

## TRACK 3: HEALTH SYSTEMS AND HEART DISEASE

### Abstract no: 2

#### Changing policy in screening low-risk pregnancies for fetal heart diseases can improve early detection of congenital heart disease: Lessons learnt from an integrated healthcare system

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**Background:** A large percentage of significant congenital heart disease (sCHD) is not detected in utero or immediately after birth. Pre-natal detection rates of sCHD of around 30% have been reported, even in the current era. Utilising the electronic medical record (EMR) in an integrated healthcare system, incidence, outcome and pre-natal detection rate of sCHD within a defined low-risk population was documented. Influence of policy to document fetal cardiac outflow tracts on screening pre-natal ultrasound was explored.

**Methods:** During a 6-year period, patients/fetuses <1 year of age with sCHD were identified. Mother and child EMR were used to gather data. Incidence was determined using the number of live births within the defined population and time period. The outcomes, pre-natal detection rate and post-natal timing of detection were documented. The pre-natal detection rate of patients undergoing cardiac surgery <1 year of age was compared to a similar group within the same healthcare system where there was no policy to document fetal cardiac outflow tracts.

**Results:** sCHD was identified in 101 patients/fetuses. The number of births within the same period was 25 666, giving an incidence of 4.0 per 1 000 live births. The overall pre-natal detection rate of these infants was 74%. Detection rate prior to discharge was 95%. A significant difference in pre-natal detection rates was found when there was a policy in place to obtain fetal cardiac outflow tract views in pre-natal screening (58 vs. 28%).

**Conclusions:** Within an integrated healthcare system and use of an EMR, a detection rate of sCHD of 95% can be demonstrated before hospital discharge and 74% can be detected in utero. A concerted programme that includes documentation of fetal cardiac outflow tracts in pregnancy screening can result in improved pre-natal detection of sCHD.

### Abstract no: 60

#### A national video conferencing system for paediatric cardiology

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**Background:** Sweden is a sparsely populated Nordic country with a population of 10 million, with 100 000 births annually. With only 32 paediatric cardiologists and 2 operating centres - all located in the major cities and university departments - rural small hospitals must rely on local paediatricians for primary diagnosis and early treatment of heart disease.

**Methods and material:** In order to help ensure correct diagnosis and optimal early treatment of congenital heart disease, a national video conferencing system was installed in all 36 hospitals with delivery units and paediatricians or paediatric cardiologists on call. A commercially available codec was customised for high-resolution (1 080p) and high frame-rate (60fps) video conferencing. Dual streaming over a secure national broadband network allowed for part-to-part conferences. Up to all 36 hospitals could participate simultaneously. The Swedish Heart-Lung Foundation financed the system that was installed in 2011.

**Results:** The system is frequently used by small hospitals for acute consultations with university departments and operating centres. Echocardiographic examinations are presented and discussed. Decisions are made on acute treatment, time and mode of transportation and information given to referring paediatricians and parents. Life-saving decisions have been made using the system. Follow-up outpatient visits have been made with the patients, parents and paediatricians in the remote local hospital and the paediatric cardiologist or cardiac surgeon at the university centre. The system is also used for training, clinical rounds, research and business meetings.

**Conclusions:** This telemedicine video conference system and network facilitates an improvement of diagnostic skills and enhances knowledge about heart disease in infants and children, especially in the small hospitals. It gives both the patients and the local paediatricians access to instant specialist knowledge and provides operating centres improved information about patients to be referred for treatment. Infants with critical heart disease arrive in a better condition and results are likely to be improved.

### Abstract no: 68

#### Pattern of cardiac disease among patients in a paediatric cardiac clinic

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**Background:** JUSH is the only specialised referral hospital in south-western Ethiopia. Paediatric care is given by specialist and subspecialist doctors. Cardiac diseases are one of the leading causes of morbidity and mortality in children. Both congenital and acquired heart diseases are common in children. The paediatric cardiac clinic gives regular follow-up for these groups of patients every Friday afternoon.

**Methods:** A retrospective chart revision was made in those paediatric patients who came to JUSH and were diagnosed with cardiac illnesses and on follow-up. Data collected from a structured questionnaire was filled in by the physician at the time of chart review. Analysis using SPSS version 16 was made after clearing the data.

**Result:** Mean age of patients was 3.8 years with 51% females, and mean duration of follow-up was 1.3 years. Echocardiography was done for 89% of patients who were on follow-up in the paediatric cardiac clinic. Acquired heart disease scored the highest value, with a predominance of CRVHD. Among congenital heart disease patients, ventricular septal defect (VSD) was the leader, followed by patent ductus arteriosus (PDA) with 50 and 21% prevalence, respectively.

**Conclusion:** The majority of patients were receiving echocardiography at the time of follow-up. The leading cause of cardiac illness in our children is still CRVHD from acquired, and VSD from congenital heart diseases respectively. A more detailed study needs to be done to find further management options.

**Abstract no: 189**

**The development of paediatric cardiac surgical nursing in Mongolia**

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**Introduction:** The mission of WSPCHS is to promote the highest quality comprehensive care to all patients with paediatric and/or congenital heart disease. As mission teams help developing countries establish paediatric cardiac surgery programmes, the mission of the WSPCHS must be extended to include nursing; realising that perfect surgical repair is not enough to assure a successful recovery.

**Methods:** Since 2005 the Mongolian Minister of Health has invited a team from the United States to Mongolia to perform cardiac surgery and catheterisation procedures for children with congenital and acquired heart disease. Each year a nursing conference is conducted in collaboration with the nursing department at Shastin Medical Centre in Mongolia. Mongolian ICU nurses then partner with a visiting nurse to care for the children after surgery. The goal is that for the Mongolian nurses is to will be fully responsible for the care provided by the end of the week.

**Results:** Since 2005, over 350 nurses have attended the conference and 840 hours of clinical mentoring have been provided. In addition, nursing rounds have been conducted each year to encourage the Mongolian nurses in their roles. The team has provided over 200 stethoscopes and provided assessment training and practice. The nurses, who had never used stethoscopes before our team's arrival, have used their new assessment skills with the post-operative patients.

**Discussion:** This abstract describes one mission team's efforts to improve the post-operative nursing care of children in Mongolia. The nurses in Mongolia have been eager to learn and have taken seriously their role in the success of a paediatric cardiac surgery programme for their country. In order to meet the mission of the WSPCHS, education and training of nurses must be included whenever cardiac surgery teams are working in developing countries.

**Abstract no: 191**

**Medical mission or outreach clinic? Operationalising paediatric cardiology services with a portable electronic medical record (EMR) and medical scribe**

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**Background:** We operationalised our paediatric cardiology services in the Federated States of Micronesia (FSM). Located in the Western Pacific Ocean just north of the equator, FSM comprises 600 islands spread over an area of 1 000 000 square miles and is a medically underserved area. Previous outreach trips took 5 weeks and consisted of a visit with a brief handwritten entry in the patient's medical record. Our team consisted of a paediatric cardiologist, an echocardiography technician with a portable Philips CX-50 echocardiography machine, and a medical scribe for data entry.

**Aim:** Using a portable EMR we hypothesised that we could improve the efficiency of our outreach. In addition, we sought to characterise the spectrum of congenital and rheumatic heart disease (CHD and RHD) in the region.

**Methods:** We created a customised mini-EMR using a Microsoft Excel® spread sheet. Drop-down lists with common diagnoses, surgeries, physical examinations, echo findings and medications were used to fill in the spread sheet. Additional data were free-texted as needed. Data entry for each patient took <2 minutes by the medical scribe and a consultation note was generated using the Mail Merge feature in Microsoft Excel®.

**Results:** We evaluated 328 patients on 4 different islands over a period of 3 weeks (compared to 5 weeks previously). The portable EMR generated comprehensive individualised notes with complete treatment plans for local providers. Perimembranous and/or supracristal VSDs are the most common forms of CHD in this population. The clinical spectrum of RHD is similar to previous studies of Asian/Pacific islanders.

**Conclusions:** We improved the efficiency of our paediatric cardiology outreach services to FSM using a customised portable EMR along with a medical scribe for data entry. In addition, we documented the clinical spectrum of CHD and RHD in this region.

**Abstract no: 229**

**Innovative organisational strategy for critical congenital heart disease**

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**Objective:** We described an innovative organisational strategy for neonates who have prenatal diagnoses of critical congenital heart disease (cCHD) with a focus on the earliest surgical repair, using autologous umbilical cord blood (AUCB). The programme, First Hours of Life Cardiac Surgery, was innovated and applied at the Ukrainian Children's Cardiac Centre.

**Methods:** From September 2009 - May 2012, 350 neonates with cCHD were operated on at our institution. For patients with pre-natal diagnoses, new management was proposed. This included:

- Re-examination by Echo at the 36th week of gestation to confirm the diagnosis;
- Checking the pregnant women for blood infection and referring them to the maternity department;
- Planning labour for an early morning on a working day by induction or Caesarean section due to the obstetric indications;
- Harvesting of AUCB in utero and testing it at the blood transfusion service in accordance with standards for blood products;
- Immediate transfer of the newborn to the cardiac department;
- Complete primary surgical repair of cCHD in the 1st hours of life after specification of the anatomy; and
- Using AUCB for peri-operative blood management.

**Results:** During this period, 47 neonates underwent the new strategy. In 27 cases (57%) labour was induced, and 20 patients (43%) were delivered through Caesarean section. Mean volume of harvested cord blood was  $85 \pm 24$  ml (50 - 140). Neonates were admitted to the cardiac department within an hour of birth. Mean age at operation was  $3.9 \pm 1.1$  hours (2 - 6). No patients required ICU admission, interventional procedures, mechanical ventilation or medications before surgery, which resulted in significant positive economic effects, compared with the conventional approach. 37 neonates (78%) underwent open cardiac surgery without homologous blood transfusion.

**Conclusion:** The proposed innovative organisational strategy for cCHD allows avoidance of pre-operative ICU stay, balloon atrio septostomy and reduction in homologous blood transfusions, and shows significant positive economic effect.

#### Abstract no: 255

### Attending to the unattended: Establishment of the 1st paediatric cardiology outreach clinic in Uganda

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**Background:** The burden of paediatric cardiac disease in the developing world is substantial and under-resourced. Several million children in sub-Saharan Africa suffer with acquired conditions such as rheumatic heart disease (RHD) and endomyocardial fibrosis (EMF). >90% of these children live in areas of inadequate or absent care. Our aim was to create an outreach clinic in an under-served community in Uganda to address this care deficit.

**Methods:** A paediatric cardiology outreach clinic was started in the Luwero region of Uganda in 2011. This clinic was a coordinated effort between Kiwoko Hospital (clinic site) and the Uganda Heart Institute. Funding for the clinic was established by the Uganda Heart Institute and the ISIS Foundation (a non-governmental organisation). Kiwoko Hospital supplied a portable echocardiogram machine (Acuson Cypress Portable Ultrasound) and laboratory support. Prescriptions were supported by the National Medical Stores. The Uganda Heart Institute provided skilled clinic personnel.

**Results:** A total of 4 outreach clinics took place in 2011. The mean number of patients seen was 11 (range 7 - 15). The cost of a single clinic day was 650 000 Uganda shillings (\$263 US dollars), covering allowance for 2 outreach doctors, 2 outreach nurses, a single driver, and 40 l of fuel. Several conditions were identified, including: EMF; RHD; non-pathologic murmurs; and patent ductus arteriosus. All of the patients cared for in the clinic did not have the necessary means to pursue care outside of their local community. Follow-up was successfully managed for several patients.

**Conclusion:** The outreach clinic represents the first-ever successful and sustained paediatric cardiology outreach clinic in Uganda. The financial cost of the clinic is not over-burdensome, and the clinic allows children to obtain much-needed subspecialty care. Efforts are ongoing to expand the number of patients served and to improve the available diagnostic and therapeutic tools.

#### Abstract no: 312

### Impact of an integrated electronic health record system on paediatric cardiac clinic documentation at a tertiary healthcare facility

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**Background:** We hypothesised that the introduction of an Electronic Health Record system (EHR) in an ambulatory clinic setting would significantly improve time-lines and uniform availability of paediatric cardiology consultation reports.

**Methods and results:** Clinic report records of 3 full-time paediatric cardiologists were reviewed for 4 consecutive typical weeks (fully staffed for 5 days, not preceding prolonged physician absence >1 week) immediately before rollout of an integrated EHR and from 4 consecutive typical weeks 1 year later. Pre-EHR reports (164 in total) were prepared from transcribed dictation with subsequent editing by a physician. Documentation methods of post-EHR reports (159 in total) varied by physician. Total report preparation time (RPT) was defined as the number of days from patient visit to final signature and report release.

**Conclusions:** Institution of an integrated EHR at this tertiary healthcare facility significantly reduced out-patient consultation report preparation times on average over 65% (>1 week), and markedly improved uniformity of practice among physicians, despite variable documentation methods. Prior performance did not predict results post-EHR. EHR benefits included improvements in patient care communication with positive implications for referring provider satisfaction and healthcare system fiscal performance.

#### Abstract no: 402

### Parent education and discharge instruction: Themes from India

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**Background:** Discharge teaching has been associated with improved patient and family satisfaction and earlier recognition and treatment of complications. Traditionally, in developing countries physicians give orders and nurses carry out those orders. The role of the patient and family discharge teaching is not typically within nurses' scope of practice. We hypothesised that Indian nurses can effectively expand their role to include discharge teaching for parents after a child's cardiac surgery.

**Methods:** Study participants were recruited from a tertiary paediatric heart hospital in India. Paediatric cardiac nurses and parents of children undergoing cardiac surgery were eligible to participate in the qualitative aspect of this mixed-methods study. Study participant interviews were conducted by the PI with assistance from a trained Indian interpreter and translated into English. Methodological and conceptual memos were developed and a multi-phase analysis occurred. The research team read the text and open-coded data according to themes. The thematic analysis included a group discussion for salient themes among several researchers and coding by 2 separate researchers. Salient themes were integrated into higher-order categories and given conceptual labels. The meanings of these categories were interpreted and validated by data illustration.

**Results:** 3 themes were generated from the study and included role expansion, agency, and easing recovery for nurses and parents. Nurses and parents reported taking an active role in contrast to their previously passive role during a child's transition to discharge. This active role was described as satisfying to nurses and parents alike.

**Conclusions:** Parent teaching offers an opportunity for nurses to help parents care for their sick children.

#### Abstract no: 490

### Improvement in results and progress of independent surgery with international co-operation in a single Ukrainian centre

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**Background:** Surgery for congenital heart disease has been slow to develop in parts of the Ukraine. We describe the impact of our 4-year surgical collaborative assistance programme between the International Children's Heart Foundation (ICHF) and Institute of General and Urgent Surgery, AMS of Ukraine, Kharkov.

**Methods:** Data were analysed from ICHF and Kharkov databases prior to and since commencement of assistance (era A: January 2000 - May 2008, era B: May 2008 - May 2012). We evaluated differences between era A and era B for: case volume per year, ( $\pm$ SD), 30-day/hospital discharge mortality, case complexity (RACHS-I model), and RACHS adjusted standardised mortality ratio (SMR: observed/expected mortality). For era B, we evaluated year-by-year the number of collaborative operations where a Ukrainian surgeon was the primary operator.

**Results:** In era A, 154 surgeries were performed; mean annual case volume was  $17.3 \pm 4.8$ , with an overall mortality of 4.55% and an SMR of 3.6. RACHS category I comprised 75% of the total. In era B, 361 surgeries were performed. Mean annual case volume increased to  $90.2 \pm 30.9$  ( $p < 0.001$ ) with higher case complexity, and an overall mortality of 5.82% and SMR of 1.6. In era B, 237 surgeries were performed during 16 trips, 124 between trips; 140/237 (59.1%) cases were led by a Ukrainian surgeon with either the visiting surgeon (87/140) or local surgeon assisting (53/140).

**Conclusions:** An assistance partnership in the model applied significantly reduced mortality, increased case volume and complexity, and developed independent operating skills in an economically disadvantaged centre in a relatively short time period. This model of assistance to developing countries is not "surgical tourism", and should always be open to scrutiny and evaluation by proven clinical and educational outcomes.

#### Abstract no: 494

### Real time mobile tele-medicine using scalable video coding for neonatal heart disease

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**Background:** An efficient system of real-time tele-medicine requires being applicable to a variety of devices and networks that consulting medical providers utilise. Scalable video coding (SVC) enables a video stream to be broken into multiple resolutions, quality levels and frame rates, and to be flexibly conformed to device capabilities and network conditions. We evaluated the applicability of H.264/SVC to neonatal tele-echocardiography and devised a system of real-time mobile tele-medicine using SVC for underserved and disaster regions in east Japan.

**Methods:** Echocardiograms of newborns with critical congenital heart disease with resolutions of  $640 \times 448$  and frame rates of 30fps were encoded into 2 layers for scalability with resolutions of  $640 \times 448$  and  $320 \times 224$ . Four sets of bit-rate were tested; no compression, 2mbps, 1mbps and 0.5mbps. Images were coded by VP8 system and randomly transmitted to decoders in 3 device/network conditions; PC/local network, PC/wide area network (WAN) and tablet/WAN. Fifteen blinded board-certified paediatric cardiologists subjectively assessed images and scored between 0, i.e. unsuitable for diagnosis and 1.0, i.e. compatible with normal studies. Subjective assessments were compared with objective quality metrics peak signal-to-noise ratio (PSNR).

**Results:** In PC/WAN condition, SVC images with resolutions of  $640 \times 448$  required bandwidths of more than 1mbps to get average scores of 0.5 or more. At bandwidths less than 1mbps, scores for images with resolutions of  $320 \times 224$  were significantly higher than values for  $640 \times 448$  images (0.47 vs. 0.27). Images in tablet/WAN condition at 1mbps scored 0.42. Subjective assessments were significantly correlated with PSNR. An application (Video Inc) using SVC showed successful transmission of images with  $950 \times 540$  and 30fps at 768kbps on mobile devices in a pilot LTE environment, allowing interaction between participating medical staff.

**Conclusion:** The real-time mobile system using SVC may be useful for neonatal tele-cardiology in a unreliable wireless network.

**Abstract no: 539****Save a child's heart: Specific ethical questions in a charity programme****Akiva Tamir**<sup>\*,#</sup>, **Sion Hourii**<sup>\*,†</sup>, **Alona Raucher Sternfeld**<sup>\*,#</sup>, **Ilan Cohen**<sup>\*,†</sup>, **Livia Kapusta**<sup>\*,#</sup>, **Sagi Assa**<sup>\*,#</sup> and **Lior Sasson**<sup>\*,‡</sup><sup>\*</sup>Save a Child's Heart, Israel, Holon, Israel<sup>#</sup>Paediatric Cardiology Unit, Edith Wolfson Medical Centre, Holon, Israel<sup>†</sup>Paediatric Intensive Care Unit, Edith Wolfson Medical Centre, Holon, Israel<sup>‡</sup>Cardiothoracic Surgery Department, Edith Wolfson Medical Centre, Holon, Israel

**Background:** Save a Child's Heart is a charity programme that has treated over 2 900 paediatric cardiac patients from 43 underdeveloped countries during the past 17 years. Throughout the years many ethical questions have arisen.

**Aim:** The purpose of this presentation is to table these questions, describe our approach to solving them and open the subject for further discussion.

**Method and materials:** A relative paucity of available openings for treatment due to both money restraints and bed limitations imposes ethical problems that are not faced by most programmes. Patients' acceptance into the programme induces a conflict between the referring and accepting systems due to the medical severity of cases, chances of success and, sometimes, due to secondary benefits.

**Results:** The feasibility of further medical follow-up needs to be considered before acceptance into a charity programme, especially if there is a potential need for a prosthetic valve or a pacemaker, and the possible continuation of expensive medications. A very important issue is whether patients should be admitted for palliative treatment, considering the availability of future surgeries and catheterisation as a part of the planned repair of the specific patient. As a paediatric charity, what is our commitment to adults who were treated by us as children?

**Conclusions:** Air travel is a risk for cyanotic children. Are there benefits in a medical escort on the flight and, if not available, should we avoid transferring cyanotic children for treatment? In charity programmes where the parent and physician have a language and cultural barrier, the meaning of consent forms is questionable. There is a relative absence of parental supervision and when parents have no choice, quality control may be jeopardised. So far we have dealt with all these questions in accordance with our personal and cultural morals and attitude. These dilemmas are open for different approaches and merit further discussion.

**Abstract no: 585****Hospital variation in post-operative infection and associated outcomes following congenital heart surgery****Sara Pasquali**<sup>\*</sup>, **Xia He**<sup>#</sup>, **Marshall Jacobs**<sup>†</sup>, **Matthew Hall**<sup>‡</sup>, **J. William Gaynor**<sup>§</sup>, **Samir Shah**<sup>¶</sup>, **Eric Peterson**<sup>¶</sup>, **Kevin Hill**<sup>¶</sup>, **Jennifer Li**<sup>¶</sup> and **Jeffrey Jacobs**<sup>¶</sup><sup>\*</sup>CS Mott Children's Hospital, University of Michigan Medical School, Ann Arbor, Michigan, United States of America<sup>#</sup>Duke Clinical Research Institute, Durham, North Carolina, United States of America<sup>†</sup>Cleveland Clinic, Cleveland, Ohio, United States of America<sup>‡</sup>Child Health Corporation of America, Shawnee Mission, Kansas, United States of America<sup>§</sup>The Children's Hospital of Philadelphia, University of Pennsylvania School of Medicine, Philadelphia, United States of America<sup>¶</sup>Cincinnati Children's Hospital Medical Centre, Cincinnati, Ohio, United States of America<sup>¶</sup>Duke University School of Medicine, Duke Clinical Research Institute, Durham, North Carolina, United States of America<sup>¶</sup>All Children's Hospital, St Petersburg, Florida, United States of America

**Background:** While previous studies demonstrated the association of post-operative infection with morbidity and mortality following congenital heart surgery, variation across hospitals has not been well described. This study evaluated hospital infection rates across a large multi-centre cohort, and association with other hospital-level outcome measures.

**Methods:** The Society of Thoracic Surgeons Congenital Heart Surgery database was linked to resource utilisation data from the Paediatric Health Information Systems Database for hospitals participating in both databases (2006 - 2010). Hospital infection rates (sepsis, wound infection, mediastinitis, endocarditis, pneumonia) adjusted for patient risk factors; case mix and delayed sternal closure were calculated using Bayesian methodology. Association with hospital mortality rate, post-operative length of stay (LOS), and total costs were evaluated.

**Results:** The cohort included 32 856 patients (28 centres). Across hospitals, the adjusted infection rate varied from 0.9 - 9.8% (median 4.1%). The most common types of infection were sepsis (51%) and wound infection (35%). On a patient level, infection was associated with increased mortality (OR 2.8, 95% CI: 2.2 - 3.6,  $p < 0.001$ ), prolonged LOS (25.5 vs. 11.2 days,  $p < 0.001$ ) and increased hospital costs (\$115 800 vs. \$63 300,  $p < 0.001$ ). Similar results were observed when hospitals at the extremes of infection rates were excluded. Hospitals were divided into tertiles according to adjusted infection rate. Hospitals with the highest infection rates (vs. lowest) had longer average LOS (13.2 vs. 12.0 days,  $p < 0.001$ ) and hospital costs (\$70 900 vs. \$58 200,  $p < 0.001$ ), but no significant difference in mortality (OR 0.9, 95% CI: 0.7 - 1.1,  $p = 0.2$ ).

**Conclusions:** Post-operative infection following congenital heart surgery contributes to prolonged LOS and increased costs on a hospital level. Initiatives aimed at reducing post-operative infection may reduce variation and improve outcomes across centres.

**Abstract no: 702****Tracking cardiovascular morbidity: Utility of a hand-held device to monitor cardiovascular complications****Derek Human**<sup>\*</sup>, **Sanjiv Gandhi**<sup>\*,#</sup>, **Andrew Campbell**<sup>\*,#</sup>, **Martin Hosking**<sup>\*</sup> and **James Potts**<sup>\*</sup><sup>\*</sup>British Columbia Children's Hospital, Vancouver, Canada<sup>#</sup>University of British Columbia, Vancouver, Canada

**Background:** In this era of declining cardiovascular mortality, other measures of quality assurance (QA) become important. We have previously described the utility of a hand-held device to track complication rates (chosen from a pre-defined pick list including all body systems) related to cardiac procedures [cardiac catheterisation, closed-heart surgery or open-heart surgery (OHS)].

**Objective:** To record the complication rate for OHS and document variation related to changes in clinical practice.

**Methods:** Five cardiologists used Palm OS-based software (Smart-list to Go) to enter all procedures and related complications. Data were analysed over 5 years, the last 2 years encompassing changes in surgical and peri-operative practice aimed at facilitating early extubation and decreasing ICU and hospital length of stay (LOS).

**Results:** Complication rates were expressed as total number per 10 OHS, and rates were summarised quarterly with 95% confidence limits (CI). In the past 2 years, complications have decreased significantly from 5.2 (CI 4.6 - 5.8) per 10 procedures to 3.0 (CI 2.4 - 3.6) per 10 procedures ( $p < 0.0001$ ). The rate in each era has remained stable and, despite an increase in case complexity in the recent era, the ICU (6.3 vs. 2.6 days,  $p < 0.0001$ ) and hospital LOS (12.6 vs. 6.2 days,  $p < 0.0001$ ) have decreased.

**Conclusions:** Implementation of new strategies for reducing patient morbidity, ICU and hospital LOS has been successful. Control charts with quarterly rates for all complications were readily derived, and these allow estimation of current morbidity trends. The effect of QA processes can be assessed in a timely manner.

**Abstract no: 772**

**Beating the odds: An original adventure in favour of Mexican children with congenital heart disease**

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**Background:** Mexico has a total population of 112 336 538, a population growth index of 1.40, and every year 21 151 babies are born with congenital heart disease, the 2nd biggest cause of child mortality before the age of 5.

The country has 10 public hospitals that can perform paediatric heart surgery but with >50 million people living in poverty, all the public hospitals are overcrowded, with not enough infrastructure or human resources to give appropriate attention to our heart patients.

An estimation of the number of annual surgeries that are performed on paediatric patients per year in public and private hospitals hardly reaches 25% of the children that are at risk. Some children are born into a family that can pay for medical attention in a private hospital, but the majority of Mexicans have no medical cover or social security. These families need our help the most.

The country faces a serious health problem that is difficult to change. On the one hand it has public hospitals that have many heart patients who cannot pay for private medical attention, or, because of the large number of cases treated, cannot be cared for by best heart specialists.

On the other hand, private hospitals have money to spend but few cases to work on, and do not support the huge investments required for medical equipment, human resources and training. We decided to transform this situation, joining 3 groups together: a private hospital, a government-funded paediatric hospital and a foundation dedicated to the medical care of children with congenital heart disease. We share our strategy, programme, and how we have started to make it work.

**Abstract no: 888**

**Can a comprehensive congenital programme with limited resources which can maintain quality outcomes be developed in Russia?**

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**Background:** Worldwide <15% of children born with congenital heart disease have access to appropriate medical care.

**Aim:** To evaluate the effectiveness of the Heart-to-Heart International Children's Medical Alliance's multi-disciplinary training programme to improve the care of children with congenital heart disease in Russia by creating sustainable centres of excellence.

**Methods:** The process begins with site assessment encompassing evaluation of medical, administrative, governmental support and desire for the programme. It is followed by a multi-year commitment to the US - Russian training programme consisting of:

- Strategic guidance and team building: year-round guidance on programme development, and specific recommendations for the "next steps";
- Data collection and analysis: for detailed feedback to improve results;
- Annual surgical educational missions: the Heart-to-Heart team works side-by-side with Russian colleagues to diagnose, perform cardiac surgery and catheterisation, and provide post-operative care;
- Scholar exchange: Russian physicians travel to centres of excellence in the USA or Russia, and attend international conferences; and
- Continuing education: professional educational materials, participation in US journal clubs, and attending medical conferences.

**Results:** Composite outcome data from 2 centres (Samara and Tomsk) are presented. Over a 5-year time frame, the total number of cardiac operations increased from the baseline 186 in year one to 514 in year 5; the complexity of cases RACHS 3 - 6 increased from 11.5 - 26.5%; children less than 12 months of age at the time of surgery increased from 21 - 46%; mortality decreased from 14 to 4%. The median cash expenditure per site per year was 99 612 USD (range 73 977 - 182 030 USD).

**Conclusions:** The goal of creating a comprehensive, sustainable programme to care for children with congenital heart disease can be accomplished in a fairly short period of time with modest financial investment. The individualised, multi-disciplinary training and educational strategy developed by Heart-to-Heart International Children's Medical Alliance has proven successful in increasing patient complexity over time, with excellent surgical results.

**Abstract no: 946****Save a child's heart: 17 years of activity**

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**Background:** Save a Child's Heart (SACH) is a hospital-based, non-governmental organisation founded by Dr Ami Cohen in 1994 at the Wolfson Medical Centre in Israel.

**Aim:** Its goal is to improve the cardiac care of children with heart diseases from developing countries.

**Methods & material:** This is achieved through 2 main channels: (1) treating children with heart disease through surgery and/or cardiac catheterisation in Israel, and (2) training medical personnel from partner countries. >2 900 children have been treated so far and >70 physicians and nurses have been trained. The main mode of action is by direct cooperation with a medical facility trying to help their patients.

**Results:** 50% of our patients are Palestinians, referred by their local physicians to our free clinic for further treatment. With regard to children from our overseas partner countries, we travel to the country to screen patients, discuss their problems with the local team and the child is wait-listed to be brought to the SACH centre in Israel. In addition, we offer training positions in an attempt to build a local team who will treat their own patients. As a part of this endeavour, we also go on surgical missions to the partner country and operate together with the local team. Individual patients who contact us via different channels are also accepted according to feasibility of treatment.

**Results:** The presentation will describe our activity during the past 17 years, the structure of the organisation, mode of action, problems and achievements.

**Abstract no: 1014****State of the art humanitarian paediatric cardiac missions: A design for sustainable delivery of assistance**

**William Novick<sup>\*,#</sup>, Frank Molly<sup>#</sup>, Christian Gilbert<sup>#</sup>, Martina Pavanic<sup>#</sup>, Stacey Marr<sup>#</sup>, Caroline Lonsdale<sup>#</sup> and Kathleen Fenton<sup>#</sup>**

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**Background:** Paediatric cardiac development assistance is widely but sporadically practiced. The delivery of >1 assistance mission per year is beyond the ability of many centres. We describe an organisational structure enabling the sustained delivery of assistance through a NGO-based multi-national, multi-institutional team-member approach. Our results over the last 20 years are presented.

**Methods:** The database of the NGO was reviewed since its inception in 1993. Totals were harvested for: trips made; sites of assistance; number of team members; country and institution of origin of team members; and number of operations. Data were analysed by 5-year periods (eras) for differences. A p-value of <0.05 was considered significant.

**Results:** Total number of years of assistance was 20. Total team members were 3 578 on 289 trips. Team members came from 106 institutions in 43 countries. The average number of trips and team members/year increased between all eras ( $p < 0.001$ ) from 3.6/48 in era 1 to 29.0/401 in era 4. The maximum number of trips in a year was 36, requiring 509 team members. The number of institutions and countries of origin of the team members increased over time and the average was significantly different between eras ( $p < 0.01$ ). The single largest number of institutions and countries represented on a trip was 13 and 11. Previous recipients of assistance became team members in 2000. A total of 26 countries have received assistance, with the greatest number of trips and operations provided in Central America and Asia, at 61/1 132 and 58/1 128, respectively.

**Conclusions:** Paediatric cardiac education and service can be provided to multiple sites simultaneously utilising this model. We are not aware of a single hospital, institution or charitable entity that can provide a similar level of assistance.

**Abstract no: 1024****Necessity of bio-medical engineering support on humanitarian medical missions**

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**Background:** Due to less complex technology for medical equipment in the past, there was little emphasis placed on the importance of biomedical engineering support for humanitarian medical missions. However, as the evolution of technology for medical equipment progressed at a rapid pace, and the complexity of procedures increased, it is evident that the role of biomedical engineering has expanded. An education in this field is not enough. A discipline in computer engineering, anatomy and physiology, and knowledge of equipment that is procedure-specific must be incorporated. In under-developed countries, it is quite common for these disciplines to simply not exist.

**Methods:** Data were analysed from ICHF's (International Children's Heart Foundation) database over the past 5 years. During this period, a total of 677 pieces of medical equipment was sent to 23 locations in 16 different countries. Some specific types of medical equipment included; patient monitors; anaesthesia machines; cardiopulmonary bypass machines; ventilators; defibrillators; electro-surgical units; syringe pumps; hypo/hyperthermia units; and cardiac echo ultrasound units. Additionally, the ICHF biomedical engineering staff/volunteers have made 49 trips to provide biomedical engineering support and emergency repairs.

**Results:** The analysis provides a common link between the various types of equipment needed across all developing countries where humanitarian medical programmes have been started.

**Conclusions:** The ICHF has created a paradigm shift and raised the bar of expectation on the level of education and expertise for biomedical engineering support. This support is defined as installing, servicing, repairing and providing staff training on biomedical equipment. The end result has allowed ICHF medical programmes in developing countries to grow at accelerated pace, by ensuring better patient safety and improving surgical results.

**Abstract no: I116**

**Rheumatic heart disease health worker training and system strengthening in 4 Pacific island nations**

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**Background:** The Pacific region has the highest documented rheumatic heart disease (RHD) prevalence globally. Since 2005 the World Heart Federation and Menzies School of Health Research have been working to strengthen rheumatic heart disease prevention and control with Pacific Island nations. Additional funding was secured in 2011 to assist 4 additional Pacific countries, Nauru, Tuvalu, Kiribati and the Solomon Islands.

**Methods:** The programme is based on WHO international recommendations for register-based prevention and control. An Australian-based team assists local staff from the Ministries of Health to expand capacity and strengthen existing activities.

**Results:** Health professionals from the 4 Pacific countries have received RHD training. Each country has been supported to develop clinical information materials, patient injection cards and national protocols for the diagnosis and prevention of ARF. A regional RHD trainer's manual has been developed to support local staff to extend RHD training to health workers on the outer islands and provinces. National registers have been developed for each country. In Nauru, 2011 baseline data showed that 46% of patients were receiving 50% or more of their injections. Echocardiography screening to define baseline burden of disease has been conducted, showing a prevalence of 15.1/1 000 in Nauru and 35.1/1 000 in Tuvalu. Screening will be conducted in the Solomon Islands and Kiribati in 2012 - 2013. A community and patient-education campaign plan has been developed, which includes: patient-peer support groups and multi-media campaigns to raise awareness of ARF and RHD.

**Conclusion:** The Pacific RHD programme has seen an increase in disease notification and awareness among health staff and the community. It is anticipated that system and capacity strengthening will contribute to a more sustainable programme, including a more efficient and user-friendly service for patients and an increase in the delivery of secondary prophylaxis in patients, and improve primary healthcare for RHD patients.

**Abstract no: I162**

**Donor expectations in paediatric surgery: Are the selection criteria justified?**

**Lynda Bleazard**

Former CEO, Walter Sisulu Paediatric Cardiac Foundation, South Africa

**Background:** The purpose of this research was to determine the best practice in case selection to ensure that the use of donor funds is effective for sustainable and maximum impact. Bearing in mind that the objective of donors is to save as many children per donated rand as possible, it is therefore incumbent that the Foundation's selection committee select cardiac cases that are correctable with a good prognosis and outcome. The researcher created a strategy to guide the members of the selection committee in their selection of cardiac beneficiaries. The cases selected should have predictable, good outcomes that meet the donors' expectations and achieve sustainability for the Foundation.

**Methods:** The research question is: How can donor funding be allocated in a fair, evidence-based and sustainable way to achieve maximum beneficial impact on indigent children requiring cardiac surgery in Africa? I chose to do a focus group and held a question-and-answer group interview and discussion with 15 people selected from all of the Foundation's stakeholder parties.

**Outcomes:** The key outcomes of the focus group included the need for surgical hubs to be developed in Africa and skills transfer to occur, the correct diagnosis being key to the outcome of the cases selected, the selection of complex cardiac cases directly impacting on the costs involved, and the appropriate use of donor money being in keeping with the avoidance of selecting cases that may have difficult outcomes and extended in hospital length of stay.

**Conclusion:** We want WSPCF to make a real difference in the lives of children with cardiac disease on the African continent. The result of this study shows that the current selection criteria are sound and meet the donor expectations.

**Abstract no: I168**

**Challenges in implementing a paediatric cardiovascular home tele-health project**

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**Background:** Infants with single-ventricle physiology are at high risk of sudden death following discharge (8 - 12%) despite palliative management, presumably due to intravascular volume depletion, shunt occlusion, and/or arrhythmia. Therefore, we developed a pilot home tele-medicine project to evaluate the feasibility of using web-based daily reporting of clinical parameters to reduce unscheduled events and death.

**Methods:** Subject enrolment began following IRB approval. We enrolled 6 single-ventricle subjects following palliation over a 12-month interval. Parents electronically recorded and transmitted daily weight and peripheral oxygen saturation data then completed an automated 10-point phone questionnaire related to nutrition, activity and distress. Subject enrolment in the project continued until a 2nd palliative surgical procedure (n = 4) or sudden death (n = 2). All transmitted data were managed on a customised website with hardcopy backup. We collected comprehensive clinical data in all enrolled subjects and 12 historical controls. We analysed subject clinical management including success in out-patient telephone surveillance, scheduled and unscheduled office and emergency room (ER) visits, hospitalisations, procedures and adverse events, including death.



**Results:** Subject recruitment was more difficult than expected. We found a high success rate in transmitting subject weights but poor correlation between oxygen saturation values measured by the study saturation monitor and monitor provided to discharged patients (Massimo). Success rate for out-patient telephone surveillance for historical controls, independent of this tele-medicine project to date was approximately 30%. After technical adjustments, all enrolled subjects (100%) were able to transmit questionnaire data. There were 14 unscheduled ER visits for controls versus 2 ER visits for study subjects. Sudden death occurred in 1/12 controls and 2/6 enrolled subjects.

**Conclusion:** Home tele-medicine monitoring for high-risk patients with congenital heart defects is feasible, may reduce unscheduled visits, but may not impact on the primary endpoint of preventing sudden death.

#### Abstract no: 1587

### Preparation of the visiting team for technology transfer to 3rd world countries

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**Background:** The visit of a medical team for the purpose of technology transfer from the developed world is a useful tool in capacity building of cardiologists and cardiac surgeons in 3rd world countries. Such visits, when taking place between 2 countries with diverse socio-economic conditions, involve a number of difficult issues. The visitors are often not aware of these facts, which reduce the effectiveness of their dedication and effort. Between 1996 and 2012, we had the experience of hosting 15 foreign teams or individuals in Bangladesh for technology transfer. Various arrangements had to be made for them. Sharing those experiences through this article may be of interest for the future visitors.

**Methods:** Hospital records served as the major source of information. The involved doctors, nurses and other staff were interviewed. We also contacted the visitors for their comments. After collection of all data, we discussed our own experiences and compiled it in an organised manner.

**Results:** The important issues for the visitors, identified by our research are addressed under the following headings:

- Selecting a suitable site for the visit;
- Need assessment of the recipient institute;
- Travel and immigration;
- Government permission and registration issues;
- Safety and security;
- Arranging logistic support;
- Patient selection and management;
- Local hospitality and team healthcare;
- Organising technology transfer;
- Budget and finance;
- Press and media; and
- Conclusion and reporting.

**Conclusions:** Visiting a 3rd world country for the purpose of technology transfer is often not an easy job. There are a number of issues making it a highly specialised subject. Analysing our experience, we have identified some key features for making such trips successful. This may be useful for future visitors preparing for such missions.

#### Abstract no: 1613

### Cost-effectiveness analysis of congenital heart surgery in developing countries

**Kathleen Fenton\*<sup>#</sup>**, **Sergio Hernandez Castillo<sup>#</sup>**, **Carlos Duarte Claro**, **Nubia Berrios<sup>#</sup>** and **William Novick<sup>#</sup>**

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**Background:** Of the estimated >million children born worldwide every year with congenital heart defects (CHD), more than 95% are born in developing countries with inadequate access to surgical repair. Since surgery for CHD seems expensive, it may be given a lower priority in the allocation of scarce economic resources. The World Bank uses \$100 per year of life saved as the marker for highly cost-effective interventions in poor countries. Cost-effectiveness analysis is warranted.

**Methods:** Total cost data were gathered for the 1st 5 years of a congenital heart surgery programme in a developing country. Cost per case included local costs plus the value of donated medical supplies sent to support the programme. Local costs were obtained from the business plan of the local foundation and included all costs, including: paying the hospital; physicians; and all administrative costs of the programme; assuming an annual case volume of 100 operations; and including pre-operative evaluation and post-operative care. Cost per year of life saved was calculated based on known average life expectancy of <2 years for unoperated CHD, versus an estimated post-operative life expectancy of 40 years, minus our reported mortality of 7%.

**Results:** The value of the donated medical supplies was \$190 329 over 5 years. Total local programme costs averaged \$216 600 per year, making overall costs \$2 800 per surgery or \$3 011 per survivor. Cost per year of life saved is \$75.28.

**Conclusion:** The cost of surgery for CHD falls well within the World Bank's definition of highly cost-effective interventions. Cost of surgery for CHD compares favourably with other interventions such as BCG vaccination for children, condom distribution to attempt to prevent HIV, and general/trauma surgery. Future work should attempt to incorporate disability data and cost of medical care for unoperated children.

**Abstract no: 1614****Is it dangerous to live on an isolated island if you are a child with congenital heart disease who needs an operation?****Inger Fosdal Tevebring\* and Katharina Hanseus#**

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**Background:** Sweden has very good results for paediatric cardiac surgery with 30-day mortality <2%. These results depend on a functioning chain of care from the 1st suspicion of a congenital heart defect (CHD) to primary examination, transportation, operation, peri-operative care and follow-up. In order to achieve safe treatment and to optimise long term prognosis, all these links have to be efficient and of high quality all the time and available for inhabitants in all geographic locations. Sweden has 9 million inhabitants and 21 counties. The island of Gotland, with its isolated location in the Baltic Sea is the smallest county with approximately 57 000 inhabitants and 500 deliveries/year.

**Aim:** The paediatric cardiac service is provided by a paediatrician with additional training in paediatric cardiology and a radiologist performing echocardiography. The hospital collaborates with the Children's Heart Centre in Lund for tertiary-level care, mainly paediatric cardiac surgery and interventions. In addition, a senior consultant from Lund visits Visby twice a year. The aim of this study was to validate the results of paediatric cardiac care in Gotland. Retrospective studies were done of hospital files in Visby and Lund for children (<18 years) born between 1 January 2000 and 31 December 2009, who had treatment for cardiac conditions.

**Results:** Thirty four children underwent surgery (31) or catheter treatment (16) (1.5 per patient). The median age at operation was 4.6 months (range 4 days to 16.9 years). There has been no surgical acute or late mortality during follow up (3 - 18 years). Forty children visited the centre on a total of 63 occasions: 1.5 visits/patient (range 1 - 6); 25% of the visits were cardiac investigations such as MRI or diagnostic catheterisation.

**Conclusion:** Care of children with congenital heart disease can yield excellent survival rates, even in an isolated area such as the Island of Gotland. Close collaboration between all health professionals on the local level and between the local hospital and the tertiary-level centre are cornerstones for delivery of a high quality service.

**Abstract no: 1623****Multi-national, multi-lingual volunteer teams in paediatric cardiac surgical assistance missions****Frank Molloy\*, Martina Pavanic\*, Jean Towne\*, Siarhai Liauchonak\*, Pavel Shauchenka\*#, Eugene Suslin\*#, William Novick\*† and Elizabeth Novick\***

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**Background:** The International Children's Heart Foundation (ICHF) – a US based Non Governmental Organisation (NGO) has operated on over 6 000 children in collaborative educational programmes 45 cities, in 35 developing countries since 1993. The majority of programmes receive 3 or more trips per year in a partnership of 5 or more years which has been shown to be effective in increasing surgical numbers and complexity.<sup>(1)</sup> We describe the origin and numbers of our volunteer pool and draw conclusions about the sustainability of our assistance model.

**Material and Methods:** We analysed the ICHF volunteer database from 2012 back to 1996. Of interest was city of origin, country of origin and volunteer participation from previously assisted programmes.

**Results:** Over 16 years there were 260 trips, 1 124 volunteers, originating from 185 departure cities. Analysis of contributing institution was not possible with accuracy but we can confidently infer that this volunteer pool came from greater than 185 contributing cardiac centers, since many cities have more than one cardiac program. Volunteers were of 42 separate country origins, with 350/1 124 (31%) volunteers as non US volunteers. Thus a significant pool of volunteers from close proximity Spanish and Russian speaking countries enable cost efficiency and a working practice in the local language. Of the 45 assisted sites, 11 eventually became volunteer contributors to teams with 66 volunteers from such programmes contributing the knowledge and skills developed during our mutual partnership to newer programmes.

**Conclusions:** A mixed, multi-center, multi-national volunteer pool as presented above enables the delivery of multiple annual assistance missions without excessive strain on any single center. Furthermore it enables targeted optimisation of volunteers for location and language skills, and sustains an ongoing partnership with "graduated centers" by utilising their staff as volunteers.

**References:** 1. Novick WM, Stidham GL, Karl TR, et al. Paediatric cardiac assistance in developing and transitional countries: the impact of a fourteen year effort. *Cardiol Young* 2008;18(3):316-323.

**Abstract no: 1624****Data mining with natural language processing (NLP) for a paediatric cardiovascular problem list****Pouya Hemmati, Robert Bill, Serguie Pakhomov, Genevieve B. Melton and Lee A. Pyles**

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**Background:** A problem list is a basic building block to ensure effective medical management of children with cardiac diseases by facilitating electronic health record (EHR) use. We hypothesised that problem lists can be generated from discharge summaries using natural language processing (NLP).

**Methods:** We identified concept-unique identifiers (CUIs) for each diagnostic term using Metamap software with standard settings. After analysing Metamap output in the paediatric cardiovascular domain, we extracted noun, verb, prepositional and adjectival phrases using the Stanford parser, and weighted each phrase by occurrence frequency and overlap with the Paediatric Cardiac Care Consortium (PCCC) diagnosis list augmented with acronyms and lexical variants. The weighted-phrases method was applied to discharge summaries from 884 patients using the Biomedical Information Collection and Understanding System (BiomedICUS). A random sample of 100 records was manually analysed to compare output of the weighted-phrases method to primary cardiac diagnosis.

**Results:** The Metamap analysis found 982 terms of which 345 had cardiovascular meaning; of these 205 did not map to any CUI. From this we concluded Metamap was neither sensitive nor specific for identification of paediatric cardiovascular diagnosis. The weighted-phrases method found the primary cardiac diagnosis in the highest-weighted phrase (report line 1) in 87/100 subjects (87% sensitivity). Although 10 - 20 phrases per patient were available, these added little to sensitivity beyond the 1st 5. Sensitivity with the 5 highest-weighted phrases was 97% for primary diagnosis.

**Conclusion:** The low rate of CUI mappings to the PCCC diagnostic list using Metamap indicates inadequate inclusion of paediatric cardiac diagnoses in standard biomedical terminologies. Our NLP method using phrases weighted by frequency and overlap with a paediatric cardiac diagnostic terminology allows BiomedICUS to accurately generate diagnostic phrases from discharge summaries. This early use of NLP in the paediatric cardiovascular domain offers promise to facilitate EHR implementation for these patients.

#### Abstract no: 1625

### A new cardiac surgery programme in Aswan: Working towards creating a sustainable humanitarian academic centre of excellence

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**Background:** Until recently, no paediatric cardiac services were available for 20 million people in Upper Egypt and adult services were difficult to access. The Aswan Heart Centre started in April 2009. It provides care free of charge and aims to become an academic and clinical centre of excellence.

**Methods:** Surgical activity between the centre's start and the end of July 2012 were retrospectively reviewed.

**Results:** The total number of procedures performed was 761. Initial operations took place during missions by international teams who created a culture of training and knowledge transfer. With their ongoing support, the local team increasingly performed operations, resulting in more continuous activity. A large proportion of patients underwent surgery for rheumatic valve disease, aiming at reconstructive procedures. Surgery for congenital heart disease dealt with advanced cases in children and adults, but increasingly also in small children, including neonates. A HOCM service was established, and over the last 18 months coronary revascularisation commenced. Intra-operative TEE was used routinely with a low threshold to revise repair if the technical result was suboptimal. Post-operative patients were initially managed by early extubation and ICU fast-track. Sicker patients and neonatal surgery required further development of ICU. In spite of increasing complexity and number of small children, mortality has remained below 5%. Outpatient and imaging services were established. Research and teaching are an integral part of the service.

**Conclusions:** A shared vision and the ongoing collaboration between visiting experts and the host team facilitate the development towards a sustainable centre of excellence.

#### Abstract no: 1650

### A CardioStart (CS) performance and compliance scoring system for emerging paediatric and adult cardiothoracic and vascular healthcare programmes

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**Background:** Paediatric cardiac surgery is especially challenging in emerging healthcare programmes that are personnel and/or equipment deprived; priorities include: improving outcome; reducing waiting time; and teaching new techniques. No uniformity in structure or technique exists to ensure that best standards of cardiological surgical management are implanted; outcomes may not reflect individual or team competence or programme worthiness. Local teams may be dazzled but afterwards, overwhelmed and financially depleted. We have devised a dual-language performance-score (part of a full international database evaluation already in operation, UMN & OHSU, USA) to monitor and assist various systems improvements.

**Methods:** Visiting and local team performance during the peri-operative period was evaluated discreetly, without direction or encouragement, using a scoring system addressing admission, transfer from intensive care and discharge. Admission scoring included: use of medications; dental checks; antiseptic/antibiotic use; laboratory tests; consent; allergic status; "time out"; and completion of CS's anaesthetic and perfusion checklists. Transfer from intensive care scoring evaluated: airway management; respiratory rate; oxygen requirement; chest X-ray; ECG/monitor normality; bleeding; serum electrolytes; neurology; and central line status. Discharge from hospital scores evaluated: exercise limit checks; incision and electrolyte status; completeness of charts; communication with family members; and readiness for discharge.

**Results:** Total possible scoring for admission (19), transfer (38) and discharge (23) (total = 80) were similar and >80% among most of the 128 patients evaluated. Minor differences between countries did not impact on peri-operative management or outcome. Local doctors responded well to the structured check list, which helped self-organisation.

**Conclusions:** CS scoring encourages better discipline in patient care and transfer, helps identify shortcomings and assists teams to evolve components of peri-operative management vital to success and a platform to help programme building. This will be refined in the future by statistical analyses to develop the scores that are predictive of survival and positive outcomes.

**Abstract no: 1667****Paediatric cardiology in public health: A tele-network covering over 55 000km<sup>2</sup> of underserved regions in Brazil**

**Sandra Da Silva Mattos, Claudio Teixeira Régis, Juliana Sousa Soares de Araújo, Lúcia Roberta Didier Nunes Moser, Carolina Paim Gomes de Freitas, Rossana Severi, Felipe Alves Mourato, Thiago Ribeiro Tavares, Renata Grigório Silva Gomes and Sheila Maria Vieira Hazin**

Circulo do Caracoa de Pernambuco, Recife, Brazil

**Objective:** To describe the initial results from a paediatric cardiology network set up to reverse a picture of high mortality and morbidity from CHD in a population of around 2.5 million poor people.

**Methods and material:** This prospective, multi-centre project was divided into stages, including problem definition, network structure, and training and initiation of medical services. Thirteen institutions have been linked and equipped with iPads, pulse oximeters and portable echo machines. Physicians from the referral centre travelled once a week to perform key activities such as cardiac surgery, and local teams were supervised by tele-medicine. Between January and July 2012, 10 858 pulse-oximetry tests were performed, 554 (5.1%) were considered abnormal and 217 babies underwent a screening echo; 138 anomalies were detected.

**Results:** The relationship between collected/abnormal oximetries decreased from 17.2% in January - 3.1% in July, suggesting a learning curve in the use of the test. The number of screening echoes increased over the time of the study. The network has clinically evaluated over 2 500 patients and 74 surgeries were performed, with 7 deaths. Previously, most of these children had lengthy stays on waiting lists to be referred outside the State for diagnosis and treatment.

**Conclusions:** Diagnosing and managing children with CHD is a major challenge in developing countries. The establishment of partnership programmes between reference, primary and secondary centres with the aid of tele-medicine is one way to ameliorate this problem. Careful planning, training, supervision and performance of key activities by trained personnel are requirements to achieve successful results.

**Abstract no: 1676****Status of paediatric cardiac surgery in the least-developed countries**

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**Background:** The least-developed countries (LDCs) are a group of countries that have been identified by the United Nations in terms of their low gross national income (GNI), weak human assets and high degree of economic vulnerability. As per 2011 statistics, the average GNI in these countries is US\$567, far below the world average of US\$9 488. Currently there are 36 countries in this category, mostly in Africa and Asia. Paediatric cardiac surgery in these nations is poorly developed or totally absent. The developed world has a responsibility to recognise the deficiency and to help the growth of cardiac surgical facilities in these countries.

**Methods:** Cardiac surgeons and cardiologists of these 36 countries were contacted through e-mail, phone calls and postal questionnaires to gather information about the status of paediatric cardiac surgery in the respective countries, with an emphasis on quality, cost and number, if any. The cardiac societies and national heart foundations were also approached for information.

**Results:** The estimated total population of these countries is 816 810 477, which is 11.7% of the world population. Their combined GDP is only 0.6% of the world GDP. This unfair distribution of wealth makes these countries vulnerable in terms of healthcare facilities. Facilities for paediatric cardiac surgery are either absent or primitive but, where present, the cost of surgery may be surprisingly low, sometimes as low as US\$1 000.

**Conclusions:** LDCs are part of our world. Unfavourable economic circumstances deprive 11.7% of the world's population of this expensive modality of cardiac treatment. Cardiac surgeons from the developed world should help grow the facilities in the LDCs. They can take advantage of relatively inexpensive surgery and boost growth, thereby saving thousands of lives in these parts of the global village.

**Abstract no: 1677****A bottom-up multi-disciplinary approach to improve paediatric cardiological care in Sweden**

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**Background:** Paediatric cardiac surgery in Sweden is concentrated at 2 centres (paediatric cardiology is practised in about 30 hospitals) and the results of surgery regarding survival are excellent, with a mortality rate <2%. In order to promote survival and good quality of life, collaboration between all levels of care is mandatory, however distances, diagnostic ability and accuracy, follow-up and resource use varies greatly within the country. Every 3rd year, a multi-professional (including representatives from the parents' association) meeting is held, with the aim to improve communications and cooperation in different levels of care. At the 4th meeting in 2011 a new approach was tried in order to promote national collaboration, inter-disciplinary work and evidence-based care.

**Methods:** Four areas of concern were defined: follow-up, communication, education and incoming referrals. Locally used guidelines, healthcare programmes and "tips and tricks" were presented on a public webpage. About 150 persons (of approximately 300 possible), mainly physicians and nurses, but also medical secretaries, biomedical laboratory scientists, physiotherapists, dieticians, occupational therapists, psychologists and social workers attended this 3-day meeting. The congress' main part consisted of multi-professional workshops, with the objective to share and develop material and improvement ideas. The workshops were led by professional facilitators and the results were further discussed in a plenary session, and plans of actions were created.

**Results:** Thirty specific topics were defined, called "heroic deeds" and for every topic a leader with responsibility for the continuing progress was defined. Seven new professional networks were also created.

**Conclusion:** With a bottom-up approach, involving different professions nationwide, it is possible to create a foundation for national guidelines and standardised care, which has the potential to make better use of resources and increase the quality of care for children with heart disease.

**Abstract no: I688****Five centres, 1 heartbeat: a network approach to health care delivery****Angela Krizan**

Western Canadian Children's Heart Network, Canada

**Learning objectives:**

- Develop an understanding of the factors to consider when looking at a regionalised approach to providing specialised health care services
- Identify the benefits/challenges to regionalising specialised services
- Impacts of regionalisation of specialised services on families – the good and the bad
- Sustainability of this model

**Summary of topic:** For more than 10 years, the Western Canadian Children's Heart Network (WCCHN) has coordinated and integrated cardiac and surgical care for patients across the 4 Western Canadian provinces. The WCCHN clinicians work collaboratively across all jurisdictions to ensure the highest standard of care is accessible to all patients and families. Surgical care is regionalised in 2 surgical centers ensuring adequate volumes to maintain a high standard of technical skill and optimal outcomes.

**Outline:**

- History of Pediatric Cardiac Surgery in Western Canada
- Outcome data that necessitated looking at a different approach to providing highly specialised services to pediatric cardiac patients
- Stakeholders – how they came together and reached the decision to regionalise services
- Building a Network of Pediatric Cardiac and Surgical Care
- Successes/Challenges encountered along the way
- Reflection after 10 years of practicing this way
- Future directions for this model of delivering health care

**Abstract no: I720****The “virtual ICU”: Adding experience in paediatric cardiac surgery**

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**Introduction:** Similar to other developing countries, some areas in Brazil experience a shortage of resources to establish paediatric cardiology (PC) programmes. Within this context, a tele-medicine PC network was established between 2 states to add competences and train local teams.

**Objective:** To report on the experience with a new model of tele-medicine, the “virtual ICU”, within a PC network for poor children in north-east Brazil.

**Methods:** Besides medical equipment and a TV screen, an iPad and wireless internet connection were added to the ICU. Local teams had face-to-face and online training sessions. Surgical and post-operative checklists were developed. Cases are discussed online. Specialised teams travel once a week to perform more complex surgical cases and initial post-operative follow-up (24 hour). Local teams, under online supervision, perform the remaining post-operative and surgical cases of lesser complexity.

**Results:** From October 2011 - July 2012, 74 surgeries were performed in children aged 20 days - 17 years. Cardiac bypass was used in 59.6%. Jenkins' complexity scores were 1:3 in 50%, 3:6 in 44.5% and >7 in 5.4%. Total mortality was 9.9%. Infection and bleeding were the most frequent post-operative complications (14.8%). “Virtual ward rounds” took place daily and there was an average of 3 - 5 extra consultations per week, most related to clinical instability, drug management or echo revision. In a qualitative review, ICU teams reported a feeling of security from the new system, although some still regard telephone calls as simpler as, and more efficient than Internet connections.

**Conclusion:** Our results do not focus on surgical numbers, as this experience, despite being aligned with current literature, is still incipient. The emphasis is on the model provided by the “virtual ICU”, which adds experience and diffuses knowledge between centres, thus providing a safer environment to initiate such complex programmes in less-developed areas.

**Abstract no: I727****Pulling the patient through the system: Pro-active care at Great Ormond Street Children's Hospital, London, England****Liz Smith and Alessandro Giardini**

Great Ormond Street Children's Hospital NHS Trust, London, United Kingdom

**Background and aims:** A streamlined patient journey provides a process where clinical staff, families and children can manage their expectations of the system. With the present high financial pressures on the National Health Service (NHS), a current review of national children's surgical heart services and the opening of a new cardiac unit in 2012, our aim was “to reduce over a six-month period the hospital stay by 5% in children with congenital heart disease, by removing inefficiencies, and improving quality of service provision, meanwhile ensuring that each child is discharged when medically ready”.

**Methods and materials:** Quality improvement tools used were affinity diagrams, interrelationship diagrams and rating final sub-groups. The final drill down highlighted areas of “plan, process, journey and structure”. The group of champions looked at 4 keys areas: patient and family preparation; medication and discharge; investigations; and pre-discharge Echo. Data were obtained using tally sheets and the Great Ormond Street Hospital cardio respiratory database: length of stay in hours; discharge times, with balancing measures around patient experience questionnaires; and repeat prescriptions.

**Results:** The improvement project is currently on-going using a range of interventions, with an aim to review data monthly and monitor outcomes over the next 6 months as to whether we achieved our aim.

**Conclusion:** Learning points have however been evident around timing and current work pressures, culture and structure, and engaging clinically based individuals to make it a real and tangible experience and outcome.

**Abstract no: 1744****Quality of care that children with heart problems receive in the South African health system****Mark Patrick\*<sup>#,†</sup> and Cindy Stephen\*<sup>†</sup>**

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**Background:** The quality of care children with heart problems receive in the broader South African health system is not well described. The Child Healthcare Problem Identification Programme (Child PIP) uses mortality audits to assess quality of care. >150 South African hospitals have used Child PIP since 2005, recording >700 000 admissions and >29 000 deaths. This Abstract provides information on children dying with heart problems.

**Methods:** The study population included children admitted to and dying in participating South African hospitals. Data were gathered from 2005 to 2012. The mortality review process established cause of death and modifiable factors.

**Results:** Of the 29 000 deaths, 800 died with a heart problem as the main cause of death. Most cardiac deaths occurred in infants, 12% were severely malnourished. HIV status was unknown in 1/3. >1/3 died within 24 hours of admission, 16% of deaths were considered avoidable. There were 1.7 modifiable factors per death, 52% of modifiable factors occurred within the health system, of which 55% were attributed to health workers. For rheumatic heart disease there were 2.2 per death. A substantial number were attributed to caregivers' health-seeking behaviour. A lack of high-care facilities was most significant for administrators, and inadequate history, assessment and investigations were the most common for health workers.

**Conclusion:** These findings for children dying with heart problems suggest areas of concern. Co-morbidities of HIV and malnutrition may influence decision-making about definitive cardiac care. The high proportion dying within 24 hours of admission and the higher rate of modifiable factors occurring in children with rheumatic heart disease call for further investigation and may present opportunities for improving cardiac care systems. Resource allocation, in particular critical care, is a problem that needs attention, and improved awareness of heart-related danger signs in the general population is necessary.

**Abstract no: 1791****Home-based palliative care in children with cardiac problems****Joanna Dangel<sup>†</sup>, Tomasz Dangel<sup>#</sup> and Malgorzata Murawska<sup>#</sup>**

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#Warsaw Hospice for Children, Warsaw, Poland

**Introduction:** Warsaw Hospice for Children (WHC) is the first non-governmental organisation (NGO) in Poland that provides home-based palliative care for children with life-limiting conditions and their families. Children in whom curative treatment was completed could be admitted to the palliative home-care programme. The aim of this study was to evaluate patients with cardiac problems who were under hospice care between 1994 and 2012.

**Methods:** Over 18 years, 96 children with different cardiac problems were under WHC care: Duchenne muscular dystrophy (17 teenagers); inoperable heart defects (13), mainly due to pulmonary hypertension or severely hypoplastic pulmonary arteries; post-operative complications, Down's syndrome (4) and pulmonary hypertension (54 with lethal chromosomal aberrations, mainly trisomy 13); and heart defects (18).

**Results:** Until 2000, 7 teenagers with heart defects complicated by pulmonary hypertension, heart failure or hypoplastic pulmonary arteries were under palliative care. All of them died after 31 days to seven years in hospice care. Since 1999, peri-natal palliative care has been established, mainly for children with lethal chromosomal aberrations complicated by congenital heart defects, 37 patients were admitted to the hospice programme after pre-natal diagnosis and consultation. None of those children was operated on. Period of palliative home care lasted from 3 to 1 269 days, mean 161 days. Just one newborn with hypoplastic left heart syndrome diagnosed prenatally was in the hospice care for 35 days.

**Conclusions:** Palliative care should be considered in all children with life-limiting conditions. In patients with complicated heart defects in whom surgical treatment failed, such options should be discussed with the parents. Palliative care should be the method of choice for fetuses and neonates with lethal chromosomal disorders whose parents are against termination of pregnancy.

**Abstract no: 1826****Cardiac care in Africa: The Namibian Children's Heart Project****Henning du Toit<sup>\*</sup>, Andreas Willberg<sup>\*</sup> and Christopher Hugo-Hamman<sup>\*,#</sup>**

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**Background:** There is limited access to cardiac care in Africa, and <2010, there were no cardiac services in Namibia. The Ministry of Health and Social Services commissioned a heart centre at Windhoek Central Hospital (WCH) on 18 October 2010. We report early results from a new single-surgeon programme over the 1st 2 years.

**Methods:** This was a case series of 231 patients between October 2010 and 31 August 2012. In year one, surgery was limited to children >20kg and in year two those >10kg body mass. Data were entered prospectively into a hospital-based registry, File maker pro data.

**Results:** 231 patients had surgery, 208 on cardio-pulmonary bypass. Age ranged between 4 months and 83 years, of whom 56% were <18 years; 105 cases (45%) had rheumatic heart disease (RHD) with aortic valve replacement (20), mitral valve replacement (41), and a mitral valve-sparing anuloplasty and repair in 33; 86 patients had congenital heart disease (25 adults). The common lesions were: VSD (31); secundum ASD (20); primum ASD (16); PDA (16); tetralogy (17); aortic coarctation (4); DORV (3); and Ebstein's anomaly (2). There were 9 post-operative (<28 days) deaths with a mortality rate of 3.6%.

**Conclusions:** This new service is a novel model of integrated cardiac care that dispensed with age-related barriers to delivery and concentrated on "uncomplicated" and common diseases. Adults with CHD represent survivors of native heart disease. Low numbers of small babies reflect strategic choices in a resource-limited environment but also the parlous state of diagnostic services for children with CHD. High numbers of patients needing surgery for RHD reflect the absence of a national programme for prevention and control of RHD. Without further development and support, the future of this new service remains precarious.