**Cardiac Disease in Rwanda: Increasing Access to Cardiac Care from Primary Health to Surgery to Establish a New Cardiac Center of Excellence**

The collaboration of Team Heart, USA, King Faisal Hospital and the Rwanda Ministry of Health,

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**Mission Statement:**

**To address the burden of Cardiovascular Disease in Rwanda by increasing access to care through the improvement of facilities, skill transfer, and access to essential cardiac medications and supplies for all.**

**Program Components:**

1. Increasing access to cardiac surgery and comprehensive cardiac care: Since its inception in 2007, Team Heart (TH) has collaboratively worked with the Rwanda Ministry of Health, Rwanda Biomedical Center and medical personnel to identify patients with near end-stage Rheumatic Heart Disease (RHD), and to offer life-saving surgery to a defined number of patients during annual surgical mentoring trips.
2. From the outset, Team Heart has desired to establish a critically needed, sustainable, independent cardiac care center in Rwanda to address the medical and surgical burden of known cardiac disease. Team Heart currently is engaging King Faisal Hospital with the MoH to allow a sustainable permanent home for cardiac surgery in a country 12 million in the country and 40 million in the surrounding region.
3. Rheumatic and Congenital Heart Disease Registries: Working together with the Rwanda Biomedical Center, TH regional office supports improved and expanded development of a RHD registry and shared data obtained from unique mHeart program.
4. Education and Research: Through advocacy programs in education, TH will focus implementing programs on specialty training in cardiology and cardiac surgery, nursing education and skill transfer for echo diagnosis, prevention, and awareness of Rheumatic heart disease. Efforts to collaborate and share evidence-based research is critical to increase access to care in the ever-changing landscape of cardiovascular diseases. (CVD).

**Background:**

Cardiac disease continues to be the leading cause of death in the world. Not a great deal is known about the amount of heart disease in Rwanda because of the lack of diagnostic and treatment options which currently exist in the region. A STEPS WHO survey study in 2013 of Rwandan households ranks CVD has the third most prevalent disease. We do know that rheumatic heart disease (RHD) is the leading cause of cardiac hospitalizations in the population at the teaching hospitals in urban settings. We also know that despite the world knowing that every country in the world has congenital heart disease (CHD) with an incidence of 8-12/1000 of live births, that figure is not known in Rwanda, but is at least that frequent and most likely contributes to under-five mortality and the extremely high ranking of neonatal diseases. Coronary ischemic heart disease, (CAD), the leading cause of death worldwide, is largely unrecognized in Rwanda, and, when seen is most often identified in the private office of a cardiologist, suggesting the diagnosis is available to those who can access private funds or insurance. In the public sector, an EKG machine, key to CAD diagnosis is found in only 14 district and referral hospitals country-wide. There is no catheterization lab yet in the country, and only four hospitals have the capability to do physician-directed diagnostic cardiac echo as recently as June 2019.

Team Heart, with representatives from Cardiac Surgery, Cardiology, Anesthesiology, Nursing, (based in New England, but with volunteers from 15 states in USA, 3 countries) in collaboration with the Rwandan Ministry of Health, enter year thirteen of this project designed to address the most common heart problem in Africa: rheumatic heart disease. Heart disease in sub-Saharan Africa continues to represent one of the consequences of a generation of healthcare divestment and poverty. Rheumatic heart disease leaves young adults suffocating for years on the brink of death, a result of heart valve injury from untreated streptococcal infections of the throat. Early intervention with long-term penicillin protection could prevent heart failure in most of these patients. Even for the most neglected cases, however, prompt surgical intervention would restore a more productive life to those previously deprived of even primary care.

Following the genocide in 1994, war-torn Rwanda’s medical care delivery infrastructure lay in shambles. Few physicians and nurses remaining in the country survived the genocide. Providing the most basic medical care was difficult; today, less than 750 physicians and 6000 nurses remain to provide care for more than 12 million. Even nearing twenty-six years later, the numbers of physicians and nurses have increased at a very slow pace, and this remains a country-wide challenge. Hospitals and medical clinics were also destroyed during the war and had to rebuild with very limited human and fiscal resources. Investors in the country have not until very recently, identified health care as a potential source for growth.

Today, patients in Rwanda with advanced rheumatic heart disease still languish, at high costs, hospitalized when possible during acute illness, but rarely receiving the opportunity for transfer outside the country for surgical care. At the same time, few of those with less severe heart damage who should be receiving the benefits of penicillin prophylaxis do so. Since 2007, Rwandan cardiologists joined other African countries in a call to join the fight against rheumatic heart disease, however for lack of human and financial resources and the restrictive foreign Aid funding supporting only lesser prevalent TB and HIV and malaria.

 **2019-2020 Comprehensive Cardiac Disease Program Components.**

(1) Direct Care Through Cardiac Surgery

Addressing the surgical burden of the most critical cardiac disease by surgical repair or replacement of heart valves severely damaged by rheumatic disease currently offers the most dramatic benefit to individual patients. According to local health survey studies, these patients account for as much as 20 percent of hospital time in the adult hospital wards and is the leading cause of deaths in hospitalized patients.

As the ability and will to diagnose heart failure has improved in Rwanda, the numbers of patients needing interventional care has continued to increase. Rwanda, like almost all sub-Saharan African countries, transfers a limited number of these patients, (averaging near 30 a year with 200 on the waiting list) at substantial cost, to centers in middle and high-income countries, such as Sudan, and India, South Africa or Kenya. This point emphasizes more clearly the case for the establishment of a dedicated cardiac care center for Rwanda. Careful coordination and attention to the development of such a center to perform surgical procedures in Rwanda will provide a more practical and less costly alternative for these sick children and young adults, allowing them to remain close to home and family for support during their medical and surgical intervention.

To address the surgical burden of cardiac disease, in annual trips, since 2008 Team Heart has performed surgical procedures in young adults, as of today, a total of more than 190 patients have received surgery with excellent surgical in-hospital results. There has been a 4% in-hospital mortality rate. Procedures were performed with a focus on high quality and consistent patient care, skill transfer, and safety. Mentoring and education of Rwandan caregivers by Team Heart has also been a primary strategy. Patient selection is a collaborative effort among Rwandan cardiologists and Team Heart screening and surgery teams. Case presentation and patient selection are used as one critical teaching conference, and in 2019, this conference was attended by more than 50 residents, local team nurses and medical students, as well as all members of Team Heart and local caregivers.

Team Heart, in collaboration, the Rwandan Minister of Health, has initiated the challenging process of establishing the local capacity to perform cardiac surgery. The identification of potential Rwanda surgeons and of potential sites for such individuals to train is a lengthy process. Team Heart supported location of training and financial scholarship for a 6-yr cardiac surgical training, and the first candidate completed his training, passed board certification and returned to Rwanda June 2019.

Since 2014 Team Heart proposed to the Ministry of Health the establishment of a dedicated cardiac care center in Rwanda. This center is envisioned as a center of excellence for medical and surgical care for patients with all forms of heart disease and as the country’s leading site for cardiovascular medical and nursing education, and for research into new and better therapies for the region.

(2) Building excellent post-operative care in partnership

In 2012, TeamHeart was asked to develop a curriculum to improve the cardiology knowledge base of internal medicine physicians. The curriculum was accepted and approved by the MoH, MoE, and Parliament, however, 8 years later never reached funding priority. The curriculum is undergoing updating with a regional partner and revised to digital content with ambitious in-country faculty and international partners, implementing in 2020 in partnership with Eldoret, Kenya program to decrease expenses. However, there needs to be a consensus by stakeholders to move this agenda forward, to bring all stakeholders together and it needs to be driven by Rwandans.

Post-operative patients should soon see benefit from Rwandan-driven non-communicable disease (NCD) chronic care clinics, currently under expansion in 9 sites around the country. This RBC led effort is staffed by nurses placed at selected district hospitals around the country. Providing the most basic standard of post-operative care for patients with advanced disease has the benefit for individuals at risk of rheumatic fever recurrence to receive prophylaxis. However, many of the more vulnerable patients remain unable to access the health care center due to financial and time constraints resources. There remains challenges in training and supply chain, but unique opportunity to improve the system to meet the needs of patients .

With over 650 patients in Rwanda having had heart surgery in the past 13 years by 4 expatriate teams out of country transfers, there has been efforts towards collaboration with colleagues in Rwanda for the much-needed development of the infrastructure necessary to provide safe follow-up care and maintenance, including anticoagulation management for those requiring Coumadin maintenance for mechanical heart valves. Team Heart is proud to be a leader in Rwanda toward safe and reliable anti-coagulation, however we continue to push forward to achieve more reliable care.

An SMS communication and smartphone app mHeart is under development and has been piloted in 2018 by Team Heart. Using set messages with number rated responses, the most rural areas and basic of cellphones can be utilized to collect data. Data is collected to contribute to the country-wide registry and symptoms documented before problems become acute, such as swollen ankles, fever. The patient or the nurse can activate SMS.

(3) Developing partnerships through Academics and Research

In January 2016, a Team Heart-sponsored project was funded by a prestigious NIH RO-1 award as part of the Rheumatic Heart Disease Genetics (RECHARGE) study. Dr. Danny Muehlschlegel, Chief Scientific Officer of Team Heart, and his Rwandan collaborator, Leon Mutesa, and Rwandan cardiology colleagues, have enrolled children and young adults with rheumatic heart disease (RHD) in Rwanda. There is a high degree of heritability for RHD, yet there exists an underrepresentation of genomic research in Africa.

Team Heart volunteers list the leading cardiac programs in the US and their academic homes.

 (4) Primary Care focus through collaborative care

Barriers to primary care -- including lack of transportation to the nearest health center – are such that children and young adults in Rwanda are slow to seek attention for the sore throats and minor skin infections that may precipitate bouts of rheumatic fever. Even those who develop rheumatic fever and are identified may not be able to actively seek care or receive the correct diagnosis and therapy at health center level without significant delays. For this reason, to prevent progression to advanced rheumatic heart disease, TH supports our Rwanda partners to assist Rwanda in developing national strategies to identify patients earlier in the course of their disease.

To determine the extent of rheumatic heart disease present outside the healthcare system, and to determine which age groups to target for active case finding, Team Heart proposed an echocardiographic prevalence survey in one sector of the country, which includes Kigali. This survey in 2011, under the direction of Mucumbitsi and Ruzingiza, helped to raise awareness of the problem of rheumatic heart disease in Rwanda through public education and identify the age groups most affected to establish the prevalence in a sector near Kigali. Although the prevalence was lower than expected at 6.8/1000, most of the disease was found to be in the more rural schools visited. The data analysis and findings published in 2017. A more comprehensive country-wide screening and prevention program coordinated by Team Heart and the Rwanda Biomedical Board is planned 2020.

Key stakeholders agree that a dedicated cardiac care facility is the critical next step to this plan. King Faisal Hospital, the Rwandan flagship hospital, is under new leadership and has been the home to Team Heart as the cardiac adult surgical program host. Efforts from the Government of Rwanda (GoR) contribute financial support though mutuelle de Sante to reduce further the disparity of care known to exist in category 1.

Team Heart is currently working with King Faisal to expand the high-quality facility at King Faisal Hospital that would provide surgical care for those who need it the most but otherwise are unable to pay for such care in private facilities. Our vision is a center of excellence, staffed by Rwandese and augmented by expatriates while Rwandans are mentored by international leaders in the field, with eventual transition to a Rwandan-staffed hospital for the Rwandan people.

In a 2015-2019 collaboration between health care economist, Professor Diana Bowser, a health care economist at Brandeis University, Team Heart, and the Rwanda Social Security Board was initiated to determine a sustainable path of Rwandan support. A financial model for a resource-poor setting was developed and shared through this collaborative to critical stakeholders.

 Summary

In 2019-2020, Team Heart will lead the efforts:

1) to continue efforts to increase access to care for the surgical burden of disease and complete our fourteenth and fifteenth life-saving surgical trip.

2) continue to support CVTS training of Rwandan physicians directed toward sustainability of an independent program, with continued scholarship support and training placement

3) support, facilitate and expand a survey model country-wide for the post-operative valvular disease to identify challenges and solutions for supply chain

4) continue progress for a comprehensive in-country Cardiac Center of Excellence to provide care for all citizens using the sustainable economic model developed.

5) Work with the University of Rwanda School of Nursing to strengthen the cardiology component of NCD illness

6) Implement a national program for awareness, early detection with triage of positive results.

These activities will be shared with a wider international audience as one model of care illustrating a story of collaborative success in addressing the burden of rheumatic and other heart diseases in sub-Saharan Africa, as our experiences are shared through national and international venues.

Our EIN/TIN is 27-1435443. A W-9 is available on request

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