

REPORT

LAUNCH OF MACHAKOS RHEUMATIC HEART DISEASE (RHD) PATIENT SUPPORT CLUB ON 5TH DECEMBER 2015 AT THE CCC BOARDROOM, MACHAKOS LEVEL 5 HOSPITAL, MACHAKOS, KENYA



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What is Rheumatic heart Disease?

Rheumatic heart disease (RHD) is the most common acquired heart disease in children (common age group is 5 to 15 year olds) in developing countries. It is estimated that approximately 15 million people are affected globally with 233000 succumbing to it.

RHD is a chronic heart condition caused by rheumatic fever – whose main symptoms include fever, muscle aches, swollen and painful joints, and in some cases, a red rash. Rheumatic fever is as a result of an untreated strep throat that is caused by bacteria called group A streptococcal (strep) infection.

Risk factors :

- Overcrowding
- Poor housing conditions
- Under-nutrition
- Lack of access to healthcare
- Recurrent sore throat
- Untreated sore throats
- Inadequate treatment for sore throat

Facts about RHD

- It is completely preventable.
- It is caused primary by (Streptococcal) sore throats.
- Closely linked with poverty and poor medical services.
- Some of the developed countries have successfully eradicated this disease, however the developing countries still are struggling. All this can be attributed to poor health systems, lack of education and poor health seeking behaviour.

The experience/situation in developing countries:

- RHD is closely associated with poverty and poor quality medical services, and most of the affected patients are not able to access medical services.
- The level of education and awareness is still very low.
- Poor health seeking behaviours. Most patients present for care when the disease is already advanced disease and complicated.
- Poor health systems. Even after presenting for care, most of the patients are lost to follow up.
- Lack of proper health care financing. Most still pay for their health services via out of pocket. Considering the long course of treatment, the cost becomes expensive over time. The use of health insurance is slowly picking up though still out of reach for many.
- Limited diagnostic resources are the order of the day. RHD requires specialized care, that can only be accessible in a few urban centres across Kenya.
- Inadequate trained personnel. Management of RHD requires specialised care by cardiologists and cardiothoracic surgeons. The capacity to train more specialists in the area is still very low.
- The role of health promotion and prevention is yet to be fully utilised, thus the huge gap in knowledge and practise. This in turn leads to late presentation of patients.

History of RHD Support Clubs in Kenya

To date Kenya has two rheumatic heart disease support clubs.

The inaugural RHD Patient Support Club was in Nairobi launched at the School of Medicine, University of Nairobi on 8th March 2014.

It was well attended by representatives from policy makers, professional organizations, NGOs, media, private sector, universities and the international community. At the launch, a total of 11 RHD patients and families committed to be part of the club.

The club borrowed heavily from the patient support group model used by an Australian NGO CLAN (Caring and Living as Neighbours - an Australian NGO).

The same model has been adopted by several other patient support groups in Asia Pacific region.

The model to improve quality of life for children and adolescents living with a range of chronic health conditions in low-income settings in the Asia Pacific region. CLAN utilizes a rights-based, community development framework for action, and focuses on multi sectoral, internationally collaborative action on five key pillars seeking to maximise quality of life for all children living with chronic health conditions in resource-poor countries of the world:

- Affordable access to medicine (monthly penicillin) and equipment (echocardiography)
- Education (of children with RHD and their families, health care professionals, policy makers and the national and international community), research and advocacy
- Optimal Medical Management (through primary, secondary and tertiary prevention)
- Establishment and development of RHD family support clubs
- Reducing financial burdens and promoting financial independence of families living with RHD.

Machakos RHD Support club

The newest and most recent is the Machakos patient support club, launched on Saturday 5th December 2015 and coordinated by Dr. Duncan Matheka and Dr. Mellany Murgor.

The family members invited arrived at the expected time. Accompanying the affected patients, some even had three representatives. they not only came to show support but to also learn for themselves about this condition. A total of 10 patients of all ages and at different stages of the rheumatic heart disease diagnosis and treatment.

Following a similar fashion as the Nairobi support club launch, we were able to meet the following objectives for the Machakos RHD Club:

1. Ensuring Access to Affordable medicine and equipment



The family members were able to share their experiences in quest for treatment. Luckily most were able to access the monthly penicillin injections.

On the other hand though, the cost for echocardiography seemed to be far out of reach for most. For instance in Machakos, it would cost approximately 50 USD to have one performed. This is too much to ask for going by the World Bank statistics where more than 19% live on less than a dollar per day.

During this particular launch we offered free echocardiography. The results revealed 3 cases of severe valve incompetencies with whom we linked up with cardiologists for follow up. The remaining 7 were within normal findings and were to continue on monthly benzathine penicillin and their clinical follow-ups.

2. Education, Research & Advocacy

Education ... A story of triumph in Rheumatic heart disease / He overcame the disease...



Amidst the pain and struggle of dealing with Rheumatic heart Disease, there is always a way out. You just need to get diagnosed and receive the appropriate treatment. This were the words shared by Benard Kipkoech, who is currently a second year nursing student at the Machakos Kenya Medical Training College (KMTC). He shared his experience and struggle after only being diagnosed at a tender age of 9.

The travel from hospital to hospital in search of cure, the glances and stigma by the community.

How he missed playing his favourite sports at a tender age because his heart could not sustain too much strenuous activities.

He explained almost at tears how he watched his colleagues in school progress while he remained at home, sickly and devastated. The monthly painful penicillin injections which he described as if it was just a few hours ago.

He was diagnosed of mitral valve stenosis 9 years ago and underwent a mitral valve repair. Currently he lives a normal life and is able to carry out duties he earlier could not. His word of encouragement the children affected that not all hope is lost. His Echocardiogram done on the club date revealed normal heart function.

Research - A voluntary questionnaire was provided to each of the families. This was to assess, among other things, the burden of the condition to the families, the main worries of the families, the common presenting symptoms, the most likely health personnel to make the diagnosis and availability of treatment and follow up modalities once a diagnosis is made. The results of the study will be published and circulated within the local and international health networks to enable placement of better prevention and intervention strategies.

Advocacy - Social media was harnessed to promote the launch of the Mahcacos RHD Club. Hash tags used for social media included:

#RHDClub #RHDKenya #Machakos [#Kenya](#) [#NCDs](#) [#everychildmatters](#) [#LeaveNoChildBehind](#)
[@clanchildhealth](#) [@worldheartfed](#) [@YPCDNKE](#) [@RhEACHout](#)

In addition, a video was filmed on the day to help tell the story of families living with RHD in Kenya. Footage is available online: <https://youtu.be/BFuLbw9Kf-k>

3. Optimal medical management

In addition to clinical support with management of RHD (in particular, medical management directed by results of echo testing performed free of charge on the day), families and individuals living with RHD were also empowered to self-manage their RHD through education and support as well as the development of a new mHealth platform to facilitate communication.

Question and answer session - The participants were accorded an opportunity to ask any issues of concern. They had the myths demystified and their doubts clarified by the doctors.



Resources materials distributed - Materials on RHD from RHD Australia were distributed to the patients and families present.



Mobile text messaging - To ensure regular follow up and communication, a monthly follow up system using mobile phone short message service will be explored.

The mHealth platform will be used to send updates, educational messages and details of upcoming events to families.

4. Encouragement of Family Support Group Networks

The support group model works on the premise that the affected families are unified by the similarity of challenges presented by having a child with Rheumatic Fever or RHD. However, the patients are at different stages of the disease continuum: those awaiting surgery and those who have already had surgery. The support group therefore provides the families with opportunities to draw strength from one another at whatever stage of the disease they are. There was interaction and networking among the families.

The members exchanged contacts so that they could communicate with each other regularly. They also agreed to update the club co-ordinators on the children's status every month or sooner, as necessary.



Two families volunteered to be the leaders of the family support club as well as links with the organizing doctors. It was agreed as follows: 3 monthly meetings (April, August and December) coinciding with the 3 school holidays in Kenya. Meeting venue will always be at Machakos Level 5 Hospital.

5. Alleviation of Poverty By Reducing Financial Burdens

In the short term, by ensuring families have access to healthcare, financial burden will be alleviated. Various speakers emphasised the need for the patients who are still in school to put in more effort in their academics despite the rigors of illness so that they don't exert further financial burdens on their families. Families were encouraged to seek national health insurance.

The family's travel expenses to the club meeting were reimbursed at the end of the launch. Plans are underway to find ways to help families to find a pathway to financial independence. This will help them better take care of the patients' health.

The next expectations / steps:

To ensure sustainability several approaches will be used including:

- a) Funding - longer term, there will be engagement of private sector, public and private partnerships, and multi-sectoral engagement so the entire burden doesn't fall on the health system.
- b) Capacity Building - In addition to a focus on strengthening existing health systems to promote sustainability, it is worth noting that in HICs all chronic conditions have support networks in place already (eg American Cancer Society, the JDRF for Diabetes Networks, Multiple Sclerosis Society, Australian Down Syndrome Association etc). However, such networks are not well established yet in LMICs, and in particular, by virtue of the fact RHD exclusively affects the poorest and most marginalized. The capacity of the RHD Community in the past to initiate and maintain support networks and clubs has not been strong, so by investing in the RHD Community, we are increasing their own capacity to drive change in future.
- c) Youth Engagement and Empowerment – With so many young people as members of the RHD community, there is investment in these young people and there is a focus to help them drive advocacy efforts in the future. They will be a powerful vehicle for change and advocacy.
- d) Community Development & RHD – There are plans to help strengthen the capacity of the RHD Community as an organisational vehicle in future, and over time develop their logo and website.
- e) MHealth - We will use short message texting to update, send educational messages and for monthly briefings.
- f) Ensure access to proper medication – health facilities, echocardiography
- g) Family networks - Encouraging family and patient networking
- h) Working with Kakamega and Nairobi RHD communities, as well as international RHD communities
- i) Advocacy - we will advocate for access to better medical care of RHD patients in Kenya

Conclusion

Support clubs offer material, moral, and psychological support within a cost-effective, strategic, sustainable, health system strengthening, multi-disciplinary approach. Successful engagement of a broad network of national and international multi-sectoral organizations around the Machakos RHD support club launch of 5th December 2015 established the Machakos RHD Community as a visual hub for ongoing person-centred health care in the country. The many and varied stakeholders engaged around the RHD club meeting took up roles to support and work in partnership with the RHD community over the longer term, to ensure no affected child will: go without their monthly injection of penicillin; be lost to follow-up; miss out on education due to this disease; have their life cut short because they cannot access medical services; or suffer unnecessarily because of lack of understanding of the best ways to manage RHD. Moreover, it offers an impetus for more sustained national action to reduce the prevalence of RHD in Kenya.

Early indications suggest support clubs as modelled in the Asia Pacific region have potential for empowering families and communities in Kenya to engage with a broad range of partners around a united vision of improved quality of life for children who are living with RHD. Moreover, the club offers the members an opportunity to advocate for their needs collectively, while encouraging and supporting each other. Proper medication and networking among the families present is key.

Acknowledgements

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Partners

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RHD Australia,

Young Professional Chronic Disease Network (Kenya),

Machakos Level 5 Hospital

Machakos Heart Evaluation Centre.

We are also grateful to the young doctors who volunteered to assist with the logistics of the launch- Dr. Eric Irungu

We are very grateful to the patients and their caregivers for being part of this launch and declaring to keep the fight for rheumatic heart disease going, besides committing to be ambassadors and spread the word of prevention to the rest.

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