America
73	La Chaine de l'Espoir/United Surgeons for Children	United States of America
74	MD1 World	United States of America
75	Mended Little Hearts	United States of America
76	Mending Kids	United States of America
77	Newborn Foundation Bloom Standard	United States of America
78	Ollie Hinkle Heart Foundation	United States of America
79	One Heart Health	United States of America
80	Parent Heart Watch	United States of America
81	PEN-plus; Center for Integration Science, Brigham and Women's Hospital	United States of America
82	Project Adam	United States of America
83	Project Singular	United States of America
84	Saloni Heart Foundation	United States of America
85	Save a Child's Heart Foundation US	United States of America
86	Simon's Fund	United States of America

(Continued)

Table 1. (Continued)

Count	Organisation name	Country
87	Sisters by Heart	United States of America
88	Sri Sathya Sai Sanjeevani Pediatric Cardiac Medical System	United States of America
89	Strong Heroes	United States of America
90	Sudden Arrhythmia Death Society	United States of America
91	Surgeons of Hope	United States of America
92	The William Novick Global Cardiac Alliance	United States of America
93	Zipper Sisters	United States of America
94	Multidisciplinary Medical Center Akfa Medline	Uzbekistan
95	Fundación Estrellita de Belén Corp	Venezuela
96	Brave Little Hearts Zimbabwe	Zimbabwe

development of sustainable systems of care, and improving access to high quality and equitable healthcare for children with heart disease as well as adults with congenital heart disease worldwide. The document was developed by patients, families, clinicians, and clinical and health policy experts. This *Washington DC WCPCCS Call to Action* calls for several key actions to recognise and address the glaring inequities in recognition, access to, and investment in health services to address congenital and paediatric heart disease throughout the lifespan of our patients; this *Washington DC WCPCCS Call to Action* calls upon multiple organisations and entities to engage in and address these key actions, including:

- governments,
- multilateral organisations,
- funders,
- professional societies,
- research and teaching institutions,
- civil society, and
- the private sector.

The *Washington DC WCPCCS Call to Action* is based on the recognition that congenital heart disease is a major global health issue, and the *Washington DC WCPCCS Call to Action* was built on the *Invisible Child Call to Action* from 2018. The *Washington DC WCPCCS Call to Action* requests changes and sets a 2030 goal in four areas, as they relate to the Sustainable Development Agenda:

1. Increasing capacity to care for people with paediatric heart disease and adults with congenital heart disease.
2. Building the paediatric and congenital cardiac workforce aligned with the vision and goals of the World Health Organization's global strategy on human resources for health: workforce 2030.¹⁹
3. Closing the data gap necessary to assist decision-makers in the development of appropriate policies for paediatric heart disease and congenital heart disease.
4. Financing paediatric and adult congenital cardiac care to assure families and patients are protected from catastrophic expenses related to their care.

We urge individuals and organisations to sign the *Washington DC WCPCCS Call to Action* either before or during *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*. With such broad support, we believe the *Washington DC WCPCCS Call to Action* will be a useful advocacy tool for anyone wishing to

advocate with their government to bring attention and solutions to this pressing issue.

Global Health and Advocacy Village at the Eighth World Congress of Pediatric Cardiology and Cardiac Surgery

Another important initiative during *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* will be *Global Health and Advocacy Village*. *Global Health and Advocacy Village* will be the first-of-its-kind gathering at WCPCCS. Organisations from around the world will gather and share their experiences, research, and knowledge in the field of paediatric cardiology and cardiac care; these organizations will include:

- patient and family-led organisations,
- medical mission organisations, and
- non-governmental capacity building and advocacy organisations.

Global Health and Advocacy Village will bring together 96 organisations from 37 countries (see Table 1). *Global Health and Advocacy Village* intends to promote collaboration, networking, and discussion among professionals in the field, but the most important goal of *Global Health and Advocacy Village* is to create a *unified* voice for those impacted by paediatric heart disease and congenital heart disease. *Global Health and Advocacy Village* will be an inclusive global gathering of the paediatric and congenital heart community, presenting an incredible opportunity to collectively support the *Washington DC WCPCCS Call to Action*. Both *Global Health and Advocacy Village* and the *Washington DC WCPCCS Call to Action* are top priorities for the Organizing Committee of *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*.

Global Health and Advocacy Village will include exhibit tables as well as networking and educational activities for attendees. *Global Health and Advocacy Village* will offer an opportunity for participants to:

- learn about strategies for advocacy,
- learn about opportunities for advocacy, and
- connect with colleagues and experts from around the world.

Therefore, *Global Health and Advocacy Village* will help promote the exchange of knowledge and ideas among professionals working to improve health equity and the lives of both children

with cardiac conditions and adults with congenital cardiac conditions.

The goal of *Global Health and Advocacy Village* is to bring together leaders of humanitarian organisations, patient and family groups, and clinical professionals to strengthen our common voice and accelerate action to improve global access to lifelong high-quality paediatric and congenital cardiac care. We hope that this group will continue to connect after the WCPCCS and build a global coalition to bring attention to these neglected issues.

Summary

Overall, the goal of the advocacy efforts during *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery* is to promote equitable healthcare and associated policies and practices that improve the lives of neonates, infants, and children with cardiac disease and adults with congenital heart disease, as well as to help bring the paediatric and congenital cardiac community together under one cohesive agenda to address global inequities. Paediatric and congenital cardiac care is labor intensive and expensive; however, the investment of additional money and resources to provide paediatric and congenital cardiac care will save and improve countless lives.

We invite attendees of *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*, everyone in the paediatric and congenital cardiac community, and anyone who believes paediatric and congenital heart care should be available and accessible to all to join us in these efforts by signing the *Washington DC WCPCCS Call to Action* on the website <https://www.wcpccs2023.org/> and by visiting the *Global Health and Advocacy Village* during World Congress.

On behalf of the Organizing Committee of *The Eighth World Congress of Pediatric Cardiology and Cardiac Surgery*, we would like to invite you to sign the *Washington DC WCPCCS Call to Action* on Addressing the Global Burden of Pediatric and Congenital Heart Diseases highlighting the global inequities in paediatric and congenital heart care.

This *Washington DC WCPCCS Call to Action*, developed by patients, families, clinicians, and clinical and policy experts, calls upon governments, multilateral organisations, funders, professional societies, research and teaching institutions, civil society, and the private sector for several key actions to improve equitable recognition, access, and investment in health services to address childhood-onset heart disease.

Please sign either as an individual or organisation to endorse the *Washington DC WCPCCS Call to Action* on Addressing the Global Burden of Pediatric and Congenital Heart Diseases. At the time of the writing of this manuscript, the *Washington DC WCPCCS Call to Action* on Addressing the Global Burden of Pediatric and Congenital Heart Diseases has been signed and endorsed by 126 organisations from 38 countries (*Appendix 2*) and has also been signed and endorsed by 415 individuals from 60 countries.

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involved individuals and organizations will only add value and growth by cooperating and supporting each other.

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APPENDIX 1:

The Washington DC WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases

“There can be no keener revelation of a society’s soul than the way in which it treats its children” Nelson Mandela 1995

We, the pediatric and adult congenital cardiac community from around the world, gathered here in Washington, D.C., United States of America from August 27 to September 1, 2023, to share and learn from each other during the 8th World Congress of Pediatric Cardiology and Cardiac Surgery. We issue an urgent call for action by all governments, all health and development agencies, and the world research and academic community to protect and promote the health of all people with pediatric and congenital heart diseases. To that end, we call to action:

WASHINGTON, D.C. CALL TO ACTION ON ADDRESSING THE GLOBAL BURDEN OF PEDIATRIC AND CONGENITAL HEART DISEASES

Background

Across the world children with heart disease suffer appalling and shameful neglect. The tremendous advances made in reducing childhood mortality from pediatric and congenital heart diseases are confined to high-income countries (HICs) leaving low- and middle- income countries (LMICs) far behind. Of every 100 children born around the world, one will have a malformation of the heart, congenital heart disease (CHD). Nearly half of the children with CHD will need a medical intervention in their lifetime, and a quarter of them will need it in the first year of life in order to survive.

Up to 90% of those born with CHD in LMICs do not have access to cardiac care, and they continue to suffer the high levels of death and disability HICs began to overcome more than fifty years ago. In HICs, medical advances increased childhood survival from an estimated 10% in 1950 to over 90% by 1990, and individuals with even the most complex heart defects are now reaching their fifth and sixth decade of life. In contrast, children born with CHD in LMICs face a vastly different prognosis. CHD is quickly becoming a leading cause of mortality in neonates and children in LMICs, and for those who survive, it can be a life-limiting condition if left untreated.

This problem is not limited to CHD. Rheumatic heart disease (RHD), a preventable non-communicable disease, is the most common acquired heart disease among children and young adults in Africa and affects 1.5 – 3% of school-aged children. More than 10% of affected individuals die within 12 months of diagnosis; RHD accounts for a substantial proportion of maternal mortality and significant economic burden. In 2010, the economic burden associated with RHD was estimated to be US\$791 million – \$2.37 billion.

Other heart conditions acquired in childhood (Those include conditions such as myocarditis, cardiomyopathy and Kawasaki disease.) also contribute significantly to the burden of pediatric and congenital heart disease and all have less favorable prognoses in LMICs. Whether or not these children survive and grow to reach their full human potential depends largely on birth location and access to heart care treatment throughout their lifetime. There is a dire need for more comprehensive treatment facilities and programs to prevent the deaths of these children, and to provide them with ongoing care as they enter adulthood.

Accelerating progress to address the burden of pediatric and congenital heart disease globally is in line with the 2030 Global Agenda for Sustainable Development (SDG3). We believe that the existing gross inequity in the health status of people with pediatric and congenital heart disease, particularly in LMICs, is politically, socially, and economically unacceptable, and is therefore of concern to all countries. Long-term investment into the lifelong well-being of children should be a guiding value for investments in health and a key priority.

We hereby call upon the global community in general, and every responsible government, for an effective policy response supported by adequate financial investment to address the needs of all with pediatric and congenital heart diseases. To this end, we recommend to governments, multilateral organizations (the World Health Organization, the United Nations Children’s Fund, the World Bank and others), funders, professional societies, research and teaching institutions, civil society, and the private sector, the following key actions:

Increase capacity to care for people with pediatric and congenital heart diseases

2030 Goal: The timely diagnosis, treatment and lifelong care of pediatric and congenital heart disease will be integrated into all health system strengthening and surgical scale-up plans.

- ① Domestic and global investments to increase capacity for pediatric and congenital cardiac care at secondary and tertiary hospitals.
- ② Harness private sector capacity and innovations in areas of digital, primary care and diagnostics, task shifting if available.
- ③ Support of local referral networks by ministries of health and regional academic institutions to improve early diagnosis, surveillance, and lifelong care of heart disease, and to develop diagnostic and treatment guidelines for low-resource settings.
- ④ Universities, NGOs (Non-Governmental Organizations) and teaching hospitals should invest in multi-year partnerships focusing on leadership, infrastructure development and training to increase the technical capacity and financial sustainability of local hospitals.

Build the pediatric and congenital cardiac workforce (These recommendations for training of pediatric cardiac care staff align with the vision and goals of the World Health Organization’s Call to Action: Addressing The 18 million Health Worker Shortfall, and the Global Strategy on Human Resources for Health: Workforce 2030.)

2030 Goal: Health professionals will be able to recognize the basic signs and symptoms of congenital and rheumatic heart disease. Accredited pediatric cardiac training programs will be available in all countries.

Ministries of health, finance, and education, and regional professional bodies collaboration to:

- ① Evaluate workforce needs in pediatric and congenital cardiac care.
- ② Develop accredited pediatric and congenital cardiac training and education centers and programs that include developing the technical and leadership capacity of specialist pediatric cardiac nurses, physicians, pharmacists, perfusionists, and respiratory therapists, and others.
- ③ Develop pediatric and congenital cardiac workforce strengthening plans with appropriate recruitment and incentivization to minimize attrition, promote career satisfaction and skills retention in the nursing and pediatric cardiac care professions.
- ④ Support the careers of existing pediatric and congenital cardiac care professionals and build mentorship programs and viable career path options for the next generation.

Close the data gap

2030 Goal: Data on pediatric and congenital heart diseases will be collected in national health surveys and included in burden of disease and cause of child death statistics.

- ① Update the burden of disease data on pediatric and congenital heart disease with a particular focus on LMICs. Congenital heart disease should be included in all national child health, surgical, burden of disease and cause of death surveys and reported to national health ministries and international organizations such as the World Health Organization and the World Bank.
- ② Research and advocacy on ending preventable child deaths must include pediatric and congenital heart disease as a significant contributor.
- ③ Publication by pediatric and congenital cardiac care providers in LMICs of outcomes research, cost analyses, and other topics relevant to low-resource settings, especially to inform health policy.
- ④ Prioritize the application of cost-effective technologies and quality improvement strategies that can reduce costs and improve outcomes for children with heart disease in low-resource settings.

Finance pediatric and congenital cardiac care

2030 Goal: Care for pediatric and congenital heart disease will be included in benefits packages in universal health coverage and social protection platforms, protecting patients from catastrophic expenses related to their care.

Ministries of health, finance, and education, and regional professional body collaboration to:

- ① Mobilize increased funding at domestic and international levels in order to achieve scaling of cardiac surgical and anesthesia care in LMICs.
- ② Provide support to individuals and families of children with heart disease who experience indirect expenses related to accessing and sustaining care, particularly those at risk of poverty.
- ③ Track and report financial data at hospitals in LMICs with functional pediatric cardiac care services using standardized metrics such that analyses can be made on the cost of scaling up care for children with heart disease.
- ④ Develop and strengthen cross cover and mutually beneficial funding relationships between public and private health providers.
- ⑤ Mobilize funding for LMIC-focused research and data collection.

APPENDIX 2:

Organisations that have signed The Washington DC WCPCCS Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases at the time of the writing of this manuscript

At the time of the writing of this manuscript, the *Washington DC WCPCCS Call to Action* on Addressing the Global Burden of Pediatric and Congenital Heart Diseases has been signed and endorsed by the 126 organisations from 38 countries and has also been signed and endorsed by 415 individuals from 60 countries.

Importantly, the *Washington DC WCPCCS Call to Action* has been signed and endorsed by **The World Congress of Pediatric Cardiology and Cardiac Surgery** (WCPCCS) and the International Steering Committee of The World Congress of Pediatric Cardiology and Cardiac Surgery.

	Organisation name	Country
1	Steering Committee, World Congress of Pediatric Cardiology and Cardiac Surgery	GLOBAL
2	Baby Blue Sound Collective	GLOBAL
3	International Quality Improvement Collaborative (IQIC) for Congenital Heart Disease	GLOBAL
4	Team Heart	GLOBAL
5	The International Society for Nomenclature of Pediatric and Congenital Heart Disease (ISNPCHD)	GLOBAL
6	World Heart Federation	GLOBAL
7	World Society for Pediatric and Congenital Heart Surgery	GLOBAL
8	World University for Pediatric and Congenital Heart Surgery	GLOBAL
9	Child Heart Trust Bangladesh	Bangladesh
10	Congenital Heart Desk Foundation	Bangladesh
11	ABECCAI	Bolivia
12	Kardiozentrum	Bolivia
13	Amigos do Coração Goiás	Brazil

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	Organisation name	Country
14	CardioPedBrasil - HCM - FUNFARME/FAMERP	Brazil
15	Círculo do Coração	Brazil
16	Child's Heart Association	Bulgaria
17	Global Cardiac Surgery Initiative	Canada
18	Kawasaki Disease Canada	Canada
19	Fundación Corazones Luchadores	Chile
20	A Big Heart To Small Heart Association	Croatia
21	Jimma University Medical Center (JUMC)	Ethiopia
22	African Society for Pediatric and Congenital Heart Surgery	Ghana
23	Panhellenic Heart Disease Association	Greece
24	Neistinn, Children's Heart Foundation in Iceland	Iceland
25	Association for Socially Applicable Research (ASAR)	India
26	Child Heart Care Project, National Institute for Woman and Child Development	India
27	Hearts for Hearts	India
28	Justice for Heart Warriors	India
29	Kokilaben Dhirubhai Ambani Hospital	India
30	Society of Pediatric Cardiac Critical Care	India
31	Tiny Hearts Fetal and Pediatric Cardiac Clinic	India
32	Congenital Heart Defects Protective Mission	India
33	Congenital Heart Disease India	India
34	Frontier Lifeline Hospitals	India
35	Indonesian Society of Pediatric Cardiology	Indonesia
36	National Cardiovascular Center Harapan Kita	Indonesia
37	National Women and Children RSAB Harapan Kita	Indonesia
38	The Indonesian Association of Thoracic, Cardiac and Vascular Surgeons	Indonesia
39	Alkafeel Super Speciality Hospital	Iraq
40	Kenya Mended Heart Patients Association	Kenya
41	Brave Heart	Lebanon
42	Children's Heart Center - American University of Beirut	Lebanon
43	Malaysian Congenital Heart Foundation	Malaysia
44	Malaysian Pediatric Cardiac Society	Malaysia
45	National Heart Institute	Malaysia
46	National Heart Institute Kuala Lumpur	Malaysia
47	CHD Malaysia	Malaysia
48	Rakan Institute Jantung Negara	Malaysia
49	ADANEC	México
50	Kardias A.C.	México

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	Organisation name	Country
51	Operación Corazón	México
52	Salud Pública en México	México
53	Ayuda a Corazón de Niño AC	México
54	Brave Little Hearts Namibia	Namibia
55	Ministry of Health and Social Sciences	Namibia
56	Namibia Rheumatic and Congenital Hearts	Namibia
57	Connecting Hearts to End Heartbreak - CHEER Hearts	Nepal
58	Hearts4kids New Zealand	New Zealand
59	EL-AGED CARE LTD /GTE	Nigeria
60	The Congenital Heart Disease Foundation of Nigeria	Nigeria
61	Pakistan Children's Heart Foundation	Pakistan
62	Aria for Life Foundation	Pakistan
63	Amigos de Corazon	Perú
64	Asociación de padres de niños con cardiopatía "Amigos de corazón"	Perú
65	Instituto Nacional Cardiovascular INCOR	Perú
66	Let It Echo Inc	Philippines
67	Philippine Heart Center	Philippines
68	Philippine Rheumatic Heart Disease	Philippines
69	Strong Heart	Philippines
70	Heart Warriors of the Philippines Inc.	Philippines
71	Heartlings Unified Group Support (HUGS) Foundation Corporation	Philippines
72	Rheumatic Heart Disease	Philippines
73	Rheumatic Hearts Disease Philippines	Philippines
74	Brave Little Hearts SA	South Africa
75	Heart Kids SA	South Africa
76	Heart of Hope	South Africa
77	Paediatric Cardiac Society of South Africa	South Africa
78	Paediatric Cardiology Service of the Western Cape	South Africa
79	SA Heart	South Africa
80	Fundación Menudos Corazones	Spain
81	Sudan Heart Center	Sudan
82	Hjärtebarnsfonden	Sweden
83	Jakaya Kikwete Cardiac Institute	Tanzania
84	The Cardiac Children Foundation of Thailand	Thailand
85	Pediatric Cardiac Surgery Foundation	Thailand
86	Action for Disadvantaged People	Uganda
87	RHD Patient Support Group (Uganda Heart Institute)	Uganda

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	Organisation name	Country
88	Medical Aid and Education to Kenya	United Kingdom
89	Sickle Cell Cohort Research Foundation	United Kingdom
90	Chain of Hope UK	United Kingdom
91	Somerville Heart Foundation	United Kingdom
92	A+J Patient Advocacy	United States
93	Advocate Children's Hospital	United States
94	American Association of Cardiologists of Indian Origin	United States
95	American College of Cardiology	United States
96	American Heart Association	United States
97	American Society of Echocardiography	United States
98	Cardiac Kids Foundation of Florida	United States
99	Cardiology Care for Children	United States
100	Children's National Hospital	United States
101	Congenital Cardiac Anesthesia Society	United States
102	Conquering CHD	United States
103	Divine Will Foundation, Sri Sathya Sai Sanjeevani Hospital	United States
104	Global Alliance for Rheumatic and Congenital Hearts (Global ARCH)	United States

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	Organisation name	Country
105	Heart to Heart Global Cardiac Care	United States
106	HeartGift Foundation	United States
107	Hearts Unite The Globe	United States
108	International Society of Cardiovascular Ultrasound	United States
109	Jeffrey R. Boris, MD LLC	United States
110	Novick Cardiac Alliance	United States
111	NP Student®	United States
112	One Heart Health	United States
113	Pediatric Cardiac Intensive Care Society	United States
114	Pediatric Critical Concepts, Inc.	United States
115	Surgeons of Hope	United States
116	Team Heart, INC.	United States
117	The Congenital Heart Surgeons' Society	United States
118	The Mended Hearts, Inc.	United States
119	Transparent Fish Fund	United States
120	UAB	United States
121	Fundación De Todo Corazón Richard Gibson	Venezuela
122	Fundacion Estrellita de Belen Corp	Venezuela
123	Save A Heart Foundation	Venezuela
124	Children's Hospital 1 Ho Chi Minh City	Vietnam
125	University Medical Center, Ho Chi Minh city	Vietnam
126	Brave Little Hearts Zimbabwe	Zimbabwe