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Original Article

The 6th World Congress of Paediatric Cardiology and Cardiac Surgery, Cape Town 2013

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There is a view that cardiac conferences are in decline. In a recent editorial "National Cardiac Meetings – What went wrong?", Douglas Moodie notes a decline in attendance at the 2012 American Heart Association (AHA) scientific sessions.[1] In Los Angeles last year, there were "only" 17,000 attendees, a far cry from the heady days of over 30,000. He attributes this to the international economic crisis and notes, in particular, lower numbers from Japan and Europe. His pessimism is supported by evidence from elsewhere. The inaugural "World Congress of Cardiology" attracted 1200 attendees to Paris in 1950. Organised by the World Heart Federation and held every 4 years, there were 21,000 in Berlin in 1994, peaking at 32,500 in Barcelona in 2006. Since then, they have biennial World Congresses of Cardiology and attendance has declined from 17,000 in 2008 (Buenos Aires) to just over 10,000 in Beijing (2010), and last year 10,748 in Dubai.[2] Moodie extrapolated from the AHA experience to reflect on the forthcoming 6th World Congress of Paediatric Cardiology and Cardiac Surgery, which was held in Cape Town in February, 2013. Noting the "long, very expensive trip", he predicted "the numbers of attendees at the WCPCCS 2013 will be lower than in the past". We are pleased to report that despite being a long-haul destination, there were 3033 attendees. Far from a decline, this is 700 more than in Cairns 4 years ago and equal in number to Buenos Aires in 2005 (3000). There were delegates from 104 countries with over 100 more attendees from North America in Cape Town (571) than in Cairns. Although we had hoped to grow the World Congress significantly and had a figure of 4000 attendees in mind, the evidence suggests there is still life in international heart meetings in general and in the World Congress of Paediatric Cardiology and Cardiac Surgery in particular.

We believe that the World Congress of Paediatric Cardiology and Cardiac Surgery is the pre-eminent meeting for the professions devoted to heart disease in children, and given its genuinely global footprint an event that deserves respect and support from institutions and organisations across the globe. The World Congress of Paediatric Cardiology and Cardiac Surgery happens every 4 years, and given its compelling vision it was reasonable to anticipate that "competing" meetings would suspend their events for 2013. In a magnanimous gesture, the Children's Hospital of Philadelphia and the All Children's Hospital in St Petersburg cancelled "Heart Week" and their meetings for February, 2013. "Cardiology in the Young" in London did likewise. The World Society for Paediatric and Congenital Heart Surgery generously moved their 4th Congress and Scientific Meeting from 2013 to 2014 to respect the World Congress of Paediatric Cardiology and Cardiac Surgery. A few organisations, including the Association for European Paediatric and Congenital Cardiology and the Pan African Society of Cardiology, went ahead with their own meetings and PICS-AICS moved its meeting to January, 2013. Notwithstanding, we are pleased that with only one exception all invited international organisations participated enthusiastically in the World Congress. The two existing international societies – World Society for Paediatric and Congenital Heart Surgery and the International

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Society for Nomenclature in Pediatric and Congenital Heart Disease – had sessions in the programme. For the first time, the World Heart Federation participated in the World Congress of Paediatric Cardiology and Cardiac Surgery with several keynote speakers and an exhibition booth and even co-hosted one of the most important closing seminars on "Setting millennium development goals for children with heart disease". It was a disappointment that the United Nations Children's Fund inexplicably withdrew from this session just before the World Congress. Looking ahead, we hope the Association for European Paediatric and Congenital Cardiology returns to past practice and incorporates their 2017 congress with the 7th World Congress of Paediatric Cardiology and Cardiac Surgery in 2017.

There were 29 industry symposia, which were very well supported, and in fact many of them were oversubscribed. The Pediatric Cardiac Intensive Care Society, the Association for European Paediatric and Congenital Cardiology, the Japanese Society of Pediatric Cardiology and Cardiac Surgery, and the Pan Arab Congenital Heart Disease Association had symposia with their own subject choice. A total of eight North American children's hospitals – Philadelphia, Boston, Wisconsin, Texas, Toronto, St Petersburg, Stollery, and Cincinnati – and Mayo Clinic Rochester held their own symposia.

The scientific programme balanced the highest levels of achievement in research and technological innovation for complex congenital lesions, with health systems questions relevant to the distribution of cardiac care to needy children. Regenerative medicine, growing heart valves, and stem cell therapies featured prominently but so did the less frequently asked questions on how our patients are doing after they survive complicated heart surgeries? The surgical track plumbed the depths of left ventricular outflow tract obstruction with all manner of associated anomalies. This focus on a single lesion, as was the case with atrioventricular septal defect in Cairns, proved popular. On the other hand and in a departure from previous congresses, one of the six tracks was devoted to "health systems and heart disease". For those in wealthier nations, the cutting-edge systems questions relate to organisation of services, rationing and rationalising care, and to quality assessment. However, in the less well-resourced countries few children with heart disease get the treatment they require and the World Congress of Paediatric Cardiology and Cardiac Surgery strongly upheld the view that these children ought not to be denied the benefits of medical science. We fulfilled our vision – to highlight the challenges for paediatric cardiac care in less well-resourced countries and to engage government and civil society in finding solutions to the many systems deficiencies that lead to the neglect of children with heart disease. International and national humanitarian programmes were widely represented, participating in several sessions devoted to different models of service provision and system development. These included the Global Heart Network Foundation, Caring and Living as Neighbors (CLAN), NCD Child, Medtronic Foundation, Chaine de L'Espoir, Save a Childs heart, Global Heart Network, Children's HeartLink, World Heart Federation, Congenital Heart Disease Public Health Consortium, and the International Quality Improvement Collaborative.

World Congress of Paediatric Cardiology and Cardiac Surgery was held in Africa for the first time, so consequently acquired heart disease in general and rheumatic heart disease in particular were given an appropriately powerful platform. Rheumatic heart disease ran in one of 11 parallel venues for the entire week featuring in the surgical, cardiology, imaging, and health systems tracks. These sessions were very well supported, recognising that over 35 million people are affected by rheumatic heart disease worldwide,[3] and in most of the world children with rheumatic heart disease represent half of the burden of heart disease. In another progressive development – 50% of heart surgery in many developing countries is for rheumatic heart disease – the "Surgery for rheumatic heart disease" sessions were held jointly with the World Society for Pediatric and Congenital Heart Surgery.

Supported by a team from "Congenital Structural Interventions (CSI) Frankfurt", the intervention programme ran live cases on 3 of the 5 days. On day 1, Monday 18 February, transmission to the Cape Town International Convention Centre was by satellite from two venues in Europe – Frankfurt and Milano. Live transmission from four hospitals within South Africa was then streamed successfully via broadband Internet later in the week. There had been scepticism about Internet transmission, but it proved as reliable as satellite transmission with good-quality images at a much reduced cost. We expect this experience will benefit other meetings running live case interventions. Indeed, the live case programme brought forth many "firsts' in Africa, including transcatheter pulmonary and tricuspid valve implantations and was a wonderful showcase for what can be done on our continent. The intervention track showed lectures and debates in between live cases and was not an appendage to but a full and vital track within the World Congress programme. It was open to all attendees without an additional registration fee.

The nursing science track was well attended with enthusiastic participation from a genuinely

global audience. The "Adults with congenital heart disease" track among other subjects interrogated the challenges of care for Fontan and Tetralogy of Fallot patients and also women in their reproductive years. The numbers of attendees at this track fell short of our expectations. This was possibly a consequence of competing and compelling attractions across the other five tracks; however, energising the adult cardiac practitioners to the challenge and excitement of caring for adults with congenital heart disease remains difficult. This is a serious problem for healthcare planning and organisation as there are now more patients older than 18 years with congenital heart disease than there are children with congenital heart disease in Europe, North America, and other industrialised nations.[4] Speaking to this burden of disease were parent and patient support and advocacy groups such as the Adult Heart Disease Association and Congenital Heart Disease Consortium who participated in sessions on patient-centred care and advocacy. To broaden interest and feature problems of "healthy" adolescents and young adults, "sudden death" among high-performance athletes was highlighted in one of the 20 plenaries and there was a special summit on sudden death featuring Sudden Arrhythmia Deaths Syndrome Foundation, PACE AFRICA, and the Arrhythmia Alliance. Notwithstanding the popular debates, the highlights of the programme were without question the 20 plenaries and in particular the lectures that honoured Jane Somerville, "Innovation and fragility", Donald Ross, "Evolution of the pulmonary autograft aortic valve replacement", and the late Christiaan Barnard, "Mechanical alternatives to transplantation".

The carbon footprint of an international conference of 3000 attendees is appalling and it is prohibitively expensive to offset the environmental impact of intercontinental air travel with "carbon credits". Through the use of recycled materials – for the delegate bags – the avoidance of bottled water and keeping printed material to a minimum, we were able to make useful contribution to partially offsetting the damage. Happily, technology assisted us and we proved that the days of research scientists carrying paper and plastic posters across the world are now over. In the call for papers, 1405 abstracts were submitted, 1273 were accepted, and 977 were finally shown at the Congress – 123 orally by invitation and 854 as E posters. Abstracts were submitted digitally, and continuing this theme "E posters" were shown online and in the very well-attended "Abstract café". The format proved popular and we feel our decision to go with digital E posters was vindicated.

It is not a simple matter designing a World Congress programme, satisfying the curiosity of computational methodologies in CHD, integrating multimodal imaging, incorporating rotational angiography in the catheter laboratory, and yet ensuring the more common problems confronting the office cardiologist are adequately covered. There is no formula or magic recipe, and many months of discussions, meetings, consultations, and invitations were required. We feel the six tracks did justice to the diverse interests held within the World Congress of Paediatric Cardiology and Cardiac Surgery, and under the leadership of Scientific Chairman John Lawrenson and John Hewitson the International Scientific Committee did a commendable job. The "culture" of paediatric cardiac care is one in which we "work together". This is possibly true for cardiac care more than for any other area of tertiary health care. The cohort of people from junior to senior, across specialities, across nursing-physician "barriers", and together with the non-governmental organisations are marked by this common feature – that in every way possible, we work together. The World Congress of Paediatric Cardiology and Cardiac Surgery programme spoke for and to this reality, and the presentations and E posters can all be viewed at www.pccs2013.co.za.

Readers may find the challenges of financing large international meetings such as World Congress of Paediatric Cardiology and Cardiac Surgery of interest. We managed to attract a large industry exhibition with 74 companies exhibiting at 124 booths or stands. Most of these were South African subsidiaries of multinationals. Support for paediatric cardiology from the global pharmaceutical industry remains underwhelming and there were some glaring absences from medical device companies – despite the extraordinary 5-day structural heart disease intervention programme. One-third of the budget was generated by educational grants secured years before the congress from Tropicana, the South African hospital groups Netcare and MEDICLINIC, the Department of Health, and the National Lottery of South Africa. This backing enabled a successful six World Congress of Paediatric Cardiology and Cardiac Surgery and we are profoundly grateful to these institutions for their support. Despite the parlous state of the global economy, delegate fees were below that charged at the 5th World Congress of Paediatric Cardiology and Cardiac Surgery. Considering this is a 5-day meeting that included live cases, the fees were competitive with similar international cardiac congresses. Although not financially viable, the very cheap "super early bird" registration brought in over 300 paying delegates 10 months before the Congress, and those delegates served as a registration vanguard for other people from their institutions. Offering reduced rates for attendees from the less

well-resourced countries is an imperative. We followed the precedent set at the 5th World Congress of Paediatric Cardiology and Cardiac Surgery, with the World Bank "low income country" being the criteria. We believe it would be more appropriate to have low- and low middle-income countries and suggest this for the 7th World Congress. Surgeons and cardiologists from most of the world do not have the luxury of a world-class national meeting in their own country or own region every year, if ever. For them to learn from others and make their contributions to science, they need to travel. Of course, most of them hail from countries characterised by low incomes and poorly valued currencies, making international travel unaffordable. With assistance from PepsiCo, 35 World Congress of Paediatric Cardiology and Cardiac Surgery scholarships and travel grants were offered to scientists from Africa and low-income countries.

It was important for us that a project of this magnitude leaves a tangible legacy in South Africa. The Ministry of Health in our country, involved in many ways in the World Congress of Paediatric Cardiology and Cardiac Surgery, has at last taken note of the fact that the majority of children with heart disease in South Africa never get the necessary care or surgery they require and it has joined a dialogue towards finding a solution. A web-based multi-lingual patient-centred children's heart disease information system has already been launched thanks to the World Congress of Paediatric Cardiology and Cardiac Surgery and will be an enduring footprint. A free provider portal for registered clinicians from Africa is the second component of this initiative. However, the most important achievements of a World Congress must surely flow from the meeting of minds with sharing of new ideas and information, and this will be the intangible legacy. The outcomes develop slowly, out of reach, beyond awareness, and often without any measure or acknowledgement. The 6th World Congress held in Cape Town in February was the most important event in cardiac care to have ever been held in Africa. The number of delegates was three times greater than any other heart congress ever to have taken place on our continent and 1104 persons, a third of the attendees, were from Africa. The World Congress of Paediatric Cardiology and Cardiac Surgery in Africa created opportunities for many surgeons and cardiologists who have never had the benefit of attending or presenting their data in a global scientific forum. Together with our faculty of 366 – from 36 countries, we achieved something significant: an exciting, diverse forum in which to share ideas and provoke thinking, renew old and make new friendships, learn new things and explore innovative ideas, all with one common goal – the health of children with heart disease. To this end, it was a satisfyingly successful week.

Over the years, we have asked, why is there no global voice for children with paediatric and congenital heart disease? This was a recurrent theme across the health systems and heart disease track. Some have called for a "World Society for Paediatric and Congenital Heart Disease"[5,6] and the World Society for Paediatric and Congenital Heart Surgery suggested a "Global Organisation".[7] In 2011, the United Nations held a high-level summit on non-communicable diseases. There followed a September, 2011 "Political declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases". Although heart disease was recognised as one of the four non-communicable diseases, children's heart disease did not receive a mention.[8] The same is true of the programmes of the other UN institutions that are active in child health. Whereas the World Heart Federation has lobbied intensely together with other advocacy groups for adult heart disease, it is our collective responsibility to admit we have failed to ensure an effective international coalition speaking out for children with heart disease. It is time to recognise and accept a responsibility to spread, develop, and improve care for children and adults with congenital and acquired heart diseases. The Steering Committee of the "World Congress of Paediatric Cardiology and Cardiac Surgery" has now recognised it ought now to be at the forefront of developing an institution that is active and effective in global health and international public policy. Specifically, our vision is to raise awareness about paediatric and congenital heart disease, with a mandate for international advocacy to improve availability of cardiac services for children, and to drive campaigns with more specific disease-based preventative and therapeutic objectives. Furthermore, we believe this should be a democratic and inclusive institution with representation from the humanitarian organisations and advocacy groups active in the provision of cardiac services, as well as the paediatric and congenital heart disease societies active across the world. Parties have been invited to meet during the forthcoming 5th Congress of the Asia Pacific Pediatric Cardiac Society in New Delhi, India from 6 to 9 March, 2014 to consider the way forward.

The success of a World Congress is measured in many different ways. It is not just about numbers but about the simple and old values of friendship across boundaries of profession or borders of nation, fellowship, collegiality, getting together, cooperation, and collaboration. Personal contact will always

remain an endearing and irreplaceable value of these meetings. Hearing and meeting great people who have made new discoveries, invented wonderful things, or who have contributed to children's heart health in the most difficult of circumstances with meagre resources. Have faith – that this is what will ensure the survival of the World Congress of Paediatric Cardiology and Cardiac Surgery, and based on our experiences in Cape Town we expect that Istanbul, which is the destination for the 7th World Congress in 2017, will be the best ever and, for those for whom numbers are important, reach the magical figure of 4000.

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