



CHILDREN'S HEART DISEASE RESEARCH UNIT

Conduct, promote and support children's
heart research on the African continent

Annual Report 2016



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LETTER FROM DIRECTOR

Congenital heart disease (CHD) is the most common birth defect, with a birth prevalence of approximately 8 in every 1000 births and killing more children each year than all the childhood cancers combined. Yet, the epidemiology of CHD in Africa is poorly defined with a dearth of data on prevalence and predictors of mortality. Simultaneously, the population of adults with CHD is steadily increasing, and incorrect or inadequate management of this critical transition period has direct influence on maternal mortality and morbidity.

An entirely preventable condition, rheumatic heart disease (RHD) is undergoing a renewed focus in research and scientific activism, spearheaded by researchers from endemic countries. Research to identify predictors of mortality and morbidity highlight gaps in implementation and provide evidence for improved and focused interventions for children with heart disease is urgently needed.

Our unit was established with the goals to:

- Conduct, promote and support children's heart research on the African continent
- Facilitate Implementation Science
- Provide postgraduate supervision and training in children's heart research
- To achieve the University of Cape Town's minimum required standards to register as an independent unit

The overarching vision, mission and values of this unit are those of the University of Cape Town and the Department of Paediatrics and the Institute of Child Health as our primary affiliations.

In addition, the specific vision, mission and values of our unit are as follows:

Vision: integrating research and clinical practice to improve the lives of all with congenital and paediatric heart disease.

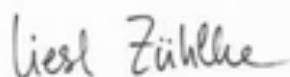
Mission: conducting innovative, patient-centered and accountable research with the focus on African areas of need.

Values:

- Child and family-centred
- Caring and respectfulness
- Striving for excellence
- Responsibility, honesty and integrity
- Multisectoral and interdisciplinary collaboration

Our annual report for 2016 demonstrates progress and significant achievements in many of the delineated areas. I look forward to the challenges of 2017 and the planned projects in this period. These represent not only a consolidation of the work over the past year but also an extension into new areas of research, new collaborations both nationally and internationally, and multisectoral and multidimensional translation of knowledge and science into action and policy.

I would like to thank all our staff, collaborators and in particular, our funders for their generosity, commitment and fervor for children with heart disease.



Associate Professor Liesl Zühlke



Rheumatic heart disease (RHD) is undergoing a renewed focus in research and scientific activism.



INTRODUCTION

The Children's Heart Disease Research Unit (CHDRU) was established in May 2015 to facilitate current research activities in congenital and paediatric heart disease, and to build capacity to support such research within the Department of Paediatrics and the Institute of Child Health. The CHDRU focuses on congenital heart disease, both in childhood and adulthood, acquired heart diseases such as rheumatic heart disease and cardiomyopathies, and the increasing tide of the cardiovascular disease burden. It addresses issues of national importance, as it is clear that NCDs will be economically crippling to developing countries, while also focusing on preventable diseases such as RHD, maternal and childhood mortality and responding to social determinants of health.

The Children's Heart Disease Research Unit endeavors to serve as a platform to bring together researchers, communities and resources to advance the campaign against paediatric and acquired heart disease on the African continent. Under the auspices of the University of Cape Town, the Unit is based at Red Cross War Memorial Children's Hospital. It is directed by Associate Professor Liesl Zühlke, a paediatric cardiologist and researcher, and is strongly affiliated with the Departments of Pediatric Cardiology, Cardiothoracic Surgery and Adult Cardiology as well as the Department of Medicine.

In 2013, Professors Zühlke of the University of Cape Town and Jonathan Carapetis, Director of Telethon Kids Institute (Perth, Australia), joined forces to make their long-standing dream of a formal global effort for Science, Policy and Action for Rheumatic Heart Disease become a reality. Their collective vision and effort resulted in the creation of RhEACH (Rheumatic Heart Disease-Evidence, Advocacy, Communication and Hope). This flagship project provides a technical support and policy translation initiative to amplify rheumatic heart disease control efforts locally, regionally and globally. Initial efforts included the development of the TIPS framework and was followed by a large 5-year grant from Medtronic Foundation in early 2015 to establish RHD Action. RhEACH is thus a member of a larger global alliance – RHD Action – that includes Medtronic, the World Heart Federation and demonstration sites in Tanzania and Uganda.

In the first months, the activities of the Unit largely revolved around RhEACH, but efforts to attract other external funding in 2016 have been fruitful with Medical Research Foundation (MRC) South Africa, MRC United Kingdom (UK) and National Research Foundation (NRF) funding, selection as the national leader site for both a global RHD study and a global paediatric heart failure medication study. The Unit has also served as the impetus and support unit to bring two large investigator-initiated projects - IMHOTEP and INVICTUS - to the Red Cross Hospital.

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The CHDRU endeavors to serve as a platform to bring together researchers, communities and resources to advance the campaign against paediatric and acquired heart disease on the African continent.

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Most notably this year, Prof Zühlke is co-principal investigator of a team that has been awarded a large MRC UK Foundation collaborative grant between the University of Cape Town and the University of Manchester entitled, "A North-South Partnership in Congenital Heart Disease (CHD)." This two-year project will be the first systematic collection of incidence and prevalence of CHD in the African population to compare to the historically established Euro-American data. The project also has genetic and imaging components that will significantly enhance the research infra-structure in these areas at UCT.

MEET THE TEAM

Associate Professor Liesl Zühlke

Professor Liesl Zühlke, MB ChB DCH FCPaed MPH FESC PhD trained as a Paediatric Cardiologist in Cape Town and Dusseldorf, Germany. She earned her MPH in clinical research methods, and a doctorate on outcomes in Rheumatic Heart Disease from the University of Cape Town. She was promoted to the rank of Associate Professor in the Department of Paediatrics in the Faculty of Health Sciences at the University of Cape Town in December 2016.

Prof Zühlke has received a number of awards including an academic excellence award from Discovery Foundation, a US National Institutes of Health Fogarty Fellowship, a Wellcome Clinical Infectious Disease Research Initiative fellowship award and an early career Thrasher award in addition to the Hamilton Naki Clinical Scholarship, an award given to clinical scholars of excellence. She is past-president of the Paediatric Cardiac Society of South Africa, the current president of the South African Heart Association and the chairperson of the paediatric task-force of the Pan-African Society of Cardiology.

This year, Prof Zühlke achieved C1 rating with the South African National Research Council for her work in Paediatric Cardiology and Rheumatic Heart Disease. Additionally, this year, her article, "Characteristics, complications, and gaps in evidence-based interventions in rheumatic heart disease: the Global Rheumatic Heart Disease Registry (the REMEDY study)" in *European Heart Journal* (7; 36(18):1115-22a) was selected as Best Publication 2015 (Early career award, Clinical Sciences) by the UCT Faculty of Health Sciences.

Dr David Watkins

Dr Watkins received a bachelor of science from Rhodes College and his medical degree from Duke University before moving to the University of Washington in Seattle, where he completed a residency in internal medicine. During this time, he also completed an MPH through the Institute for Health Metrics and Evaluation, and a research fellowship in health economics with the Disease Control Priorities Network at the University of Washington.

Dr Watkins is currently a physician-scientist in the Departments of Medicine at the University of Washington and University of Cape Town, and he is a senior researcher with the Disease Control Priorities Network based at the University of Washington.

Dr Watkins serves as a scientific advisor to RHEACH. His research seeks to inform the health system response to non-communicable diseases in low- and middle-income countries. Because RHD is a model non-communicable diseases for low- and middle-income country health systems, his projects include burden of disease analysis, mixed methods research to identify gaps in healthcare delivery, and economic evaluation of RHD interventions and policies. Dr Watkins spends approximately two months per year on-site at the University at Cape Town and attends most international meetings with the Team, presenting and in support of RHD Action/RHEACH efforts.



Professor Liesl Zühlke



Dr David Watkins

Susan Perkins

Susan Perkins holds an undergraduate degree in psychology from Salisbury University and a Master of Science in Community Health Management from Old Dominion University in the US. Her work history includes hospital management, and research administration and programme management in the academic medical setting. She was the manager of a paediatric clinical trials unit in a regional children's specialty hospital in the US where she served on the Institutional Review Board and Conflict of Interest Committee. In addition to overseeing industry multiple pharmaceutical trials, Ms Perkins also mentored post graduate medical trainees in the development and execution of their required research protocols.

Ms Perkins became involved with the RHD community while serving as a US Peace Corps volunteer in the rural Limpopo Province of South Africa where she was the administrative site manager for the REMEDY study from 2012 to 2014. She joined the Unit in a full-time, on-site capacity as Programme Manager in November 2015.



Susan Perkins

Alexia Joachim

Alexia Joachim is a professional nurse who trained at Johannesburg Hospital. Upon graduation, she began her career in the medical ward at the Children's Red Cross War Memorial Hospital and her subsequent professional experiences have been primarily based in paediatric subspecialties.

Ms Joachim was the sister-in-charge in a children's home (Place of Safety) for several years where she managed the care of approximately 30 children ranging from infants to young teens awaiting legal placement. She has worked as a Glaxo Smith Kline medical representative where she visited public health care facilities in the Western Cape to provide training in asthma care and allergy conditions.

Ms Joachim was a member of the Cape-Town REMEDY team where she enrolled and managed local participants as well as conducted site visits and training. Most recently, she worked in a private capacity doing home-based wound care in the Cape Town area. Ms Joachim joined the Unit in November 2016 as a research nurse, primarily assigned to the ADOLE-7C study.

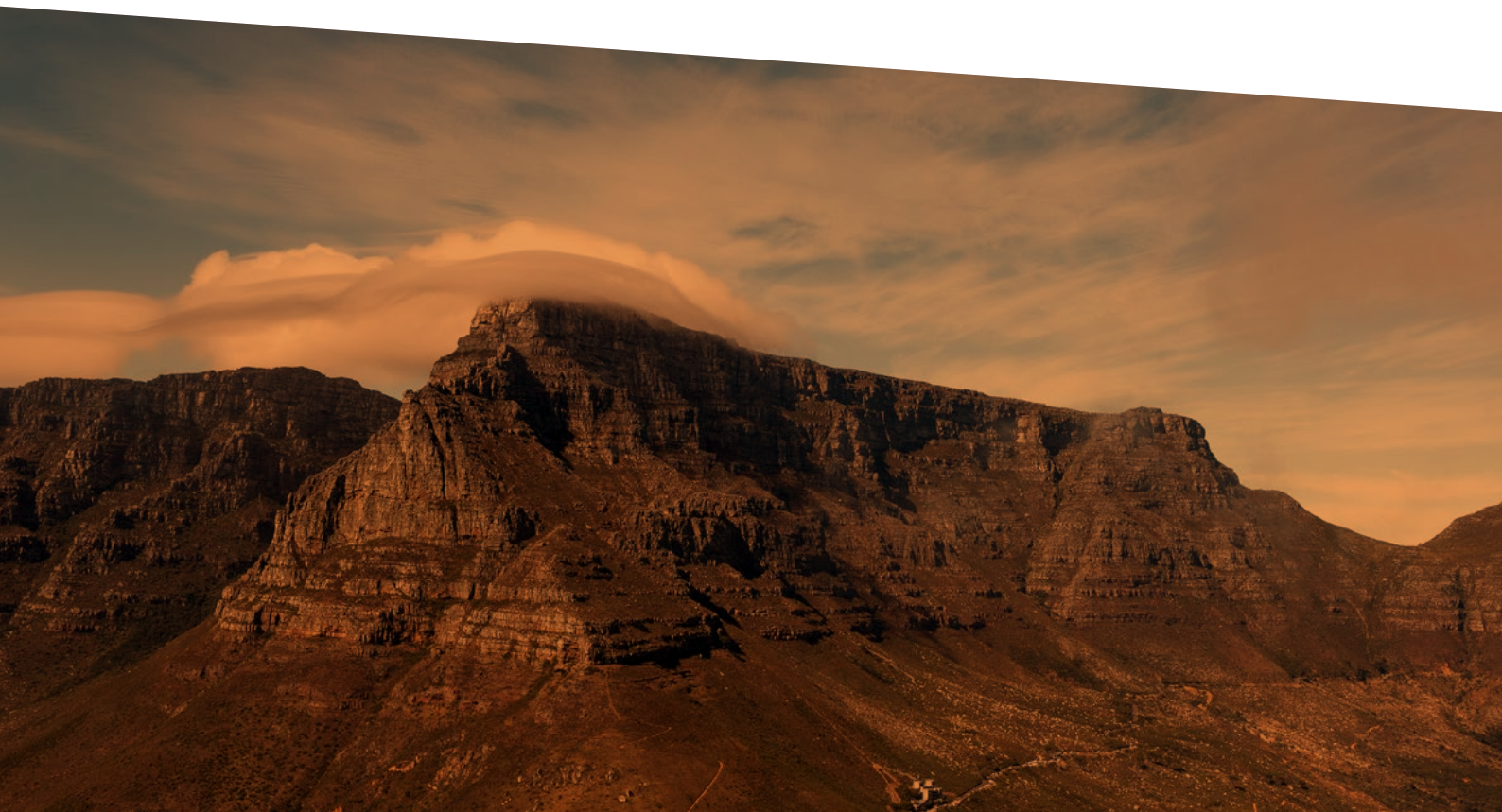
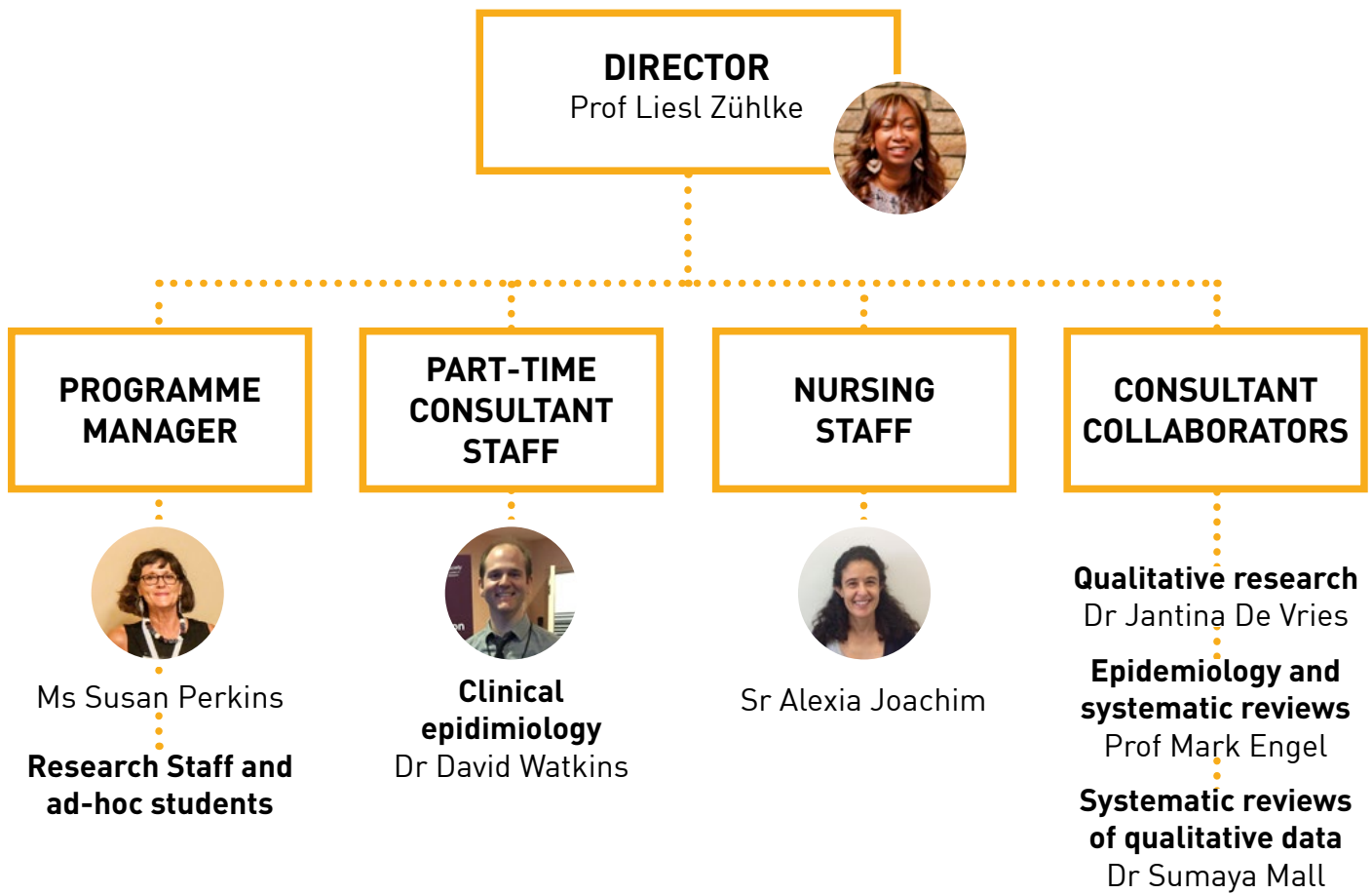


Alexia Joachim



David, Susan and Liesl on World Heart Day 2016

ORGANOGRAM



HIGHLIGHTS AND NOTEWORTHY EVENTS

2015

FOURTH QUARTER 2015

- Susan Perkins joined the staff at CHDRU
- Unit-facilitated Workshop, "Introduction to Planning, Monitoring and Evaluation" conducted by Southern Hemisphere at Red Cross War Memorial Children's Hospital for UCT Staff and Faculty Development

2016

SECOND QUARTER 2016

- World Congress of Cardiology, Mexico City
 - Launch of Needs Assessment Tool
 - Release of Global Status Report
 - Release of Global BPG Report
 - RHDA Partners Meeting

FIRST QUARTER 2016

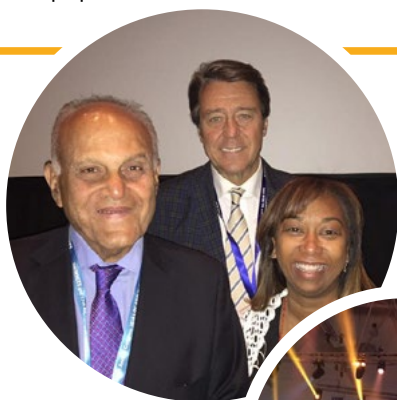
- World Health Assembly, Geneva, Switzerland
- AU All Africa RHD Workshop, Addis Ababa, Ethiopia
- Heart Valve Society Meeting, New York City
- Finalising writing and editing, and soliciting feedback on NAT Project

THIRD QUARTER 2016

- European Society of Cardiology, Rome, Italy
- Listen to my Heart Patient Event, Cape Town
- RHD Qualitative Researchers Meeting, Cape Town
- SA Heart Congress, Cape Town
- Prof Zühlke joined the clinical staff at RCWMCH
- Prof Zühlke meets with Minister of Health, Aaron Motsoaledi, in Johannesburg to discuss cardiovascular disease in the South African paediatric population

FORTH QUARTER 2016

- ADOLE 7C Award
- NRF Researcher and Student Bursary Award
- First session at London School of Economics in Executive Masters of Health Economics, Outcomes and Management of Cardiovascular Diseases.
- MRC Foundation Award, "A North-South Partnership in Congenital Heart Disease (CHD)"



2017



MAJOR PROJECTS

THE NEEDS ASSESSMENT TOOL

The major task of the Cape Town RHEACH Office was the creation of a [Needs Assessment Tool](#) that could be easily adapted and used for designing and implementing RHD Control Programmes in resource-limited settings. The NAT is meant to provide technical guidance and structure to the development of targeted interventions to prevent and control ARF and RHD. It makes use of scientifically validated methods and is designed as a collection of tools for public health practice and focuses on the key data required for developing and monitoring interventions.

Prof Zühlke and Dr Watkins began creating this document in December 2014. Susan Perkins joined the writing team in August 2015. Contributions, reviews and edits were solicited and received from RHD Action partners and other experts across the globe. Design and production services were contracted to [Lushomo](#) as the draft neared its final iterations. Mock-ups and drafts were shared and discussed with the stakeholders at the AU All Africa RHD Workshop in Addis Ababa in March of 2016.

The NAT made its online and print debut at the World Congress of Cardiology in Mexico City in June 2016. Downloadable forms were added in the following weeks.

One of RHEACH Cape Town's task at hand for the remaining years of the RHEACH project is the piloting of the individual tools and collection and synthesis of feedback from "real world" applications culminating in the production of NAT 2.0 that incorporates the experiences of end users.



Front page and graphic from the Needs Assessment Tool

NAT PILOT PROJECTS

A number of NAT tools were piloted in 2016.

1. Systematic Review

The Systematic Review Protocol Tool (NAT 1.1) was utilised to investigate RHD Action Countries Tanzania and Uganda. The study was led by Hlengiwe Mloi, during her period as a research assistant at the CHDRU supervised by Dr Watkins and Professors Zühlke and Mark Engel. The project, entitled "Epidemiology, health systems and stakeholders in rheumatic heart disease in Africa: a systematic review protocol," described the protocol for a systematic review of PubMed, Embase, and grey literature for quantitative and qualitative studies on group A streptococcal disease (GAS), acute rheumatic fever (ARF), and RHD and was followed by the application of the protocol in Uganda and Tanzania.¹

Three sets of outcomes were pre-specified: (1) disease epidemiology, (2) barriers and facilitators to healthcare, and (3) stakeholder identification and engagement. Methods included random-effects meta-analyses and a narrative synthesis of themes. No studies contained data on stakeholder identification and engagement (Objective 3).

The query resulted in 293 records and 12 of them met inclusion criteria (nine for objective 1 and three for objective 2). Most quantitative studies were at moderate or high risk of bias, and only one of two qualitative studies was high quality. The prevalence of RHD was estimated at 17.9 [95% confidence interval (CI): 4.0 to 41.2] per 1000. The most frequent nonfatal sequelae were found to be heart failure, pulmonary hypertension, and atrial fibrillation. Case-fatality rates in medical and surgical wards were 17% [95% CI: 13% to 21%] and 27% [95% CI: 18% to 36%], respectively.

Barriers and facilitators to GAS and RHD care were identified in the domains of individual knowledge, family support, provider communication and knowledge, and system design. The research team concluded that RHD remains endemic in Tanzania and Uganda, and symptomatic RHD is associated with high rates of morbidity and mortality. Critical data gaps in the areas of GAS and ARF epidemiology were identified, as well as healthcare utilization patterns and their determinants.

2. RHD Action Uganda

The Interview Guide for Country Contacts (NAT 2.11) was piloted with three Ugandan clinician researchers to explore the current policies and procedures around ARF and RHD at both country and site levels. The interviews were transcribed, coded, analysed and reported in the context of the Medtronic Continuum of Care by the RhEACH Cape Town team.

The findings were presented in a written Executive Summary to the UG Country partners and MDT Foundation. The five key findings were:

- Poor Primary Care Infrastructure for Chronic Disease Care
- Specific Gaps in RHD Prevention and Treatment
- Promising Relationships with Key Stakeholders
- RHD Action Uganda Productivity
- Need to Explore Patient Perspectives - the Demand Side

A deployment plan was developed in consensus with the UG partners that included identification of site(s) and NAT Tools (quantitative/qualitative studies)

1. Mloi AH, Watkins D, Engel ME, Mall S, Zühlke LJ. Epidemiology, health systems and stakeholders in rheumatic heart disease in Africa: a systematic review protocol. *BMJ Open*. 2016;6(5):e011266.



The research team concluded that RHD remains endemic in Tanzania and Uganda, and symptomatic RHD is associated with high rates of morbidity and mortality.



for implementation. Susan Perkins provided extensive assistance in the writing and formulation of the protocol, including consent forms and information sheets in the second quarter of 2016. The protocol was approved by Case Western University in Cleveland, Children's National Medical Center in Washington DC and finally by the Makerere University Ethics Committee in Uganda in November 2016. Project initiation is expected in early 2017.

3. RHD Action Tanzania

The Interview Guide for Country Contacts (NAT 2.11) was piloted with two Tanzanian clinician researchers and one public health academic to explore the current policies and procedures around ARF and RHD at both country and site levels. The interviews were transcribed, coded, analysed and reported in the context of the Medtronic Continuum of Care by the RhEACH Cape Town team.

The findings were presented in a written executive summary to the TZ Country partner: Touch Foundation, and MDT Foundation. The four key findings were:

- Major barriers to referral and tertiary care in general
- Human and other resource constraints are severe but improving quickly
- Overly centralized and uncoordinated care for RHD
- Lack of emphasis on prevention

As a member of RHD Action, Touch Foundation received funding from Medtronic Foundation to conduct a needs assessment to inform the development and implementation of an RHD intervention in the Mwanza/Lake Zone area. The Sengerema District, and particularly the Sengerema Designated District Hospital, was chosen by Touch as the site for conducting this endeavour.

Susan Perkins conducted a site visit to Mwanza 2-6 May 2016. The purpose of the visit was to "meet the people involved and see the landscape" at the sites identified by Touch for RHD programme implementation, and to meet some of Touch's partners based in Mwanza. The aim was to get a sense of the extent of current and future collaborations between RhEACH and Touch as RHD Action partners for pilot testing the RHD Action NAT instruments in a live environment.

The main accomplishment of the site visit was a comprehensive tour and overview of the development work in process, as well as already completed, by Touch Foundation in the Mwanza Region at the Bugando Medical Centre (Catholic University of Health Sciences) and the Sengerema Designated District Hospital facility. Touch has had a long and fruitful relationship with the local healthcare system in this region with its major focus being maternal and child health.

Touch Foundation country partners contracted with the local (Tanzanian) National Institute of Medical Research (NIMR) to conduct the needs assessment prior to a planned programme launch in the Sengerema District. Touch elected to continue to partner solely with NIMR on the community presentation of the findings of the needs assessment and eventual intervention design phase.

4. RHD Stakeholder Review

As no studies revealed in the Systematic Review of RHD in Tanzania and Uganda contained data on stakeholder identification and engagement, a preliminary investigation was launched in an attempt to identify and assess the roles of currently involved, as well as potential stakeholders, related to RHD prevention and treatment efforts. Dr Nate Tulloch, an internal medicine resident physician at the University of Washington in Seattle, Washington visited the Unit in April of 2016 to work and consult on this study entitled, "Stakeholders in rheumatic heart disease control in Uganda and Tanzania: a systematic review."



Bugando Medical Centre, Catholic University of Health Sciences



Sengerema Hospital, beds in the high-risk maternity waiting facility



Bugando Medical Centre, waiting area

Supervised by Dr Watkins and Prof Zühlke, Dr Tulloch conducted an investigation that included a comprehensive analysis of the identified peer-reviewed and grey literature, and mapped all relevant local and international stakeholders, thematically and geographically. The intent was to generate a reproducible model for quickly identifying involved and potential stakeholders that can be generically applicable from country to country, with the goal of improving efficiency of screening, diagnosis, and treatment by combining efforts of the disparate stakeholders individually invested in combatting RHD at various levels.

Individual stakeholders within studies were identified by authorship institution, direct acknowledgment, reference within the text, or as a funding-only contributor. Stakeholders within institutions were tabulated on the level of department or division within an institution if multiple stakeholders were identified. Despite being the larger country, both geographically and by population, Tanzania had markedly fewer hits in peer-reviewed literature [7] compared to neighbouring Uganda [23]. There were 11 additional grey literature sources identified for each. From this selection, 124 independent stakeholders were identified relating to Uganda, compared to 96 for Tanzania. Of those, a majority, 66%, of identified Ugandan stakeholders were international, rather than local within Uganda. In Tanzania, however, the majority, 71%, were local Tanzanian stakeholders.

These stakeholders fell generally into 5 groups: 1) Patient, family and civil society, 2) Educational sector, 3) Research, training and capacity building, 4) Service delivery, and 5) Policy and administration. Of these large groupings, research, training and capacity building represented by far the largest group of stakeholders for both countries. However, even despite a large number of international stakeholders working in each country, overlap between these two neighbouring East African countries was minimal, involving only 13% of the 194 total identified stakeholders. In the largest group (research, training, and capacity building, 83 stakeholders), only 3 stakeholders were shared between the two countries.

The stakeholders local to Uganda were located in 3 discrete locations across the country, whereas the local Tanzanian stakeholders were more widely dispersed in 6 locations across the country. A manuscript is currently in advanced draft.

5. Development of a Needs Assessment Tool for Scaling up Cardiac Surgery in African Countries

Dr Jessica Forcillo, a cardiac surgeon from Montreal, Canada, collaborated with Prof Zühlke to develop a needs assessment tool for the evaluation of cardiac surgery programmes in Africa. Dr Forcillo, who was based in the Unit's office, travelled to African medical centres in Namibia, Zambia and Uganda between September 1st and October 18th, 2016.

The three major objectives of the project were: to gather data regarding the variables that need to be included in a cardiac surgery needs assessment tool, to highlight current initiatives, challenges and goals and to develop a needs assessment tool for this type of investigation.

In-depth interviews were conducted with stakeholders in each country; facility surveys were also conducted to assess human and physical resources, and surgical capacity. Findings were synthesized using a five-block conceptual framework by assessing each programme's current capacity against a standardised definition of "adequate" surgical capacity. Based on these findings, a formal needs assessment tool for use in other countries was developed.

Findings included an obvious lack of human and material resources to adequately address the cardiac surgery needs of the populations in these countries, especially those living in the remote areas. Post graduate training and mentorship programmes are lacking. Additionally, a striking absence of capacity

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A majority, 66%, of identified Ugandan stakeholders were international, rather than local within Uganda. In Tanzania, however, the majority, 71%, were local Tanzanian stakeholders.

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Jessica with the Greats of Cardiac Surgery: Prof Alain Carpentier and Prof Sir Magdi Yacoub.

to treat rheumatic valvular heart diseases, complex congenital and adult cases was noted. Prevention, rehabilitative and palliative programmes were noted to be non-existent.

It is our aspiration that this needs assessment tool will assist ministries of health and is a critical first step in improving the sustainability of cardiac surgery and improving patient access to care through innovative Africo-centric solutions.

A manuscript of the project has been submitted for review and consideration. The abstract recently won a prize of \$250 at the "RHD: from molecules to community" meeting in Cairo.

LISTEN TO MY HEART

On 9 September 2016, RhEACH Cape Town co-hosted with the Stop RHD ASAP Programme (Awareness, Surveillance, Advocacy and Prevention) an event for people living with RHD called 'Listen to my Heart.' With the help and assistance of RhEACH Perth, World Heart Federation and RHD Action partners, the event was held alongside the combined South African Heart Association Congress and World Congress of Cardiac and Cardiothoracic Surgery at the Cape Town International Conference Center.

Co-organized by the ASAP Programme, the Mayosi Research Group at University of Cape Town and RHD Action, the Unit acted in a dual capacity in the planning and execution of the event. This event provided RHD researchers, health workers and advocates an opportunity to connect with the RHD community's most important stakeholders: people living with RHD.

Approximately 80 people living with RHD attended the event. The majority of the attendees were from the Groote Schuur RHD patient community, but others travelled from the South African provinces of Limpopo and the Western Cape, and Kampala, Uganda. All of these patients had participated in the REMEDY study.

During the event, guests had the opportunity to take part in a wide range of activities. These included measuring their body mass index (BMI); receiving an echocardiographic screening; discussing barriers and opportunities to improving RHD care in South Africa and abroad; and taking group pictures in the photo booth.



Our most important stakeholders: People Living with RHD



The Cape Town RHD Patient Community Advisory Group was introduced at "Listen to My Heart" on 9 September 2017.

Dr Jantina DeVries facilitated a session to elicit perspectives on how to improve RHD prevention, control and awareness from the PLWRHD audience. Attendees especially called for:

- More information on RHD at the district level, especially on RHD and pregnancy
- Clearer explanations from doctors regarding their RHD diagnosis
- More RHD awareness-raising programmes in schools.



RHD health workers and researchers from the ASAP Team join in the Listen to My Heart festivities.

Attendees also heard from a diverse array of speakers including UCT speakers Simpiwe Nkepu and Professor Mark Engel, who particularly thanked the people living with RHD for attending and participating in the REMEDY study. Their presentations were followed by Professor Pamela Naidoo, CEO, Heart and Stroke Foundation of South Africa, and Belinda Ngongo, representing Medtronic Foundation, both of whom called for greater patient empowerment.

The newly-formed Patient Community Advisory Group (PCAG) was introduced by Olivia Matshabane from UCT, noting that some members had been living with RHD for more than 50 years. Ms Matshabane described the role of the PCAG as connecting and communicating between researchers and the patient community. Prof Zühlke, on behalf of RHD Action, concluded the event by thanking the people living with RHD for attending and sharing their experiences.

To build on the success of 'Listen to my Heart', RHD Action and particularly RhEACH, plan to package this very important PLWRHD event to stimulate, facilitate and support similar events in the future to further strengthen patient empowerment and advocacy.



PLWRHD guests from the Limpopo Province of South Africa and Kampala, Uganda enjoyed a visit to Robben Island during their participation in the Listen to My Heart and RHD Qualitative Researchers Workshop events.

RHD QUALITATIVE RESEARCHERS WORKSHOP

On 12 September 2016, representatives drawn from different parts of the RHD global community met in Cape Town to discuss strengthening and developing a qualitative and sociological research agenda for rheumatic heart disease.

The meeting was convened by RhEACH Cape Town and the UCT ASAP team, and so again the Unit office acted in a dual capacity for organizing and executing the event. Participants included people living with RHD, health workers, researchers, clinicians and advocates. Their discussions were anchored in the experiences of people living with RHD, to ensure that future research reflects the realities of patients' day-to-day lives.

In her opening remarks, co-convenor Dr Jantina de Vries addressed the aims of the meeting: 'how can we ensure that when we talk about RHD we talk about its totality'? The session was co-convened by Dr Clancy Read (Telethon Kids Institute, Australia), who had participants break out into small groups to identify the various points at which a person might enter the health system, which barriers might prevent him or her from accessing care, and what opportunities exist to address gaps in the health system. These initial discussions drew attention to a wide variety of issues such as the stigma experienced by patients, long waiting lists at health care facilities and the lack of affordable care, particularly for cardiac surgery. Participants also found that there was a need to develop a non-medical patient journey in addition to the Continuum of Care, which focuses on how patients relate to the health system.

Following this activity, five people living with RHD – from Uganda and the South African provinces of Limpopo and the Western Cape – spoke about their experiences with the disease. Participants quickly realized that there was no typical patient journey, with each participant having experienced a different path to diagnosis and treatment.

The afternoon session began with presentations from qualitative or sociological researchers from South Africa, Tanzania, Uganda and Australia. Dr Isaac Ssinabulya and Amy Scheel (Uganda Heart Institute) praised the capacity of adult and paediatric support groups to improve patient adherence. Dr Ssinabulya also spoke about the success of a doctor-patient WhatsApp group in allowing patients to easily ask their doctor questions about RHD. Describing the initiative as an "extension of medical school," Dr Ssinabulya said that the experience "makes me feel part of a complete contribution to someone's life."

The need for clear communication between patients and health workers was evident in a presentation from Alice Mitchell, who provided a summary of research underway in the Northern Territory in Australia. The study is comprised of interviews, mostly with adolescent boys living with rheumatic fever and RHD. She pointed out that in future studies, Indigenous communities would assume more responsibility in driving research and awareness of RHD.

Tusajigwe Erio presented her small qualitative study conducted in Mwanza, Tanzania that highlighted language as a barrier to improving raising awareness and improving health seeking behaviours in Sengerema, a rural African community, indicating that there is no word for RHD or RF in Swahili. Dr John Lawrenson, a UCT paediatric cardiologist, presented on the possibilities of engaging patients using social media, in relation to a study in which researchers interview children and young adolescents due to undergo heart surgery. Presentations by Dr Jantina de Vries, Marlyn Faure and Olivia Matshabane addressed the effect of genetic attribution on stigma relating to RHD, and the



Participants quickly realized that there was no typical patient journey, with each participant having experienced a different path to diagnosis and treatment.



potential of visual media to improve the relationship between researchers and study participants. The presentations were concluded by Amy Verstappen of Children's Heart Link, who spoke on the potential for collaboration between the RHD and congenital heart disease communities, and Prof Zühlke who praised rheumatic fever week in South Africa as an important initiative for raising RHD awareness.

The workshop concluded with a discussion of recommendations and next steps. Main themes agreed on by the group included the need for a model capturing the non-medical patient journey of RHD to ensure the patient voice is heard throughout the clinical journey; partnership among the broad range of RHD researchers to foster mixed methods approaches; centrality of monitoring and evaluation of the group's outputs; and a platform for ongoing discussion on these topics, including a repository of global research and their published and unpublished learnings. These themes will be captured in a published report detailing the group's commitment to ensuring that the patient voice is at the heart of how we tackle RHD.



RHD Qualitative Workshop Attendees

CONTRIBUTIONS TO RHD ACTION PUBLICATIONS

RhEACH Cape Town contributed significant editorial and technical assistance to two RHD Action publications in 2016: The **RHD Global Status Report** and the **Global Status Report of BPG**. The lead author on the RHD Global Status Report was Joanna Markbreiter of the World Heart Federation. Dr Rosemary Wyber from Telethon Kids/RhEACH Perth, was the lead author of the BPG Status Report.

The **RHD Global Status Report** provides a 'snapshot' of the people, policies and programmes that are working to prevent and control RHD around the world today and features interviews with the people at the heart of the RHD community: both those living with RHD and the health workers who care for them. The report outlines past and present national, regional and international

policies created to combat RHD, and presents case studies on RHD prevention and control programmes, from countries as diverse as Fiji, India, South Africa, Yemen and Brazil.

The **Global Status of BPG Report** was launched at the World Conference of Cardiology and Cardiovascular Health in Mexico City (June 2016) in both electronic and paper formats. Benzathine penicillin G (BPG) is an injectable antibiotic which provides a prolonged level of penicillin in the blood. There are two major global indications for BPG: syphilis and rheumatic heart disease. Reliable, high quality formulations of BPG is vital for the treatment and control of both diseases.⁴

The aim of the report is to bring threatened BPG access issues to the forefront in an effort to keep this essential medicine safe and available to the vulnerable populations who need it most.



The RHD Global Status Report



The Global Status of BPG Report





MEETINGS: PRESENTATIONS, FACILITATION AND SUPPORT

Sudan Heart Society Meeting

The 1st International Meeting of the Sudan Heart Society in association with PASCAR. Khartoum, Sudan, 24-27 January, 2016

The first Sudanese Heart Society meeting was held in Khartoum with several talks on Rheumatic Heart Disease. Prof Zühlke delivered a talk on "Diagnosis and management of rheumatic carditis." This meeting presented an important opportunity to link with colleagues from Sudan, Egypt and other parts of Africa.

African Union/PASCAR All Africa RHD Workshop

Addis Ababa, Ethiopia, 3-6 March 2016

The Pan-African Society of Cardiology (PASCAR), in conjunction with the African Union, hosted the 4th All Africa Workshop on Acute Rheumatic Fever and Rheumatic Heart Disease in Addis Ababa, Ethiopia on 4-6 March 2016. The purpose of the meeting was to assemble experts to discuss practical steps and programmes to eradicate Acute Rheumatic Fever and Rheumatic Heart Disease (RHD) in Africa using the structure of the seven recommendations set forth in the African Union Communique adopted in 2015.



4th All Africa Workshop on Acute Rheumatic Fever and Rheumatic Heart Disease in Addis Ababa, Ethiopia March 2016.

The African Union Communique is essentially a formal acknowledgement of the burden of RHD on the African continent and a roadmap outlining a unified plan of action to eradicate this disease. The plan encompasses seven detailed recommendations that include methods, stakeholder identification, and milestones toward that effort.

The meeting embraced a wide range of clinicians, policy-makers, scholars, and researchers who represented nearly 20 African countries. Long-standing players from countries such as Egypt, South Africa, Sudan, Uganda, Kenya, Namibia and Mozambique were joined by new advocates from Botswana, Niger, Zimbabwe, Angola, Senegal and Tanzania. International attendees included WHO (Geneva), WHO AFRO (Brazzaville), WHF (Geneva), RHD Action, Medtronic Foundation (Minneapolis) and Novartis/Sandoz (USA and Germany). The meeting agenda provided a platform for each country to showcase their country programmes, addressing both successes and challenges, and afterward provided opportunities for feedback, discussion and networking.



RHD Action members at the presentation of the African Union Communique.



Conference attendees enjoying the culture and nightlife of Addis Ababa.

Heart Valve Society Meeting

New York City: March 17-19, 2016

The Heart Valve Society is aimed at promoting prevention, treatment and management of heart valve diseases in the US, Europe and throughout the world. Although degenerative mitral and aortic disease has a large burden of disease in high-income countries, this is eclipsed by the dramatic burden of rheumatic valvular disease in low- and middle-income countries. It was thus fitting and of great interest that Rheumatic Heart Disease (RHD) featured the 2016 conference, especially as the theme for this year's event, was the Heart Team in Action. It is clear that eradicating rheumatic heart valve disease requires a team approach combining physicians, policy makers and the public and is best accomplished through comprehensive, multidisciplinary prevention and control programmes. Prof Zühlke and Dr Watkins contributed towards a discussion around RHD research and to the first session dedicated to RHD and Global Epidemiology.²

Presentations:

- **Prof Liesl Zühlke:** The Clinical Burden of Rheumatic Heart Disease - Insights from the REMEDY Study
- **Dr David Watkins:** Epidemiology of rheumatic heart disease – lessons from the Global Burden of Disease



Presentation at the Heart Valve Society Meeting.

2. Watkins D, Zühlke LJ L, Engel M, Daniels R, Francis V, Shaboodien G, et al. Seven key actions to eradicate rheumatic heart disease in Africa: the Addis Ababa communique. *Cardiovasc J Afr.* 2016;27:1-5.

World Congress of Cardiology

Mexico City: 4-9 June 2016

Previously the World Congress of Cardiology (Melbourne 2014, Dubai 2012, Beijing 2010, Buenos Aires 2008) WCC has become the World Congress of Cardiology and Cardiovascular Health, reflecting the need to engage the entire health system, policy makers and individuals with cardiologists in designing and implementing the way forward in CV health. WCC's scope extends beyond cardiology to include nursing, public health and many other specialties. There were over 5000 attendees, with Prof Zühlke as the organizer of the entire RHD track (featuring over 30 sessions, 100 posters and several interactive sessions and workshops) as well as the organiser of a pre-congress workshop on paediatric cardiology and cardiac surgery, the first time that these disciplines were represented at the World Congress of Cardiology.

Presentations:

Prof Liesl Zühlke

- Track Leader/Organiser: Other cardiac diseases including Rheumatic Fever and Chagas' disease
- Workshop Co-chair: Paediatric and Cardiac Surgery - Paediatric cardiology (Pre-congress Workshop)
- Co-Facilitator: The Dragon's Den: Critical Questions in RHD Research
- Panel Co-chair with Dr Kathryn Taubert: Focus on Rheumatic Heart Disease: Implementation and Innovation
- Oral presentation: A needs assessment tool: comprehensive situational analyses
- Oral presentation: Hands-on RHD screening echocardiography: the need, the new and the controversial. Finding the highest-risk patients, methods, needs and opportunities.

Dr David Watkins

- Oral presentation: Structural heart diseases: emerging messages from DCP3
- Oral presentation: What are the needed economic evaluations in RF/RHD control?



(L-R) Ms Johanna Ralston, Professors Porfirio Nordet and Liesl Zühlke, Dr Oyere Onuma, Professor Jonathan Carapetis.



RHD Action representatives from RhEACH, World Heart Federation, Touch Foundation with key speakers Dr Oyere Onuma and Professor Porfirio Nordet.

European Society of Cardiology

Rome: 27 – 31 August 2016

The premier and largest cardiovascular event in the annual CVD calendar, it was an honour to present RHD and findings from our recently published study. The first talk was presented as a joint ESC-SA Heart presentation, with co-chair Prof Bongani Mayosi and was very well-attended.

Presentations:

Prof Liesl Zühlke

- Oral presentation: Addressing Rheumatic Heart Disease in Adult: The Burden of Disease
- Oral presentation: Clinical Outcomes of 3343 Children and Adults with Rheumatic Heart Disease from 14 Developing Countries: 2-Year Follow-up of the Global Rheumatic Heart Disease Registry (REMEDY)



European Society of
Cardiology, Rome.

Joint Congress of the World Society of Cardiothoracic Surgeons and the South African Heart Association.

Cape Town, South Africa. September 11, 2016

Presentations:

Prof Liesl Zühlke

- Oral Presentations - Plenary talk: Clinical Outcomes of 3343 Children and Adults with Rheumatic Heart Disease from 14 Developing Countries: 2-Year Follow-up of the Global Rheumatic Heart Disease Registry (REMEDY)
- Co-Facilitator: The Heart Team: Critical Questions in RHD
- Plenary talk: The Heart Team - Contributions from paediatric cardiologists
Rheumatic heart disease detected by echocardiographic screening and their implications

Dr David Watkins

Oral presentation: The global burden of rheumatic heart disease

WHO/IVI Global Stakeholder Consultation on Group A Streptococcal Vaccine Development.

Annual IVI-Shinil Global Vaccine Forum

12-13 December, 2016 Seoul, Korea

Presentations:

Dr David Watkins

Oral presentation (with co-presenter, G. Karthikeyan): Global burden of rheumatic heart disease

**Mini-seminar series, Harvard Medical School
Department of Global Health and Social Medicine**

Boston, MA. November 9, 2016

Presentations:

Dr David Watkins

Oral presentation: Rheumatic heart disease: an integral but neglected aspect of the global NCD agenda

PROMOTION, MEDIA AND PUBLICITY

Table Mountain Lit Up in Red for World Heart Day

29 September 2016

World Heart Day is the World Heart Federation's (and the world's) biggest platform for raising awareness about cardiovascular disease. This year, thanks to the persistent efforts of our office, Cape Town's Table Mountain joined the list of global landmarks that were lit up in red on 29 September 2016. Some of the 27 illuminated landmarks around the world in 2016 were in Geneva, Dubai, Auckland, NZ, Shanghai and The Maldives.

In Cape Town, World Heart Day was highlighted by statements and media releases from Prof Pamela Naidoo, CEO of The Heart and Stroke Foundation of South Africa Prof Karen Sliwa-Hanle, WHF President-elect, and Prof Zühlke, in her capacity as co-director of RHEACH and President of the South African Heart Association.

RHD Beat News Letter

Our office contributed frequently to the RHD Beat throughout 2016. RHD Beat is the quarterly e-newsletter distributed by RHEACH to the global RHD community and features synopses of publications, events and happenings on a central platform.

This year four editions of RHD Beat were released (Feb, May, Jul, Nov) in addition to four separate RHD Action communications to subscribers (Jan, May x 2, Sept). The number of active subscribers has grown from 415 in September 2015, to 715 active subscribers as of year-end 2016.

Magazines

Life Healthcare WINTER 2016 A Sore Throat Can Hurt Your Heart;

50_CARE_MyHealth_June16.indd 50

Can be accessed at: http://www.pascar.org/uploads/files/RHD_in_Life.pdf

This is an article based on the interview with Prof Zühlke and included reference to RHD Action: Visit RHDAction.org for more information on rheumatic heart disease. Life Healthcare magazines are available at all Life Healthcare hospitals, doctors' rooms and clinics across South Africa, up to and including Botswana. Life Healthcare magazine has a print run of 90 000 and a readership of 240 000.

“

Thanks to the persistent efforts of our office, Cape Town's Table Mountain joined the list of global landmarks that were lit up in red on 29 September 2016.

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Television

Cape Town Community TV Open Studio aired 7 August 2016

Interview with Prof Zühlke and Ms Susan Perkins on RHD in observance of Rheumatic Fever Week (<http://bit.ly/2jcBZTV>)

The Expresso Show SABC2 aired 6 September 2016

Topic: "The Amazing Heart" featuring Prof Liesl Zühlke

Radio

Heart 104.9 Aiden Thomas breakfast show; Heart and Soul.

A discussion of the facts, the needs and the challenges facing Children with Heart disease.



Prof Zühlke at the Heart 104.9 Aiden Thomas breakfast show.

Internet

UCT Research and Innovation Webpage feature (Dec 6, 2016):

Rheumatic heart disease: the unknown plague of the poor.

(<http://www.research.uct.ac.za/rheumatic-heart-disease-unknown-plague-poor#sthash.Cwq4YXGY.dpuf>)

Newspapers

Scanning for a Heart Beat: CHD is more common than you thought.

The Star Early Edition. Vuyo Mkize. 8 September 2016 (<http://www.pcssa.org/heart-awareness-month-chd-in-children-feature/>)

Why heart disease is on the rise in South Africa.

The Conversation. September 29, 2016 12.49pm SAST (<http://theconversation.com/why-heart-disease-is-on-the-rise-in-south-africa-66167>)



POST-GRADUATE MENTORING AND VISITING SCHOLARS

Ms Heidi Weberruss

Heidi Weberruss is a sports scientist from the Faculty of Sports and Health Sciences Institute of Preventive Pediatrics at the Technische Universität München (Technical University of Munich) University in Germany. She anticipates that her PhD will be completed in early 2017 and she has been accepted to Medical School at the Ludwig-Maximilians-Universität München, also for 2017. Ms Weberruss was a visiting scholar to the Unit from March through May of 2016.

Ms Weberruss collaborated with Prof Zühlke and Dr Andre Brooks, a paediatric heart surgeon, on the development of a protocol which has been approved by the SCAH Departmental Research Committee as well as the UCT Health Research Ethics Committee. Her project entitled, "Physical fitness, vascular health and anthropometric measures between children with univentricular hearts and healthy controls," is a pilot study that aims to measure physical fitness, cardiovascular health, and anthropometric data in children with univentricular hearts by comparing them to age and sex-matched healthy controls. The study also aims to assess the feasibility of fitness testing during children's regular examinations at Red Cross War Memorial Children's Hospital.

Children with univentricular hearts, aged 8 – 14 years, sex – and age-control group matched healthy controls (siblings and children of hospital staff) are to be recruited from the City of Cape Town and rural areas of the Western Cape. Siblings of participants will be asked to serve as the control group to account for same socio-demographics and similar educational backgrounds. Assessment measures will include anthropometric data including body height, weight and waist circumference; vascular health measured by blood pressure, pulse wave velocity, carotid intima-media thickness, and flow mediated dilation; physical fitness quantified by handgrip-strength and push-ups for strength, shoulder stretch for flexibility, and 3-minute step-test for submaximal cardiovascular capacity.

Participants of both groups will learn about their physical fitness and health status and be given encouragement to be physically active to promote cardiovascular health. So far, this is the first study measuring physical fitness in South African children with UVH.

Dr Nate Tulloch

After completing his undergraduate degree at Stanford University in Palo Alto CA, Dr Tulloch completed his PhD in Molecular and Cellular Biology at the University of Washington in Seattle, Washington in 2012. He also completed his MD, also at University of Washington, in 2014. He is currently completing



Ms Heidi Weberruss

his residency in Internal Medicine at the University of Washington which he expects to complete in 2017. His current plans are to work as a hospitalist upon graduation while continuing to pursue his interests in global cardiovascular disease/global health research.

Dr Tulloch visited the Unit in April 2016 to collaborate with Dr Watkins and Prof Zühlke on a project entitled, "Stakeholders in rheumatic heart disease control in Uganda and Tanzania: a systematic review." to identify and investigate the stakeholders discovered in the Tanzania/Uganda RHD Systematic Review project conducted by Moloji, Watkins, et al. (Please refer to NAT Pilot Projects above.)

This is Dr Tulloch's second visit to UCT/Cape Town and he will likely return as a collaborator in future years to come.



Dr Nate Tulloch

Dr Clancy Read

Dr Read is a Postdoctoral Research Fellow in the Group A Streptococcal Diseases, Wesfarmers Centre of Vaccines & Infectious Diseases at the Telethon Kids Institute (Perth, Australia). Her areas of research expertise include qualitative research, participatory action research, community-based participatory research, monitoring and evaluation research, and rapid health needs assessment. In her current position, her range of research and project activities relate to Rheumatic Heart Disease with a particular focus on qualitative program components.

Dr Read's experience spans across countries including India, the Philippines, Mexico and Australia, and across communities including rural, indigenous and minority populations.

Dr Read provided extensive consulting and written contributions to the development of the qualitative aspects and tools for the Needs Assessment Tool over 2015-2016. She additionally visited Cape Town in September 2016 when she attended the Listen to My Heart patient event and co-facilitated the Qualitative Researchers Workshop where her focus was on the non-medical journey of PLWRHD.



Dr Clancy Read

Dr Jessica Forcillo

Dr Forcillo, a Canadian cardiac surgeon, approached Prof Zühlke in early 2016 in search of a meaningful experience to fulfill her global health requirement in the Executive MPH programme at the Rollins School of Public Health at Emory University (Atlanta, GA USA) where she is currently co-enrolled in a transcatheter valve replacement and robotics fellowship programme. She is also enrolled in a PhD programme at the University of Montreal.

As a result, Dr Forcillo collaborated with Prof Zühlke to develop a needs assessment tool for the evaluation of cardiac surgery programmes in Africa in a project entitled, "Development of a needs assessment tool for scaling up cardiac surgery in African countries." (Please refer to NAT Pilot Projects above.)

After the completion of her fellowship in June 2017, she has been offered the position of Attending Surgeon, Clinical Scientist and Affiliated Surgical Professor at the University of Montreal Hospital Centre (CHUM). CHUM is the largest biomedical research centre in Canada with over 360 researchers, 400 Master and PhD students. It is affiliated with the Montreal Heart Institute and Sacré-Coeur Hospital. As a new attending surgeon, Dr Forcillo's main mandate will be to create and manage the hybrid and minimally invasive cardiac surgery programme as the first formally trained interventional cardiac surgeon in the facility.



Dr Jessica Forcillo

Ms Emily Prendergast

Emily Prendergast completed her undergraduate degree at Cambridge University in June 2016, specializing in Biological Anthropology. The focuses on human

evolution and the workings of the human mind initiated her interest in medical science and she has since been accepted to study medicine at Cambridge University to begin in September 2017.

Ms Prendergast visited the Unit during October and November 2016 for an opportunity to observe clinical scenarios in a healthcare system other than her own and to conduct a small follow-up project on the REMEDY study - a registry of individuals with rheumatic heart disease from 25 sites across Africa and Asia.

Given that these sites had vastly different incomes, numbers of patients and healthcare resources, each site's experience of participating in the REMEDY study is fairly unique. In order to explore these unique experiences, Ms Prendergast created an online survey that was distributed to REMEDY staff. Additionally, by conducting telephone interviews with 20 principal investigators, co-investigators and study nurses, she was able to collect more detailed information about the major challenges and opportunities encountered during the conduct of the study.

Currently back in the UK, she has begun to analyze and summarize the findings in order to create a manuscript for publication that is intended to be a useful reference for researchers who will work on similar projects in the future.



Ms Emily Prendergast

Prof Phillip Moons

Prof. Philip Moons is Professor of Healthcare and Nursing Science at the Academic Center for Nursing and Midwifery at the KU Leuven - University of Leuven, Belgium, and visiting professor at the Institute of Health and Care Sciences of the University of Gothenburg, Sweden. Currently, he is programme director for the Master in Nursing and Midwifery of the KU Leuven - University of Leuven

Professor Moons' research interests are outcomes and quality of life research in congenital heart disease, and he developed and implemented the role of the advanced practice nurse in the Adult Congenital Heart Disease Programme of the University Hospitals of Leuven. He additionally coordinated large-scale implementation projects on discharge management. As such, he and Prof Zühlke successfully developed the ADOLE 7C which received funding from the SA MRC in September 2016.

Professor Moons and Dr Ewa-Lena Bratt visited the Unit in November of this year to tour the facilities and meet the players in the South African side of the project which aims to explore and compare outcomes between Swedish and South African CHD patients who transition from paediatric to adult care.



Prof Phillip Moons

Dr Fenny Shidhika

Dr Shidhika is a Paediatric Cardiology Specialist Registrar (Year 2) at the Red Cross War Memorial Children's Hospital. She is a Namibian national who has trained and worked in universities and hospitals in Windhoek and Cape Town.

Dr Shidhika's project, in partial fulfillment of her M.Phil. degree, is entitled, "The Namibia children heart project; a 6-year retrospective review" and is co-supervised by Prof Zühlke and Dr Chris Hugo-Hamman from the Windhoek Central Hospital in Namibia.

The purpose of the study is to describe the clinical characteristics of over 200 Namibian children who were referred to the Chris Barnard Memorial Hospital in Cape Town for cardiac interventions over the period 2009 - 2015. The project aims to quantify morbidity and mortality and to identify prognostic indicators for perioperative and postoperative morbidity and mortality. Finally, she intends to describe and document the follow-up patterns of these patients upon return to Namibia.

Over the course of this year, the Unit has provided mentoring and guidance in scholarly writing style, study design, and statistics, as well as facilitating the



Dr Fenny Shidhika

development of a Red Cap™ database for data capture. The project has received clearance from the Department of Paediatrics and Child Health Research Committee and the UCT Health Research Ethics Committee. Dr Shidhika plans to present her results at the World Congress of Paediatric Cardiology in Barcelona in July 2017.

Dr Alicia Ferris

Dr Ferris completed her Paediatric Cardiology fellowship at the Red Cross War Memorial Children's Hospital in December 2016. During her Fellowship, Dr Ferris contributed significantly to the development of a new protocol, "International Normalised Ratio Monitoring: Determining the accuracy of portable point-of-care monitors compared to standard of care laboratory monitoring at Red Cross War Memorial Children's Hospital." With mentoring from Profs Zühlke and De Decker, the project is now ready for DRC/HREC submission for upcoming trainees to carry out.

This study aims to determine the accuracy of a portable INR Point-of-Care (POC) device against the current Standard-of-Care (SOC) laboratory testing method. With the growing number of South African paediatric patients requiring anticoagulation therapy, it is essential to optimise INR management in terms of time to results and convenience to patients. Current monitoring of anticoagulation therapies require patients to attend outpatient clinics for standard laboratory-based INR testing. Because of the inherent delay in treatment adjustment, these patients often have to wait hours for test results, resulting in parents taking a full day off from work and children typically missing an entire day of school.

Anticoagulation patients will be recruited from the Red Cross Hospital to participate in this study comparing the accuracy of the POC technology versus the SOC laboratory-based method. Data to describe the results waiting time with the POC system as compared to the SOC laboratory testing method will also be collected. A Red Cap™ database has already been designed and is in place with assistance from the Unit's Office, so that this project is shelf-ready to be carried out.

Research Assistants 2015-2016

The Unit had three research assistants spending periods between 3 and 9 months with us.

Tembekile Shato, BA, MPH worked on the Needs Assessment Tool and developed a rapid ethnographic assessment to assess facilitators and barriers experienced by patients and families with RHD. Her protocol was accepted for poster presentation and the Pan-African Society of Cardiology (PASCAR) meeting in Mauritius in 2015 and she is a co-author on the published Needs Assessment Tool. Tembe is currently in the USA on a prestigious research fellowship.³

Hlengiwe Moloi, BA, MPH was employed to develop a systematic review protocol on RHD incidence, prevalence and health system factors in Uganda and Tanzania. Both the protocol and paper have been published and form a key part of the first results of the Needs Assessment Tool. Hlengiwe is currently a PhD student within the ASAP programme at UCT under the supervision of Prof Mark Engel.

Tayla Hermanus, BA worked predominantly on the tools needed for a rapid ethnographic assessment. An arts and media student, her research assistantship also gave her writing, data capturing and scientific searching tools. She returned to UCT to undertake a post-graduate diploma in education in 2016.⁴

3. Shato, T; Hermanus, T; Engel, M; De Vries, J; Zühlke Protocol: what factors influence health-seeking behavior and adherence to secondary prophylaxis for patients with sore throat, acute rheumatic fever and rheumatic heart disease?, L Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015

4. Hermanus, T; Shato, T; Engel, M; Zühlke, L; De Vries, J.A rapid ethnographic assessment approach to exploring patient and provider experience in rheumatic heart disease. Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015



Dr Alicia Ferris



Our research assistant, Tembekile Shato, developed a rapid ethnographic assessment to assess facilitators and barriers experienced by patients and families with RHD.



HONOURS AND AWARDS

Best Publication 2015 (UCT Early Career Award, Clinical Sciences)

Prof Zühlke accepting Best Publication 2015 (Early Career Award, Clinical Sciences) by the UCT Faculty of Health Sciences for "Characteristics, complications, and gaps in evidence-based interventions in rheumatic heart disease: the Global Rheumatic Heart Disease Registry (the REMEDY study)" in European Heart Journal [7; 36(18):1115-22a]." (November 2016)



Prof Liesl Zühlke with other award winners at UCT Early Career Award.

Honorary Research Fellowship Appointment

Prof Zühlke was awarded an honorary research fellow appointment at Telethon Institute in Perth Australia in 2016. Directed by Prof Jonathan Carapetis, The Telethon Kids Institute is an Australian medical research institute focused on the prevention of paediatric disease and the development of improved treatments to improve the health and wellbeing of children.



RESEARCH, GRANTS AND SPONSORED PROGRAMMES

Medtronic Foundation RHEACH

Project/Study Title: Rheumatic Heart Disease-Evidence, Advocacy, Communication and Hope (RhEACH)

Funder: Medtronic Foundation (Subcontract with Telethon Kids Institute, Perth Australia)

Project Dates: April 2015 to December 2019

Co Programme Directors: Profs Liesl Zühlke and Jonathan Carapetis (Telethon Kids Institute)

Deputy Director: Dr Rosemary Wyber (Telethon Kids Institute)

Description:

The RhEACH project is a collaboration of UCT-based Children's Heart Disease Research Unit and Telethon Kids Institute in Perth Australia. RhEACH provides a technical support and policy translation initiative to amplify rheumatic heart disease control efforts locally, regionally and globally. RhEACH is a member of a larger global alliance – RHD Action – that includes Medtronic, the World Heart Federation and demonstration sites in Tanzania and Uganda.



RhEACH represents a collaboration between Cape Town and Perth.

ADOLE 7C

Project/Study Title:

AdolesCents reCeiving Continuous Care for Childhood-onset Chronic Conditions

Funder: South African Medical Research Council

Project Dates: 1 November 2016-31 October 2019

Principal Investigators: Prof Liesl Zühlke and Prof Bongani Mayosi

International Collaborators: Professor Phillip Moons and Dr Ewa-Lena Bratt, Institute of Health and Care Sciences, Sahlgrenska Academy; University of Gothenburg, Gothenburg, Sweden

Description:

The main aim of the 3-year Adole7C-project is to get a better understanding of the role of healthcare system factors for care gaps in adolescents with complex chronic conditions. In this project, young persons with Congenital Heart Disease (ConHD) and Rheumatic Heart Disease (RHD) are investigated as sample cases for the broader spectrum of complex chronic conditions.

The specific objectives are: (1) To investigate the prevalence of care gaps in young persons with ConHD and RHD in South Africa and Sweden; (2) To identify hospital-related predictors and healthcare system factors, above and beyond patient-related predictors, for discontinuation of cardiac follow-up in young persons with ConHD and RHD; and (3) To determine the impact of care gaps in young persons with ConHD or RHD in South Africa and Sweden.

The project will use both quantitative and qualitative research approaches. The quantitative study comprises an international, multi-centre, longitudinal study in six centres in South Africa (Cape Town, Port Elizabeth) and Sweden (Gothenburg, Lund, Stockholm, Umeå). Patients are to be selected from the paediatric cardiology outpatient clinic visit lists 2005-2011. Overall, 1500 patients will be included, providing sufficient data to reliably investigate the potential influence of the different patient-related, hospital-related, and healthcare system-related characteristics on care gaps.



National Research Foundation Competitive Support for Unrated Researchers Grant

Project/Study Title: Competitive Support for Unrated Researchers (CSUR)

Funder: National Research Foundation

Project Dates: 2017-2020

Principal Investigator: Prof Liesl Zühlke

Description: Bursary support for Masters/Doctoral student for three years for work and study based on the ADOLE 7C project.

Invictus

Project/Study Title: INVeStigation of rheumatic AF Treatment Using vitamin K antagonists, rivaroxaban or aspirin Studies: INVICTUS

Funder: Bayer AG

Project Dates: Initiation 2016

South African National Leader: Prof Liesl Zühlke

Cape Town Principal Investigators: Prof Bongani Mayosi, Prof Liesl Zühlke, Dr Blanche Cupido

Description:

The INVICTUS programme builds upon the 2014 REMEDY pilot study in 2014 of 3,343 RHD patients from 14 countries in Africa, India and Yemen that concluded that RHD, the most commonly acquired heart disease in children in many countries of the world, was being neglected and poorly treated.

The global INVICTUS programme is comprised of a registry of 20,000 participants and two clinical trials. The first trial, with participants in rheumatic valvular atrial fibrillation or flutter (AF/flutter), will test whether rivaroxaban is non-inferior to vitamin K antagonists (VKAs) for prevention of stroke or systemic embolism (the Non-inferiority Trial). In the second trial, in participants with RHD, either with AF/flutter but unsuitable for VKA therapy, or with sinus rhythm but with high risk, whether rivaroxaban is superior to aspirin for prevention of stroke or systemic embolism (the Superiority Trial).

Prof Zühlke is the South African National leader and co-PI at Groote Schuur Hospital. She is additionally the site PI at Red Cross Hospital where paediatric participants will be recruited for the registry arm of the study.



Invictus aims to be the largest RHD study enrolling over 20 000 patients.



IMHOTEP

Project/Study Title: The African Cardiomyopathy and Myocarditis Registry Programme (IMHOTEP)

Funder: Newton Fund

Project Dates: 2016

Principal Investigator: Dr Sarah Krause

Co-Is: Drs G Comitis, B Fourie, J Lawrenson and Profs L Zühlke and R De Decker

Description:

This is a comprehensive and multi-centered clinical registry database to systematically capture data on patients diagnosed with different morphological and functional types of cardiomyopathy and myocarditis in Africa. Specifically the project aims 1) to define the clinical, electrocardiographic, autonomic, imaging, histological, and genetic characteristics of cardiomyopathy and myocarditis in children and adults in Africa; 2) to describe the management of cardiomyopathy and myocarditis in children and adults in Africa; and 3) to monitor the outcome of cardiomyopathy and myocarditis and its determinants in children and adults in Africa.

A North-South Partnership in Congenital Heart Disease (CHD)

Funder: Medical Research Council Foundation (UK)

Project Dates: Second Quarter 2017

Principal Investigators: Prof Bernard Keavney, Chair of Cardiovascular Medicine at University of Manchester, Prof Bongani Mayosi, Dean, Faculty of Health Sciences, University of Cape Town and Prof Liesl Zühlke, University of Cape Town

Co-Is: Profs R De Decker and R Ramesar and Drs B Cupido and G Shaboodien of UCT

Description:

This collaborative project between The University of Manchester and UCT aims to address the lack of basic information about Congenital Heart Disease (CHD) in Africa, and whether the rate at which CHD occurs is the same in African populations as in Western populations, and whether the range of CHD conditions encountered is similar. The project aims to establish a sustainable CHD research infrastructure at UCT, and to create a model that could be applied in other South African centres and collaborating African countries.

Adult and paediatric patients who attend the UCT CHD clinics will be invited to participate in and contribute to a comprehensive clinical database containing information about both themselves and their families. Blood or saliva samples will be requested to investigate the role of inherited factors (genes) in causing CHD. The target enrolment is 1200 patients in the two year period of the grant.

The UK partner group at The University of Manchester will guide the genetic investigation of African-derived genes already shown to be important in Western populations. If the foundation project shows that it is feasible to enrol and conduct genetic studies in African CHD patients, future experiments will be designed and conducted to search for particularly African genetic causes of CHD. Studies modelling the abnormal blood flow that occurs in CHD patients using powerful computers will also be carried out to see if patterns that are useful in predicting outcomes for patients can be identified.

The data and resources developed in this project will help African researchers define the most important and feasible research topics for future study in the population they serve. The research emerging from this registry will provide clear signposts on steps that can be taken to address the extremely different outcomes of CHD, which is now a highly treatable condition, between Western and African countries.



The project aims to establish a sustainable CHD research infrastructure at UCT, and to create a model that could be applied in other South African centres and collaborating African countries.



Panorama-Heart Failure Clinical Study

Project/Study Title: Multicenter, open-label, study to evaluate safety, tolerability, pharmacokinetics and, pharmacodynamics of LCZ696 followed by a 52-week randomized, double-blind, parallel group, active-controlled study to evaluate the efficacy and safety of LCZ696 compared with enalapril in pediatric patients from 1 month to \leq 18 years of age with heart failure due to systemic left ventricle systolic dysfunction

Funder: Novartis

Project Dates: Second Quarter 2017

Country Principal Investigator: Prof Liesl Zühlke

Site Principal Investigator: Prof Liesl Zühlke

Site Co-Is: Prof R De Decker and Drs J Lawrenson, G Comitis, and B Fourie

Description:

Industry-sponsored clinical trial of heart failure medication in a paediatric population

Collaborators and strong linkages

- Department of Paediatric Cardiology, UCT and Tygerberg Hospital: Head Dr John Lawrenson
- Department of Medicine, Grootte Schuur Hospital Head: Prof Ntobeko Ntusi
- Department of Cardiology, Grootte Schuur Hospital Head: Prof Mpiko Nsekhe
- Mayosi Research Group: Head: Prof Bongani Mayosi, Coordinator Prof Mark Engel.
- Hatter Institute of Cardiovascular Research: Head: Professor Karen Sliwa-Hanle
- CDIA- Chronic Diseases Initiative in Africa: Head: Prof Naomi Levitt
- World Heart Federation
- World Heart Organization
- Telethon Kids Institute Head: Prof Jonathan Carapetis
- Pan-African Society of Cardiology; President: Prof Bongani Mayosi
- Academic Center for Nursing and Midwifery, Leuven Department of Public Health and Primary Care, University of Leuven, Head: Professor Philip Moons
- Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg
- University of Manchester
- University of London
- Brave little hearts (<https://www.facebook.com/BraveLittleHeartsSA/>)



Thaakirah was so full of smiles on her first day of school. This precious little girl has fought against all odds, but thanks to the dedication of her parents and the staff at the Red Cross Children's Hospital she's reached this amazing milestone. Read her story here <http://bit.ly/1FMtwvf> and follow her incredible journey at [Brave Little Hearts S.A.](#)

RESEARCH OUTPUTS 2015-2016

Publications

1. Moloi AH, Mall S, Engel ME, Stafford R, Zhang WZ, **Zühlke LJ, Watkins DA**. Rheumatic heart disease epidemiology and health systems barriers and facilitators in Uganda and Tanzania: a systematic review and meta-analysis in press
2. Carapetis JR, Beaton A, Cunningham MW, Guilherme L, Karthikeyan G, Mayosi BM, et al... **Zühlke LJ** Acute rheumatic fever and rheumatic heart disease. Nature reviews Disease primers. 2016;2:15084.
3. Moloi AH, **Watkins D**, Engel ME, Mall S, **Zühlke LJ**. Epidemiology, health systems and stakeholders in rheumatic heart disease in Africa: a systematic review protocol. BMJ Open. 2016;6(5):e011266.
4. **Watkins D, Zühlke LJ**, Engel M, Daniels R, Francis V, Shaboodien G, et al. Seven key actions to eradicate rheumatic heart disease in Africa: the Addis Ababa communique. Cardiovasc J Afr. 2016;27:1-5.
5. **Zühlke LJ**, Acquah L. Pre-conception counselling for key cardiovascular conditions in Africa: optimising pregnancy outcomes. Cardiovasc J Afr. 2016;27(2):79-83.
6. **Zühlke LJ**, Engel ME, Lemmer CE, van de Wall M, Nkepu S, Meiring A, et al. The natural history of latent rheumatic heart disease in a 5 year follow-up study: a prospective observational study. BMC Cardiovasc Disord. 2016;16:46.
7. Karen Sliwa, **Liesl Zühlke**, Robert Kleinloog, Anton Doubell, Iftikar EWbrahim et al Cardiology-cardiothoracic subspecialty training in South Africa: a position paper of the South Africa Heart Association CVJA Vol 27 (2) March/April 2016
8. Maylene Shung King, **Liesl Zühlke**, Mark Engel, Bongani Mayosi "Asymptomatic rheumatic heart disease in South Africa schoolchildren: Implications for addressing chronic health conditions through a school health service" SAMJ S Afr Med J. 2016 Jul 18;106(8):761-2..
9. Dejuma Yedeta, Vuyisile Nkomo, **Liesl Zühlke** et al Prevalence of Rheumatic Heart Disease among school children in Ethiopia: a Multisite Echocardiography-based screening. International Journal of Cardiology 2016 Oct 15;221:260-3.
10. Annika van Niekerk, Robyn Cullis, Lucy Linley, **Liesl Zühlke** "POPSICLE" Pulse Oximetry Pre-discharge Screening Implementation study for Critical Congenital Heart Lesions in newborns SAMJ S Afr Med J. 2016 Jul 7;106(8):817-21.
11. Rosemary Wyber, Benjamin Boyd, Samantha Colquhoun, Bart Currie, Mark Engel, Joseph Kado, Ganesan Karthikeyan, Mark Sullivan, Anita Saxena,

- Meru Sheel, Andrew Steer, Joseph Mucumbitsi, **Liesl Zühlke**, Jonathan Carapetis. Preliminary consultation on preferred product characteristics of benzathine penicillin G for secondary prophylaxis of rheumatic fever Drug Delivery and Translational Research 2016 Oct;6(5):572-8
12. GBD 2015 HIV Collaborators Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980-2015: the Global Burden of Disease Study 2015. *Lancet HIV*. 2016 Aug;3(8):e361-87. doi: 10.1016/S2352-3018(16)30087-X. Epub 2016 Jul 19.
 13. Global, regional, and national levels of maternal mortality, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016;388:1775-1812.
 14. Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters of risks, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016;388:1659-1724.
 15. Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016;388:1603-1658.
 16. Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016;388:1545-1602.
 17. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2016;388:1459-1544.
 18. Wang H, Wolock TM, Carter A et al. Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980-2015: the Global Burden of Disease Study 2015. *Lancet HIV* 2016;3:e361-87.
 19. **Zühlke LJ** et al Clinical Outcomes in 3343 Children and Adults With Rheumatic Heart Disease From 14 Low and Middle Income Countries: 2-Year Follow-Up of the Global Rheumatic Heart Disease Registry (The REMEDY Study) *Circulation* 2016 Nov 8; 134 (19): 1456-1466.
 20. Tarek Alsaied, Jouke P Bokma, Mark E Engel, Joey M Kuijpers, Samuel P Hanke, **Liesl Zühlke**, Bin Zhang, Gruschen R Veldtman Factors associated with Long-term Mortality after Fontan Procedures: A systematic review *Heart* 2016; 0: 1-7
 21. **Zühlke LJ** et al A comprehensive needs assessment tool for planning rheumatic heart disease control programs in limited resource settings *Global heart* in press
 22. **Zühlke LJ** et al Group A Streptococcus, Acute Rheumatic Fever and Rheumatic Heart Disease: epidemiology and clinical considerations Current Treatment options in Cardiovascular Medicine in press.
 23. Annesinah H. Moloji, Sumaya Mall, Mark E. Engel, Renae Stafford, Zhang Wan Zhu, **Liesl J. Zühlke**, **David A. Watkins** Rheumatic heart disease epidemiology and health systems barriers and facilitators in Uganda and Tanzania: a systematic review and meta-analysis *Global Heart* in Press
 24. **Watkins DA**, Lubinga SJ, Mayosi BM, Babigumira JB. A cost-effectiveness tool to guide the prioritization of interventions for rheumatic fever and rheumatic heart disease control in African nations. *PLoS Negl Trop Dis* 2016; 10(8):e0004860. doi: 10.1371/journal.pntd.0004860.

Book Chapters

1. Hurst's The Heart Editors Valentin Fuster Jagat Narula Editor: Valvular Heart Disease- Rheumatic Heart Disease 14th edition (in press)
2. Atlas of Pediatrics in the Tropics and Resource-Limited Settings-Editors Jonathan M Spector and Timothy Gibson 2nd edition (in press)
3. ESC Textbook of Cardiology Editors Fausto Pinto Subject editor Ferande Peters chapter Rheumatic Heart Disease (in press)
4. The Heart of Africa: Clinical Profile of an Evolving Burden of Heart Disease Editors Simon Stewart, Karen Sliwa, Ana Mocumbi, Albertino Damasceno

and Mpiko Ntsekhe Chapter: Acquired heart disease 1st edition, ISBN: 978-1-119-09700-6 May 2016, Wiley-Blackwell

5. Ajay V, Prabhakaran D, **Watkins D**. Relationships among risk factors and the burden of cardiovascular diseases, diabetes, and chronic lung disease. Chapter 2. In: Prabhakaran D, Anand S, Gaziano T, Wu Y, Mbanya J, Nugent R, eds. Disease Control Priorities, Third Edition, Volume 5 (in press).
6. **Watkins D**, Hasan B, Mayosi B, Bukhman G, Marin-Neto J, Rassi Jr A, Rassi A, Kumar RK. Structural heart diseases. Chapter 11. In: Prabhakaran D, Anand S, Gaziano T, Wu Y, Mbanya J, Nugent R, eds. Disease Control Priorities, Third Edition, Volume 5 (in press).

Refereed/peer-reviewed conference outputs

1. **Zühlke, L**; Engel, ME; Nkepu, S; Mayosi, BM, Evaluation of a focused protocol for handheld echocardiography and computer-assisted auscultation in detecting latent rheumatic heart disease in scholars. Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015
2. **Zühlke, L**; Engel, ME; Watkins, D; Mayosi, BM. Incidence, prevalence and outcome of rheumatic heart disease in South Africa: a systematic review of contemporary studies Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015
3. Shato, T; Hermanus, T; Engel, M; De Vries, J; **Zühlke, L**. Protocol: what factors influence health-seeking behavior and adherence to secondary prophylaxis for patients with sore throat, acute rheumatic fever and rheumatic heart disease?, L Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015
4. Hermanus, T; Shato, T; Engel, M; **Zühlke, L**; De Vries, J. A rapid ethnographic assessment approach to exploring patient and provider experience in rheumatic heart disease. Pan African Society of Cardiology & Cardiovascular Society of Mauritius 2015, CVJA 2015
5. **Zühlke L**, Brittain K, Bekker L-G, Rabie H, Nuttall J, Eley B, Roux P, Myer L, Zar HJ, for the Cape Town Adolescent Antiretroviral Cohort. Cardiovascular disease biomarkers in perinatally HIV-infected adolescents on ART. Conference on Retroviruses and Opportunistic Infections (CROI), 2016, Boston, Massachusetts.
6. **Liesl Zühlke**, Elizabeth Machila, Joyce Chipili Lungu, Sherri Schwaninger, Joris van Dam, Jonathan Michael Spector, Brigitta Tadmor, John Musuku Task shifting: proficiency of general radiography technicians in detecting rheumatic heart disease World Congress of Cardiology and Cardiovascular Health Global Heart 2016
7. Ahmed El Sayed, Ahmed S Ibrahim, Huda HM Elhassan, **Liesl Zühlke**, Mark Engel, Ganesan Karthikeyan Koon Teo, Salim Yusuf, Bongani Mayosi and On behalf of the REMEDY investigators The global rheumatic heart disease study (REMEDY) – data from Sudan World Congress of Cardiology and Cardiovascular Health Global Heart 2016
8. Amy Sims Sanyahumbi, Twalib Aliku, Jonathan R Carapetis, Toakase Fakakovikaetau, Melissa Karlsten, John Musuku Satupaitea Viali, Nigel Wilson, Daniel J Penny and Define RHD Registry Investigators The concept and design of DEFINERHD: a study to evaluate the progression of subclinical rheumatic valve lesions diagnosed through echocardiographic screening. World Congress of Cardiology and Cardiovascular Health Global Heart 2016
9. Bo Remenyi and the World Heart Federation criteria investigators Validation of the World Heart Federation Evidence Based Echocardiographic Criteria for Rheumatic Heart Disease. World Congress of Cardiology and Cardiovascular Health Global Heart 2016



