RHD Action | United to End Rheumatic Heart Disease

Rheumatic Heart Disease Action Alliance Launch – Keynote Speech
New York, United States, 29th September 2015

(Above) Madame Toyin Ojora-Saraki, founder and President of the Wellbeing Foundation Africa

Thank you to Rheumatic Heart Disease (RHD) Action Alliance for inviting me to speak today. It is an honour to be here with you all on World Heart Day to launch such a vital, pivotal movement against a disease that has long been a silent emergency. I look forward to learning more about the impact on lives that RHD has, as well as the opportunities at our disposal to bring succour to those women and children mostly affected, through the illuminating fireside chats, and from the experts that have been gathered here in support of eliminating RHD. By taking RHD out of the shadows of health, we can finally put RHD into the history books.

As we embark on the implementation of the Sustainable Development Goals (SDGs), the road to human dignity is inextricably linked to social determinants of health – which RHD sits within. 275,000 people die from RHD – an entirely preventable disease - each year. 275,000 families, each year, are torn apart by a disease that could be prevented so easily, so quickly, by a simple treatment. This form of cardiovascular disease affects over 32 million people around the world, with 80% of sufferers living in developing countries. RHD predominantly affects those living in poverty as overcrowding and lack of access to quality healthcare exacerbate the risks of developing it. A disease that is caused by

social determinants of health suffers the raw irony of actually contributing to poverty, with the economic impact of premature death from RHD in low and middle-income countries estimated at $56 billion. This contributes to the poverty cycle, with the economic impact resulting in further economic vulnerability and limited access to primary healthcare, setting off a cycle of poverty and poor health, for generations. We have the power and knowledge needed to end RHD. And today, with the launch of RHD Action Alliance – a multi-sector approach to end RHD – I believe we will start a global movement fuelled by political will, partnerships, and programmes.

As a maternal, newborn, and child health advocate, the link between RHD and MNCH is troubling. More than 1 in 5 maternal deaths in developing countries are from indirect causes, most commonly, the exacerbation of pre-existing medical conditions like RHD. Women with heart valves damaged by RHD are at an increased risk of complications during pregnancy and delivery. During late pregnancy, the blood volume increases and a woman's heart rate rises. This extra pressure on the heart for a woman with RHD can put them at risk of heart failure and arrhythmias – the symptoms of which are easily confused with late pregnancy: breathlessness, fatigue, heart murmurs and swelling. Yet, left undiagnosed, catastrophic cardiovascular collapse can lead to maternal death. Moreover, women with RHD that are taking anticoagulants to treat the disease are at much higher risk of bleeding during pregnancy and haemorrhaging at the time of delivery. The impact that this has on newborns is considerable – infants born to mothers with RHD are at risk of inter-uterine growth restriction, prematurity, and low birth weight, contributing to stunting – a serious early childhood development issue that further traps children in a lifelong cycle of poor nutrition, illness, impaired learning skills and lower earning abilities. For infants who survive the death of their mother, during or after labour, they begin life with a social and biological disadvantage. As Save the Children Newborn Champion, this breaks my heart because every newborn deserves the best possible chance in life – a chance that RHD can rob them of.

With the link between RHD and MNCH so apparent, Wellbeing Foundation Africa will seek to integrate RHD into our existing frontline programming and raise awareness of the link through our #MaternalMonday campaign – a online advocacy campaign that provides a digital space for sharing insights and best practices on MNCH, developing solutions that can reduce mortality rates, and facilitating discussions between health workers, advocates, and mothers. Each Monday, we go behind the global goals to share the story of children, mothers, midwives, doctors, advocates, and more who are involved in health and development. Using the hashtag, #MaternalMonday, we will be raising awareness of RHD and sharing the stories of families, like the family of Akot Lucia, a 46 year old Ugandan mother of six, who passed away before her time due to RHD. I hope you can all join us in this campaign and amplify your voice to raise awareness about RHD.

As part of our commitment to raising awareness of the disease, we will highlight RHD within our flagship frontline intervention, the WBFA Personal Health Record – a client-held, health data collection tool and information delivery platform that can be adapted and adopted in any setting. The WBFA PHR tracks patient health, ensuring a continuum of health data per patient. Through the PHR, health workers can monitor a patient's progression over time, which will help to distinguish what it looks like when strep throat escalates into RHD.

By raising awareness of the disease, we can develop solutions that ensure that the cause of RHD can be spotted, treated and prevented. RHD is a disease of poverty – for those who have been lucky to benefit from a good primary healthcare system, the idea of people dying from strep throat is simply unthinkable. When you get strep throat, you simply take high quality, affordable penicillin – a drug discovered almost a century ago – and you go on your merry way. Yet, if left untreated without access to penicillin, strep throat can lead to RHD and poor health outcomes.

In countries without a universal health coverage (UHC) system, access to quality primary healthcare that can provide effective treatment for strep throat can be prohibitively expensive, pricing out those who need it the most. Inability to afford care is a social determinant of health that must be overcome through the adoption of best practice models such as the Wellbeing Foundation's Alaafia Universal Health Coverage Fund (AUHCF). Implementing universal healthcare is by no means easy but it is possible through collaboration with the private sector, civil society, and local communities. In partnership with Hygeia Community Health Care, a Nigerian health insurance provider, and the PharmAccess Foundation, WBFA established the AUHCF. Through the AUHCF – a global best practices model - we fund insurance premiums for 5000 Nigerians each year. The AUHCF enables patients to access affordable primary health care, rather than relying primarily on expensive emergency care. This will in turn have a positive impact on overall health habits, encourage healthier home practices, and overcome a serious social determinant of health. We hope that through this scheme, more children and adults can receive quality primary health care, access to drugs like Penicillin, and avoid treatable illnesses turning into serious diseases. We hope – and urge – governments to take a similar approach of financial risk protection to cover the cost of treatment and prevent RHD taking hold.

As well as doing more to scale up access to affordable health care within communities most as risk of developing RHD, governments must begin to integrate RHD services within existing health services – for example, maternal and child health provided by midwives – to strengthen primary healthcare delivery. Integrating care can lead to the provision of services that are coherent, consistent, and can enhance the motivation, skill, and competence of healthcare workers. As Global Goodwill Ambassador for the International Confederation of Midwives, I believe that midwives – if given the right education, regulation, and midwifery associations within a global midwifery services framework – should be a key part of integrated efforts to achieve better health outcomes in low resource settings. Skilled midwives can be valuable partners in our efforts to

combat RHD and its effects by providing equitable, high quality care for mothers, newborns, and children.

Integrating the health of the mother with that of the baby is highly important for the survival of both, and skilled midwives can safeguard this. Skilled midwives can provide women with vital antenatal care during pregnancy to ensure that both mother and baby remain healthy. For pregnant women with RHD, antenatal screening tests and checks conducted by a skilled midwife are absolutely crucial to the survival of mother and baby. By monitoring the pregnancy closely, midwives can help diagnose symptoms of any potential heart failure and arrhythmias, staving off catastrophic cardiovascular collapse. Identifying these risks or illnesses early helps women make informed choices about their pregnancy and enables healthcare professionals to rapidly treat the illness before birth.

Local midwives understand the communities they serve, the mothers they treat, and the solutions needed for their patients. Learning from this, WBFA introduced antenatal and breastfeeding programmes that can be delivered by qualified midwives. Antenatal education is a crucial component of antenatal care that should be offered to all women and their partners in low resource settings. A woman's need for information and the willingness to make changes to their lifestyle is highest during pregnancy[1], thus antenatal programmes that take into account local context, including language, culture, religion and social factors have an important impact on health. Classes that are delivered in a respectful, dignified environment can alleviate fears about healthcare, as well as providing women with knowledge about their health and the health of their child – knowledge that could help them to identify symptoms of strep throat and seek treatment.

By directing further global resources and attention towards the burden of RHD, we can make progress on preventing and controlling it. Training healthcare workers – midwives, nurses, village health workers, and doctors – in developing countries, on how to prevent, detect, and treat RHD will better ensure that health systems, particularly primary care facilities are properly equipped to bring this disease to an end. Improving our healthcare supply chains will also ensure that healthcare workers can access the medicine – penicillin - that they need to treat strep throat, and prevent the stranglehold of RHD taking effect.

In the coming sessions, we will hear the stories of people living with the disease and the health workers who are on the frontlines of fighting it. We will hear of their courage, the impact of the disease on families, and their efforts to catalyse action to prevent the death of 275,000 people per year, including the life of Akot Lucia of Uganda.

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[1] Schrader McMillan A, Barlow J and Redshaw M (2009) Birth and Beyond: A review of the evidence about antenatal education. University of Warwick /University of Oxford http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131090.pdf
http://www.readperiodicals.com/201105/2341178931.html

Akot Lucia had never been to school. She was a young, God-fearing, loving mother of six, who enjoyed working, keeping animals at home, and growing crops in her garden. From developing a cough in 2009 to her eventual death in 2015 from RHD, Akot Lucia's life embodied why we need to take collective action on RHD now. The initial delay in diagnosis of her cough caused RHD, the treatment of which financially crippled her low-income family. A lack of education had prevented her from fully understanding her disease and treatment. And her premature death has emotionally devastated her family, leaving 7 more victims of RHD in its wake. In her honour – and in honour of the family she has left behind – we must take action today. I call upon all of us to join the movement to end preventable deaths from RHD in endemic regions across the world. Let's do it for Akot Lucia. Let's do it for her family.