

# Collaboration with Uganda Heart Institute: Data collection: 2007 - 2009



## Mulago Hospital Operating Theatre



## **CONGENITAL HEART DISEASE: GLOBAL PERSPECTIVE**

- **Limited access to treatment for congenital heart disease (CHD) along with environmental and genetic factors impact the distribution of heart disease in sub-Saharan Africa**
- **There are nearly 6 million children worldwide with potentially treatable congenital and acquired heart defects that do not have access to care**
- **Only 7% of the world's population has access to "first world" cardiac surgery and catheterization; sub-Saharan Africa has the least access**
- **Medical/surgical teams from around the world participate in diagnosis and treatment programs to improve the state of care for these patients**
  - **Treatment abroad is expensive and only helps a small number**
  - **Surgical team visits treat larger numbers of children**
  - **Ultimate goal must be to build independent sustainable program staffed by local physicians, nurses, and other medical support staff**

## **UGANDA**

- **Population nearly 30 million, very large pediatric population**
- **Success with HIV prevention and treatment in Uganda has increased worldwide interest in other medical issues there including heart disease**
- **Limited information is known about the distribution of CHD in Uganda**
- **The last major report came from the Pediatric Cardiology Clinic at Mulago Hospital in 1969**
  - **Incidence of CHD was 6.4/1000, with n = 9432**
  - **The three most common lesions were atrial septal defect (ASD), ventricular septal defect (VSD), and valve atresia**
- **Estimated 5,000 – 6,000 children in Uganda in need of cardiac intervention in 2009**

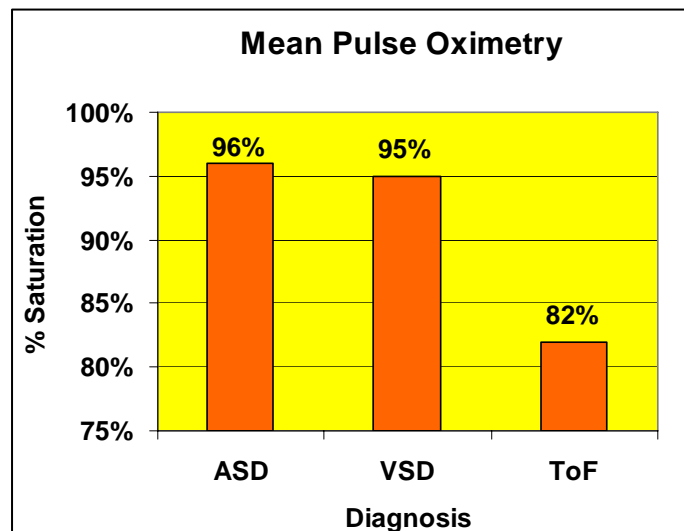
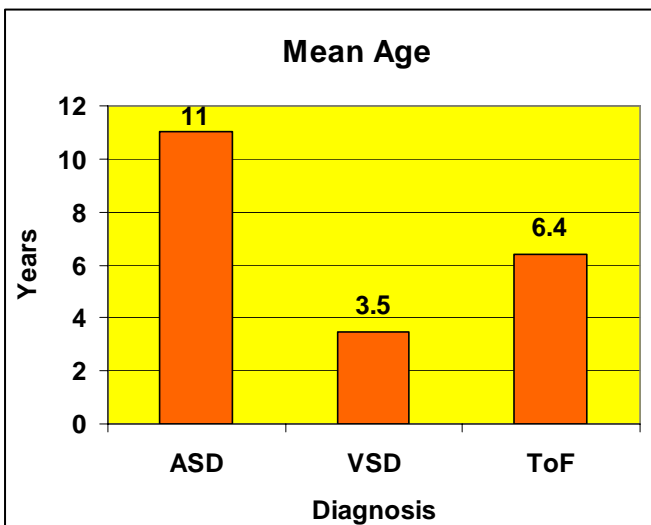
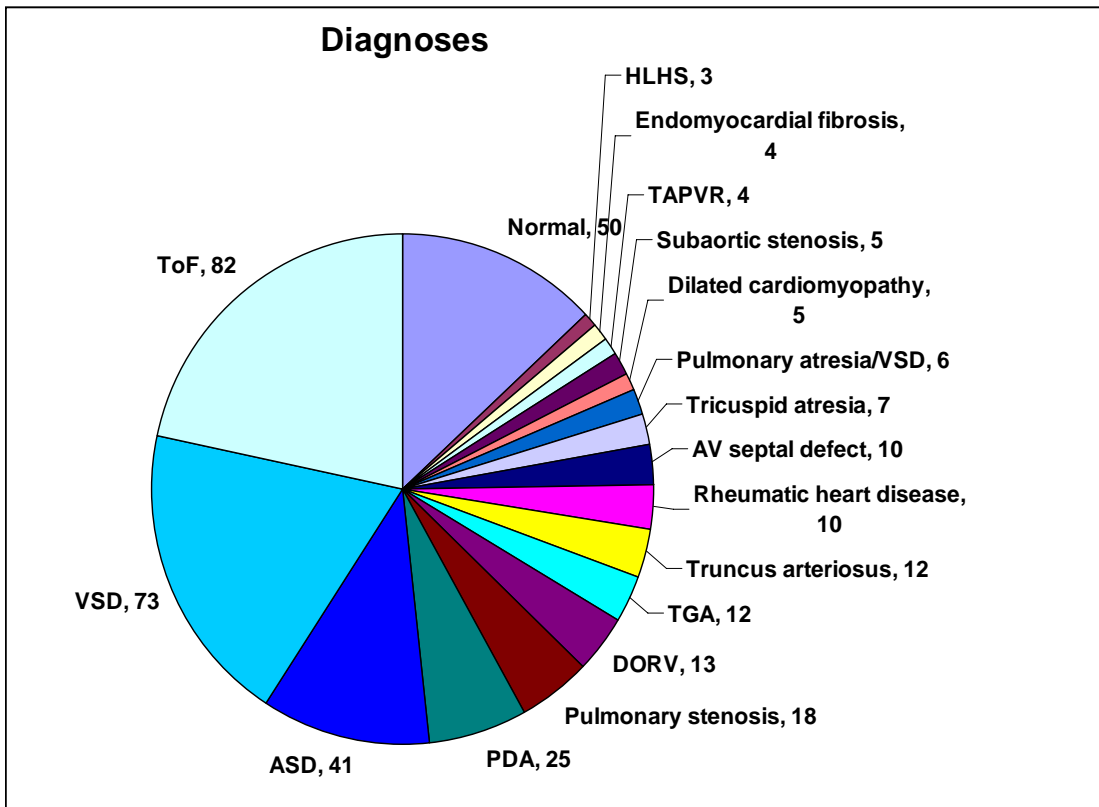
## **PURPOSE OF DATA COLLECTION**

- **Characterize the distribution CHD in Uganda**
- **Measure success of multicenter collaboration in providing treatment and building sustainable heart surgery program in Uganda**

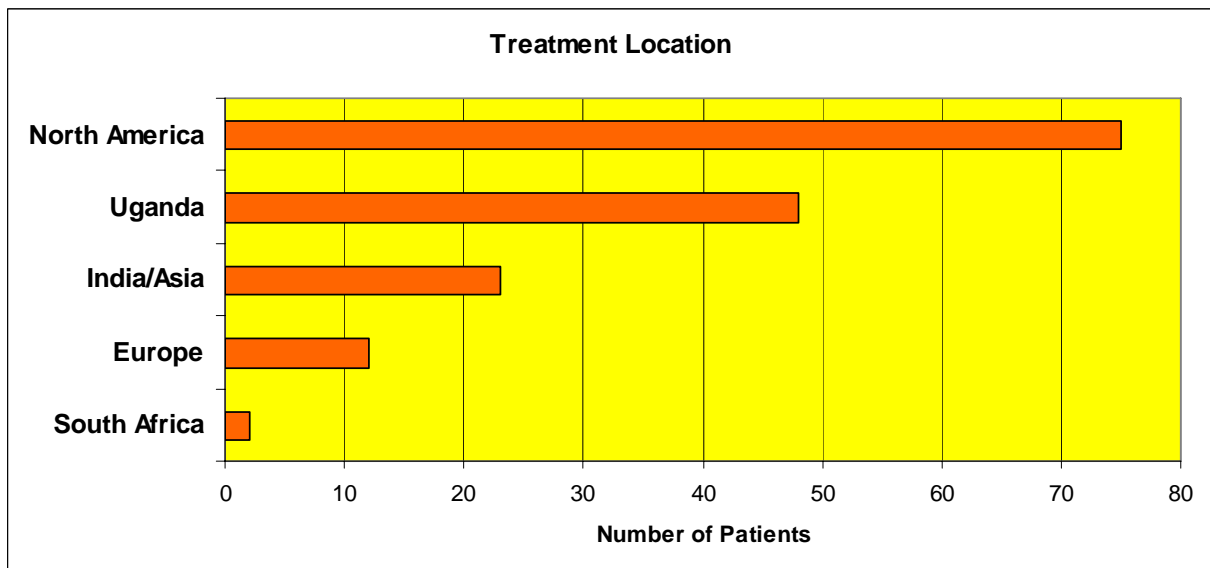
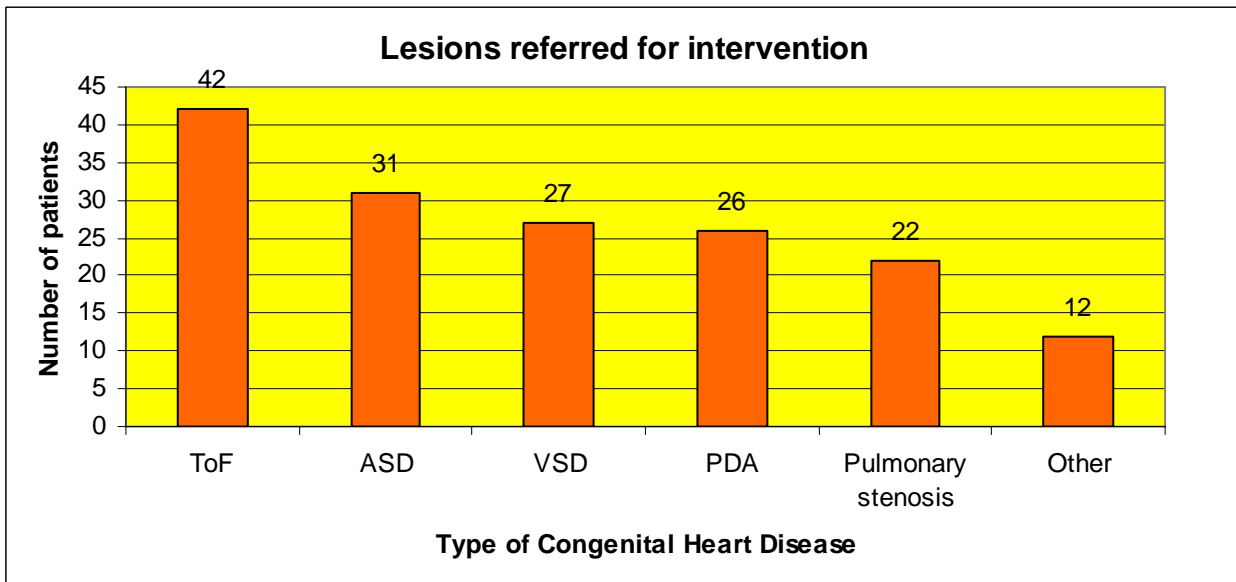
## **RESULTS**

- **Nine medical missions were carried out to Kampala, Uganda: 2003 - 2009**
  - **First 5 missions were focused on diagnosis and education**
  - **Last 4 missions included open heart surgery (7 – 10 cases/visit)**
  - **Additional adult surgical visit in 2009**
- **Uganda Heart Institute within Mulago Hospital (national teaching and referral hospital) is only dedicated cardiac care center in Uganda**
- **Goals of missions were to**
  - **Diagnose children with CHD (patients with acquired heart disease are underrepresented)**
  - **Facilitate treatment of these children abroad**
  - **Build a sustainable cardiac surgery program in Uganda through education, donation of technology, patient care, and meetings with hospital and government officials**
- **Retrospective evaluation of the diagnoses (echocardiography), age, pulse oximetry, and outcomes during the 4 most recent visits**

- 420 patients evaluated (likely less than one third of UHI patients)
  - Over 50% seen on multiple visits
  - Readily accessible patient data base with medical records, echo images, and patient contact information/accurate cell number
  - 95% patients/families show up for appointments
  - 90% of families could be contacted
- Diagnoses (**referrals based on children most likely accepted for surgery – skewed away from true representation of disease mix**)
  - Tetralogy of Fallot and VSD are the most common diagnoses
  - Other conotruncal anomalies are also highly represented
  - **Acquired heart disease patients are underrepresented**
    - **Rheumatic heart disease**
    - **Cardiomyopathy (including endomyocardial fibrosis)**



- 172 children were able to receive treatment
- Over 100 children placed for surgery and catheterization abroad
- 61 children underwent surgery in Uganda (10 in last 2 weeks)
  - 41 open heart cases in children
    - October 2007
    - October 2008
    - April 2009
    - September 2009 (numbers not included in graphs)
  - ASDs, VSDs, Subaortic stenosis in addition to coarctation and PDAs
    - *4 ASDs performed by Ugandan team in 2009 by themselves*
- Adult cardiac surgery visit by Korean team in March 2009
  - 7 cases
  - Rheumatic heart disease and ASDs
- Deaths
  - 4 children died after surgery (none in Uganda)
  - 15 children who did not receive treatment died (? Underreported)



- **POSITIVE**
  - Large equipment (echo, bypass, anesthesia machine, ventilators, monitors...) available and maintained
  - Operating room team well formed and very capable
    - Skilled cardiovascular surgeons
    - Anesthesia, perfusion, and scrub nurse
  - Diagnostics (echo, rhythm) as good as “first world” programs
    - Pediatric cardiologist diagnostic skills equal to US
    - Echo equipment (machines and digital storage)
  - Multiple charities support missions and support of patients
    - Samaritan’s Purse Children’s Heart Project
    - Gift of Life International
    - Larry King Cardiac Foundation
  - Major US hospitals and Universities involved
    - Children’s National Medical Center, Washington, DC
    - University of North Carolina, Chapel Hill, NC
    - Wolfson Children’s Hospital/University of Florida, Jacksonville, FL
  - Uganda government supportive financially and politically
    - Ministry of Health engaged
    - Met with President Museveni in 2007
    - Met with Janet Museveni on 3 occasions
  - US Embassy supportive of efforts
  - Other countries also support program (Saudi Arabia, South Korea, India)
  - Excellent follow up and access to patients
    - Uganda Heart Institute
    - Samaritan’s Purse Children’s Heart Project
  - Evolving medical record system: CureMD/Gift of Life
- **NEGATIVE**
  - Difficult to maintain inventory of disposable supplies
  - Intensive care unit team skills limited
    - Nursing staff exposure
    - No dedicated intensive care MD
  - “Brain drain” of young physicians and nurses
  - No catheterization laboratory
  - Frequency of medical missions not enough
  - Lack of consistent protocols by visiting medical teams
  - Need to advance complexity
    - Rheumatic heart disease
    - Tetralogy of Fallot
  - Ongoing costs of medical missions
    - Raising charity funds
    - Patient costs to families and Uganda Heart Institute
  - Need for dedicated rheumatic fever prevention program

## **SUMMARY**

- **Tetralogy of Fallot is the most common diagnosis in our cohort of Ugandan children with CHD; other conotruncal abnormalities also highly represented**
- **Effective intervention can be provided for a significant subset of patients**
- **Slow sustainable growth of the Ugandan surgical program is occurring, but only a small subset of patients can currently be treated there**
- **More frequent surgical missions, improved ICU care, and reliable sources of disposable supplies are critical for long term sustainability**