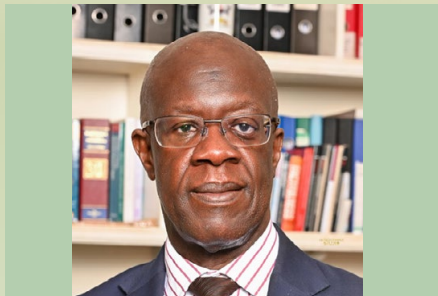


## Message

From the Principal Investigator



### *Dear Readers*

A very special welcome to the first edition of our newsletter of Makerere University's Impact research capacity building program. The program is funded by a generous grant from the NIH Fogarty International Center to reduce the impact of rheumatic heart disease across all affected ages. For more than a decade Uganda has been at the fore front of rheumatic heart disease (RHD) research in sub-Saharan Africa. Building on that Foundation Makerere University College of Health Sciences decided it was opportune time to strengthen collaboration with Uganda Heart Institute and US partners: Cincinnati Children's Hospital Medical Centre (CCHMC) and Children's National Hospital (CNH)

### Inside....

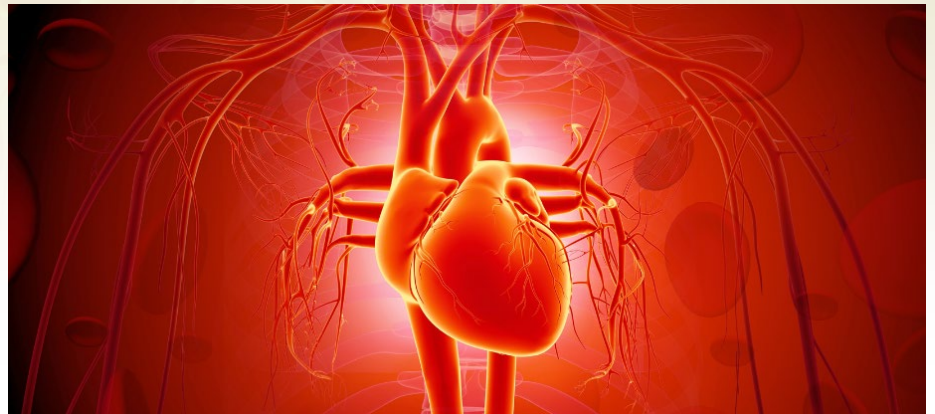
Jafesi Pulle welcomed into prestigious WHF Salim Yusuf Emerging Leaders Programme

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Impact Team shares insights at 1st World Congress on Rheumatic Heart Disease

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## Reducing the Impact of Rheumatic Heart Disease across the lifespan: The Impact Program (D43TW012255)



In 2022, the Fogarty International Center at the U.S. National Institutes of Health (NIH) awarded a five-year grant titled; 'Reducing the Impact of Rheumatic Heart Disease Across the Life Span: The Impact Program' to Makerere University's College of Health Sciences (MakCHS) in a bid to scale up research on Rheumatic Heart Disease (RHD) in Uganda. This is because there has been little innovation globally in RHD prevention, early detection, and management since the mid-1900's. Moreover, majority of evidence guiding current practice was generated in high-income countries and may not translate directly to the contemporary burden of disease in low- and middle-income countries (LMICs).

Therefore, the Impact Training Program will leverage existing resources and ongoing RHD clinical trials from a decade-long RHD research and training collaboration between Makerere University, the Uganda Heart Institute (UHI), Cincinnati Children's Hospital Medical Centre (CCHMC) and Children's National Hospital (CNH) to build capacity to tackle RHD where the burden is the highest. The Program will train multidisciplinary health professionals at MakCHS to conduct RHD-related research with a special emphasis on clinical trials capacity building. Additionally, the program will address the "double gender gap" in RHD research including (1) under-representation of women in research in Africa and (2) the dearth of sex- and gender-based analysis in RHD.

Impact trainees complete week-long training on conducting Clinical Trials

▷ 6



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to uplift Uganda's research capacity to innovate and generate knowledge critical for elimination of rheumatic fever and rheumatic heart disease in the long run.

Whereas doctoral training of doctors and nurses is the main focus of our capacity strengthening initiatives, other levels are not left behind. Training is concurrently ongoing at master's degree level and in-service for health professionals to better their research careers. The training spots were nationally advertised publicly and recruitment of trainees was competitive. Major research activities are taking place in rural communities in which rheumatic fever is relatively common. The program puts emphasis on community engagement so that the public can understand the importance and centrality of their actions in the control and elimination of rheumatic fever and achieving better quality of life and survival of those having rheumatic heart disease and its complications. The program pays special attention to gender issues in the research we do.

*Whereas doctoral training of doctors and nurses is the main focus of our capacity strengthening initiatives, other levels are not left behind. Training is concurrently ongoing at master's degree level and in-service for health professionals to better their research careers.*

## PROGRAM GOAL:

The program's goal is to equip and nurture emerging research leaders and professional scholars in Uganda to generate high-quality contemporary evidence on RHD across the lifespan and to create an enduring research training centre on the African continent that will rapidly advance progress towards the elimination of the disease in a generation.

## TRAINING OFFERED:

1

Long-term degree training at Master's, PhD and Career development fellowship levels

2

E-learning seminar and in-person immersive experience in the US to strengthen clinical trials capacity

3

Short-term trainings, seminars, webinars and workshops for degree and non-degree trainees

YEARS AWARDED



## FACULTY ON THE IMPACT PROGRAM



Prof. Emeritus Nelson Sewankambo



Dr. Andrea Beaton



Dr. Emmy Okello



Dr. James Kayima



Dr. Craig Sable



Prof. Consolata Kabonesa

## PhD CANDIDATES



Jafesi Pulle



Dr. Joselyn Rwebembera



Dr. Emma Tina Ndagire



Dr. Doreen Nakagaayi



Agnes Namaganda

## Masters CANDIDATES



Dr. John Tebajanga



Dr. Maria Nakiganda



Dr. Maria Asimwe



Dr. Samuel Jjunju



Dr. Nelson Twinamasiko

## Career Development Awardees



Dr. Iraguha Daniel Ndungutse



Dr. Peter Kangwagye



Jennifer Atala



Dr. Stella Nabirye



Dr. Isaac Mugwano

## Administrative TEAM



Harriet Nambooze  
Program coordinator



Racheal Ninsiima  
Communications Officer



Dickson Muyomba  
IT Officer

# Jafesi Pulle welcomed into prestigious WHF Salim Yusuf Emerging Leaders Programme

In a significant achievement that marks a pivotal moment in his professional journey, Jafesi Pulle, one of the IMPACT PhD Fellows, has been selected to join the esteemed World Heart Federation (WHF) Salim Yusuf Emerging Leaders Programme <https://world-heart-federation.org/emerging-leaders/>. This program, named after the globally recognized leader in cardiovascular disease research, Professor Salim Yusuf, is renowned for shaping the next generation of leaders in global cardiovascular health.

Launched in 2014, the WHF Salim Yusuf Emerging Leaders Programme is among the first of its kind, focusing on cardiovascular health policy research, health systems, and implementation science. The programme's mission is to build a network of emerging leaders from 100 countries, all committed to reducing premature mortality from cardiovascular disease (CVD) globally. This aligns with the World Health Organization (WHO) and Sustainable Development Goals (SDG) targets concerning noncommunicable diseases.

## A Journey of Learning and Collaboration

As an emerging leader, Jafesi will have the opportunity to collaborate with like-minded professionals across the globe. The programme includes a 'think tank' seminar in Mombasa, Kenya, scheduled from October 27 to November 1, 2024. This event will serve as a platform for deep engagement in the fields of cardiovascular implementation science, health systems strengthening, and health policy research.



In addition to the seminar, Jafesi will be involved in collaborative grant proposals, local/national research projects, and will participate in key activities related to CVD prevention and treatment. His role will also include presenting at the World Congress of Cardiology and other major conferences, further establishing his presence on the international stage.

## A Future Leader in Cardiovascular Health

Jafesi's acceptance into this program is a testament to his dedication and potential in the field of cardiovascular health and particularly Rheumatic Heart Disease (RHD). As part of the ninth cohort of Emerging Leaders, he will gain hands-on experience in global collaborative research projects, driving forward

the collective goal of reducing cardiovascular disease worldwide.

This accomplishment is not just a milestone in Jafesi's career, but also a step forward in the global fight against RHD.

Congratulations, Jafesi, on this well-deserved honor. Your journey as a WHF Emerging Leader is just beginning and the impact of your work promises to resonate

*The programme's mission is to build a network of emerging leaders from 100 countries, all committed to reducing premature mortality from cardiovascular disease (CVD) globally.*

# Impact Team shares insights at 1<sup>st</sup> World Congress on Rheumatic Heart Disease

The first World Congress on Rheumatic Heart Disease (RHD) held between 2-4 November 2023 brought together global experts on RHD, including Drs. Emmy Okello and Andrea Beaton, principal investigators on the Impact Program. The congress was held in Abu Dhabi, United Arab Emirates, under the theme, 'United to end RHD.'

Virtually eradicated in large parts of the world, RHD continues to have a devastating impact on vulnerable communities in sub-Saharan Africa, the Middle East,

South-East Asia and the Western Pacific, affecting 40 million people and claiming more than 300,000 lives every year. Thus, this conference aimed to shed light on the latest research in the field of RHD, facilitate meaningful dialogues with global leaders, and devise practical and tangible solutions to bring an end to this devastating disease.

Dr. Okello presentation was titled, "Know-Do Gap: Implementing and Disseminating Best Practices". On the other hand, Dr. Joselyn Rwebembera, an impact PhD

fellow, made a presentation on Artificial Intelligence empowered detection of GAS positive sore throats using smart phones in Uganda.

The two-day conference symbolized a unified, global front against RHD, and amplifies our commitment to fostering innovation, exchanging knowledge, and mobilizing resources in our battle against this preventable disease.



# Impact trainees complete week-long training on conducting Clinical Trials

Racheal Ninsiima



Trainees on the Impact Program on Rheumatic Heart Disease have undergone training in clinical trial designs, randomization and analysis by expert biostatisticians from Makerere University's College of Health Sciences. The training, held between 5-10 February 2024, was conducted by Prof. Noah Kiwanuka and Fredrick Makumbi and Drs Ronald Ssenyonga and Ssuna Bashir.

Prof. Noah Kiwanuka explained clinical trials as experimental research studies among human beings or animals whose goal is to determine the effect of an intervention. The intervention could be a drug/vaccine; medical procedure or device and a socio-behavioral, economic or education intervention.

*“For a clinical trial to happen, there must be an intervention, outcomes to be*

*measured and participants. These participants may need to be kept blind of which participants are randomized to which group and what they are receiving,” Prof. Kiwanuka taught.*

Additionally, he taught on the common methods of analysis namely: intention-to-treat (ITT); per protocol and as treated; controlled human infection models and

On the other hand, Prof. Makumbi explored levels of randomization, their application, methods, key terms and concealments. Drs. Ssuna and Ssenyonga tackled analysis of clinical trials and strategies for minimizing sample sizes respectively.

Here are some of the testimonies that the trainees gave regarding the training:



**Agnes Namaganda – PhD Fellow**

When I received an email about this training, I was excited because I

stopped learning about clinical trials during the epidemiology and biostatistics class. I have learnt how participants are enrolled into clinical trials through randomization. With this knowledge, I look forward to joining teams doing clinical trials.



**Dr. Emma Ndagire – PhD Fellow**

I was excited about this training because my PhD is about randomized control trials. I will be defining appropriate end points for acute

rheumatic fever therapeutics trial and I hope to do my postdoctoral work in the same. Through this course I have understood what adaptive clinical trials are.

to understand phases of drug development and also safety of patients. Before this training, I thought RCTs are complicated and expensive but I now know that they are doable and my colleagues and I should be able to do something around them.



**Jafesi Pulle - PhD Fellow**

I have been able to understand how to conduct cluster randomized clinical trials and the different ways to do randomization. A remarkable part of this is that we have had great teachers. I hope to use the knowledge from this course in conducting my own study in my PhD where I am using cluster randomized trials.



**Dr. Daniel Iraguha Daniel Ndungutse - Cardiology Fellow, Uganda Heart Institute**

The training has been a rewarding experience as I have learned a lot about clinical trials which I did not really appreciate during my masters in medicine. The examples used have demystified the understanding of clinical trials and I hope to do my own clinical trial work in the near future.



**Dr. Stella Nabirye - Cardiology fellow, Uganda Heart Institute**

Prior to the training, there is a lot that I didn't know but through this training, I have learned different clinical phase trials and patient safety. I have also learned about randomization and how I will use it during my study at the Uganda Heart Institute.



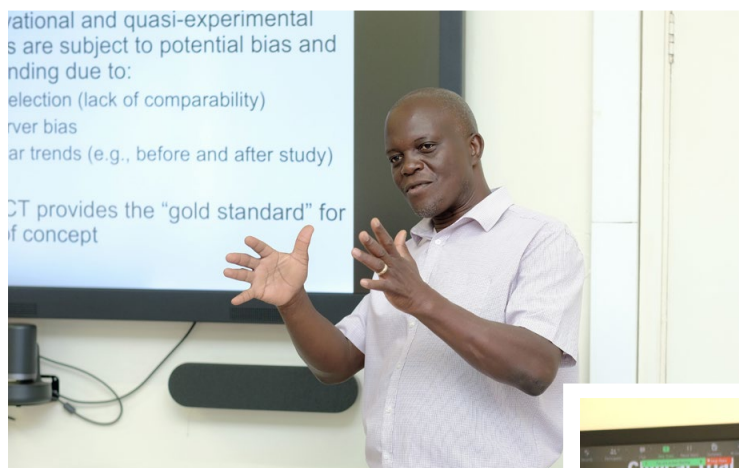
**Dr. Justine Namuli**

I gained a foundational understanding of how to conduct a trial, the stages of drug approval, and the various types of randomization, with a specific focus on block randomization for my own study. The course also covered different types of analysis, including their pros and cons, and provided me with valuable guidance on the best approach for my PhD research. This knowledge significantly clarified Objective 4 of my study, allowing me to confidently defend it in subsequent proposal presentations.



**Dr. Mugwano Isaac - Cardiology Fellow, Uganda Heart Institute**

This training has given me a good overview of how randomized control trials (RCTs) are organized and conducted. I have been able



# My journey to making Rheumatic Heart Disease care prominent in Lira district

Jenifer Atala

My journey in the Rheumatic Heart Disease (RHD) field started in 2017 when I got the opportunity to work for the Acute Rheumatic Fever (ARF) study as part of a team consisting of three staff at Lira Regional Referral Hospital (LRRH). The ARF study was a project under the Uganda Heart Institute (UHI) and supported by a grant from the American Heart Association (AHA). The overall objective of this project was to identify and characterize ARF among children presenting with fever and joint pain in the communities of Lira and surrounding districts. The nature of this study required high level engagement with key stakeholders in the district, schools as well as private and public health facilities. I was charged with this responsibility as a Community Engagement Lead.

During ARF project implementation, our team was shocked to notice that many people in the community did not know about ARF. In fact, most parents who brought children for evaluation confessed that they had never heard about Rheumatic Fever (RF). This discovery prompted our team to design a community awareness and sensitization strategy which I took a lead in executing.

I used to give health talks in school assemblies and facility out-patient departments (OPD) to patients waiting for care. I also did community awareness activities and sensitization through radio talk shows, church announcements and pinning educational posters in highly populated areas such as markets



and busy streets. Ultimately, through the referrals we received, we identified many cases of ARF and full-blown rheumatic heart disease among children.

Due to the high number of children diagnosed with RHD, an RHD clinic was established at the hospital. This nurse-led clinic that is part of Uganda Heart Institutes' (UHI) national RHD treatment registry currently handles over 400 RHD patients and offers active echo screening for the disease; enrollment to care of patients and monthly administration of penicillin prophylaxis and referral of patients to UHI. It is supported by attending clinicians and cardiologists at UHI who do quarterly visits to review those who need attention such as severe disease, RHD in pregnancy and those requiring surgical intervention.

Furthermore, the ARF study enabled me to establish key social networks and I learnt how to work with people. I also got the chance to translate my

research knowledge into practice as I regularly performed study procedures such as consenting patients, maintaining privacy and confidentiality of patient information through good record keeping and scheduling participant follow up visits.

Over time, the numbers of those with rheumatic heart disease that were attending the clinic became overwhelming and the idea of patient decentralization came in. The "Active Case Detection and







Decentralized Dynamic Registry to Improve the Uptake of Rheumatic Heart Disease Secondary Prevention (ADD-RHD)” Project evolved out of this. ADD-RHD was a technology-enabled approach to increase the uptake of RHD secondary antibiotic prophylaxis (SAP) with a focus on finding strategies to retain more RHD patients in care and to ensure that they continue receiving SAP for the recommended treatment duration to limit disease progression. This project provided me with yet another opportunity to lead as I was responsible for training, support supervision and remediation of the nurse-trainees at the different facilities. I also oversaw the collection of monitoring and evaluation data on a regular basis.

The ADD-RHD experience and lessons learnt have informed key components of the ADUNU (Accelerating Delivery of rheUmatic heart disease iNterventions in Uganda) Program, a district wide demonstration program aimed at building capacity for health workers to

identify and manage patients with RHD in Kitgum District.

I am currently leading a multidisciplinary team of case managers, research nurses, echo nurses, a data manager and Peer Group Coordinator in running a randomized clinical trial dubbed GOAL-IE (GwokO Adunu pa Lutino-Intramuscular and Enteral) in Lira and surrounding districts. Here, I provide overall oversight of trial conduct on-site as a Clinical Research Coordinator (CRC) in consultation with the study investigators. This three-year non-inferiority trial seeks to compare outcomes of children with RHD on oral prophylaxis versus those on injectable penicillin in school children diagnosed with definite RHD.

Through these studies and projects, I have had big opportunities to grow academically and professionally. I have attended international conferences and

made abstract presentations on RHD. I recently won a career development award fellowship with the Impact Program. Through this award, I seek to determine the uptake and implementation of new secondary prophylaxis recommendations for high-risk RHD patients.

Special thanks to our mentors and Rheumatic heart disease Research Collaborative in Uganda (RRCU) directors (Dr Emmy Okello and Dr Andrea Beaton) and all UHI staff who have modeled us to be who we are today. The team building spirit and continued career development programs greatly empowers us to become future leaders and mentors.



# Aiming for intervention cardiology to manage Rheumatic patients

Dr. John Tebajanga

I am Dr John Tebajanga, a final year resident pursuing my Master of Medicine degree in Internal Medicine at Mbarara University of Science and Technology attached to Mbarara University Teaching Hospital. For my master's program that is being funded by the Impact Program on Rheumatic Heart Disease (RHD), I am assessing prevalence of kidney dysfunction and associated factors among patients with RHD in southwestern Uganda.

Through my clinical practice and interaction with supervisors, senior lectures and mentors, I became aware of the deadliness of Rheumatic Heart Disease (RHD) as the most common cause of debilitating effects of heart failure among patients from low socio-economic settings. Furthermore, I realized that RHD commonly affects the young and yet early detection and prevention of the condition greatly improves patients' survival and reduces health-related costs and complications. Additionally, surgical interventions, currently available at the Uganda Heart Institute (UHI), lead to greater improvement in patient's physical functionality with prolonged life span.

While working as a clinician at Mbarara Hospital's RHD clinic, I observed that the most challenging and emotional situation is diagnosis of a young adult with severe multiple valvular disease who has no financial support to have valve replacement surgery. Also, the high treatment costs of heart failure affects patients' medication compliance.

RHD being a complication of recurrent episodes of acute rheumatic fever entails the ability to identify these patients early i.e. in the acute rheumatic fever phase so that disease progression can be mitigated. This can be done through community sensitizations and community diagnosis.

Under the mentorship of my impact's supervisors and my immediate supervisors and mentors, I hope to gain more leadership experience in order to improve patient care especially in the RHD clinic. Specifically, I hope to create an early identification system and linkage to nephrology care among RHD patients with kidney dysfunction in order to reduce their morbidity, mortality and cost of hospitalization.

I believe that the Impact Program masters fellowship grant will open doors for me in the field of cardiology (specifically intervention cardiology) that will further enlighten me in patient management. I also hope to get more involved in community outreach programs to increase awareness, community diagnosis of RHD and prompt linkage to care. I am also hoping that this would lay more ground for

further research on RHD in south western Uganda, that will aid in change of policy and management of these patients.



*Dr John Tebajanga in the Mbarara Regional Referral Hospital RHD clinic interacting and providing care to the patients*



*I with Dr OKELLO EMMY at the recent Uganda Heart Association conference in southwestern Uganda.*

# Navigating the waters of Rheumatic Heart Disease - My experience

Dr. Daniel Iraguha

During my earlier years of study to become a medical doctor, the idea then seemed to sway more to the prestige that came with owning the title, 'doctor'. It did not occur to me then that becoming a medical doctor was more than a title. Sooner than later, I qualified as a young medical doctor and I became increasingly aware of the important role I would have to play in the lives of patients that I would be serving. This stemming from personal motivation to offer the best of the training I had received from my teachers as a way of giving them a second chance at life, especially if these patients were severely ill and stood a chance of overcoming that spell of illness.

Fortunately, in the course of looking for work post internship, I was blessed to get employment at the Uganda Heart Institute (UHI) where I have worked since and been able to positively impact on the lives of a number of patients, particularly some with Rheumatic

Heart Disease (RHD). These RHD patients usually come to the institute in a dire clinical state, sometimes requiring frequent hospital admissions that warrant stabilization due to frequent heart failure symptoms. RHD causes some of them to manifest complications including strokes, heart attacks and for some, death.

The upside of my practice is that once patients are linked to the right treatment and care such as valve replacement surgery and balloon mitral valvotomy, they are in position to live a somewhat normal life. This implies that they regain their health and are able to return to school or active employment for those that had been incapacitated.

Some of the most rewarding moments in my work is the fulfillment of seeing patients lives transform for the better and striking long-lasting bonds of friendship with others. With their permission, I have presented



narratives of patients who have had unique presentation and overcome life-threatening conditions at different conferences.

Therefore, although Uganda continues to struggle with RHD, the onus is on us medical practitioners to prevent its development and link up those affected to the right healthcare so that they can have a better chance at life.



# Experts link sore throat to Rheumatic Heart Disease

## Violet Nabatanzi (New Vision)

Health experts have warned that untreated sore throats can lead to Rheumatic Heart Disease (RHD). RHD often begins with a sore throat caused by the bacterium *Streptococcus pyogenes* (group A streptococcus). The condition is common in children, typically those aged between 5 and 30 years old.

Dr. Emmy Okello, a Senior Consultant Cardiologist and Director of the RHD Collaborative in Uganda stated that their goal is to prevent sore throat infections, diagnose them early and identify stages of heart disease to treat affected children promptly.

“Many young adults are coming to the heart Institute and other hospitals seeking funds for surgeries, often too late, as this process starts 15 to 20 back. It starts is that infection of the throat that is sometimes missed and what we are trying to do is to go back and work on prevention, diagnose and treat,” he said.

Despite the high burden of RHD in Uganda and most sub-Saharan African countries, there has been very little investment in research and training. In response, Makerere University College of Health Sciences and Uganda Heart Institute under the Impact Program aim to build research capacities for young researchers to conduct RHD-related research, with a special emphasis on clinical trials capacity building.

The Program, spearheaded by Prof. Nelson Sewankambo and Drs. Emmy Okello; James Kayima and Andrea Beaton, a pediatric cardiologist at Cincinnati Children’s Hospital Medical Center, currently supports PhD,

masters and career development award fellows.

Dr. Okello mentioned that when children are identified early and treated with penicillin, they can return to a normal life without surgery.

“We are putting a lot of effort into detecting children and young adults early enough so that they can be given penicillin and return to normal,” he said.

Experts noted that RHD is very common in Gulu, Lira and Kampala. However, in the western region, particularly Mbarara and Bushenyi, the condition is less prevalent. The World Health Organization (WHO) encourages countries to collaborate with ministries of health to eliminate Rheumatic Fever and RHD globally.

Prof. Sewankambo said, “The healthcare continuum needs to improve knowledge and practice in RHD. Community health workers need to know about RHD and what causes it because that is where primary prevention starts.”

He further stated that the program

will contribute to improving the diagnosis of RHD through research.

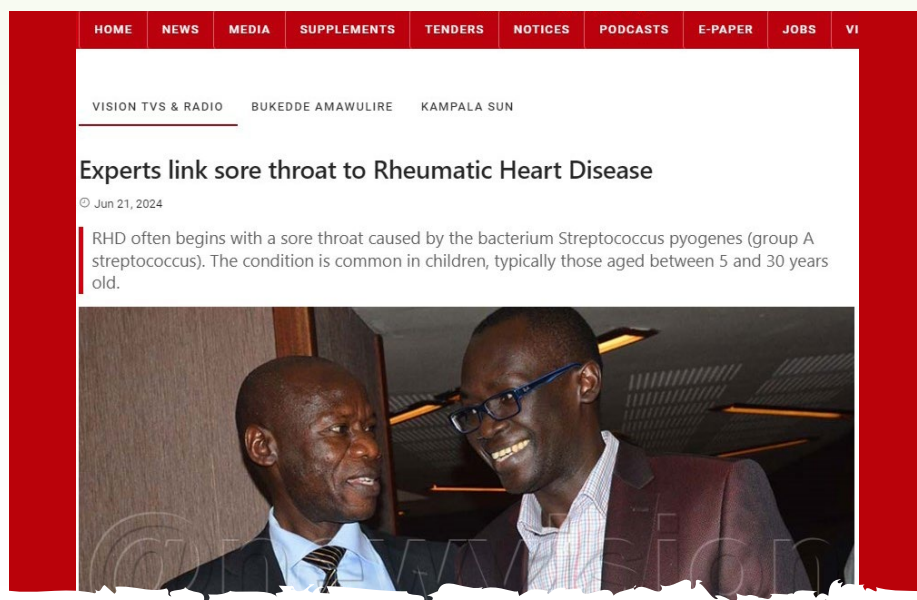
“We know that access to surgery is very limited for a few lucky individuals. We hope that the work done in this project will eventually impact patient management and improve outcomes,” he said.

During a Research Dissemination conference at Kabira Country Club, Dr. John Omagino, Executive Director, Uganda Heart Institute called for assigning a nurse to each primary school to diagnose sore throats and prevent children from developing RHD.

The cost of surgery for a child with RHD is about UGX50M which most patients cannot afford.

Dr. Omagino suggested that all hospitals must have penicillin, adding that sometimes there are stockouts and called on the Ministry of Health and National Medical Stores to prioritize penicillin availability.

**This article was first featured in the New Vision on June 21 2024.**



# Interviews for selecting masters' fellows successfully held



The Impact Program on Rheumatic Heart Disease held interviews for the selection of masters' research fellows on Tuesday 30<sup>th</sup> April 2024. The interviews were intended to get more students to focus on conducting research in the area of Rheumatic Heart Disease (RHD). Rheumatic heart disease is a serious and potentially life-threatening condition where the valves of the heart become damaged.

The interview panel had Prof. Emeritus Nelson Sewankambo and Drs. Emmy Okello, James Kayima and Peter Lwabi. Four candidates presented their research topics and were evaluated accordingly. These were: Dr. Samuel Jjunju whose proposed study aims to

comprehensively examine Acute Rheumatic Fever screening, diagnosis & referral practices in southwestern Uganda; Shamim Nabidda whose masters research is titled, 'Knowledge on prevention of rheumatic heart disease and associated factors: cross sectional study among nurses working at Uganda Heart Institute; Dr. Nelson Twinamasiko whose masters research is examining 'Health related quality of life for people living with Rheumatic Heart disease and HIV in Uganda and Dr. Maria Asimwe whose masters research is exploring Anesthetic management and outcomes of Rheumatic Heart disease among pregnant women with cardiac disease undergoing

surgery in Uganda.

RHD is a serious and potentially life-threatening condition where the valves of the heart become damaged. It is envisioned that having more researchers on board will scale up research of and innovation in RHD in Uganda.

*The Impact Program on Rheumatic Heart Disease held interviews for the selection of masters' research fellows on*

**Tuesday 30<sup>th</sup> April 2024.**

# Advancements in echocardiography machines

Technological advancements have resulted in the emergence of miniaturized handheld ultrasound equipment. Now, handheld echocardiography can be readily performed at the point of care with reasonable image quality.

In March 2023, Prof. Craig Sable, a professor of pediatrics at the George Washington University School of Medicine & Health Sciences trained impact fellows on use of echocardiographic view simulation technology. This state-

of-the-art technology enables a 3D reconstruction of the cardiac anatomy in a variety of clinical scenarios.



# Dr. Anneke Grobler equips fellows with biostatistics skills

On March 14 2024, Dr. Anneke Grobler, a senior Biostatistician at the Murdoch Children’s Research Institute (MCRI) facilitated a training on biostatics, systematic reviews and case control studies for fellows on the Impact Program. In her role as a statistician at MCRI, Dr. Grobler supports clinical trials and observational studies. She plays a major part in the design, planning, and statistical analysis for a range of clinical trials, including studies in Public Health, Health Services and Education.

Here is a pictorial of the training:





## Impact Program

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