

**ANNUAL REPORT
2015**

**HAROLD AND ETHEL PUPKEWITZ HEART FOUNDATION
(NON-PROFIT ASSOCIATION INCORPORATED UNDER SECTION 21)**

(Reg No: 21/2012/0013)

1. Introduction

1. The Harold and Ethel Pupkewitz Heart Foundation (HEPHF) was established in 2011 by the late Harold Pupkewitz with the purpose to support research into heart disease in Namibian children.
2. The grant to the organisation was N\$ 1.7 million. After his passing, the family enabled the Foundation operations with a transfer of the first N\$ 1 million.
3. Under the Chair of Mr Tom Alweendo, a public launch for HEPHF was held in Windhoek on 23 March 2014. The Minister of Health, the Hon Dr Richard Kamwi was guest speaker. Minister Kamwi used the occasion to acknowledge the important work done by the research team and most significantly, launch a national Programme for the Prevention and Control of Rheumatic Heart Disease.
4. This interim report for the year 2015 is presented to the Board of Directors in support of the budget for 2015/2016.
5. The research programme has grown substantially. With the success of our collaboration as part of the RHD GEN African consortium, so too have the financial reserves. However, with the intensity of our work and starting with the additional \$ 700 000 originally offered by Mr Pupkewitz we need give urgent attention to raising additional financial resources.

2. Activities and outputs supported by and through the HEPHF

2.1. Namibian Registry for Rheumatic Heart Disease

The registry was started in January 2010 as part of the Global Registry for RHD ("REMEDY"). Patients are recruited from the RHD Clinic at Windhoek Central Hospital but also on outreach visits by the Registry team to Oshakati and Rundu Intermediate Hospitals. Data has been obtained on over 500 patients with RHD. Data on the first 193 patients were first reported at the World Congress of Paediatric Cardiology and Cardiac Surgery in 2013. The baseline results of the Namibian sub-study of 280 patients will be presented at the annual meeting of the Pan African Society of Cardiology in Tunisia this year (abstract attached). These patients are enrolled in 12 and 24 month follow-up visits as part of their routine care. The principal investigator for this study is Dr Hugo-Hamman and the study doctor was initially Dr B Khaaya and subsequently Dr Liina Sikwaya.

2.2. The Global Registry for RHD (REMEDY)

The baseline results on the 3343 patients enrolled in REMEDY include 280 from the Namibian sub-study. The results were reported at the annual meeting of the European Cardiology Society in November 2014. The results are robust and groundbreaking and were published in the prestigious European Heart Journal on November 25 2014. Dr Hugo-Hamman is a co-author of that paper (attached). The 12 and 24 month follow-up data on those 3343 patients will be presented at the annual meeting of the European Cardiology Society in October 2015. The two most prestigious international medical journals, New England Journal of Medicine and Lancet, express interest to publish this paper.

2.3. Welcome H3 Africa RHD GEN

Based on performance through the Global Registry (REMEDY) clinical scientists at the Windhoek Central Hospital were co-applicants, with the University of Cape Town, in an application to the Wellcome Foundation to extend the Global Registry to study the genetics of RHD. This application was successful and we are now one of 8 centers participating in RHD GEN H3Africa. The question explored in the study is, "which genes are responsible for increasing or decreasing the risks for developing RHD". This is the biggest grant ever given to RHD research and is an important African collaboration.

Dr Hugo-Hamman is the Principal Investigator. The Study Doctor is Dr Tangeni Auala assisted by Dr C Brinkman. Funding from RHD Africa will amount to £44 650 plus £5 per patient recruited. This supports the study nurses, the laboratory assistants and some administration costs. This funding is spread over a 4 year period and patients were first recruited starting October 2014. To date 180 patients have been enrolled in the study. Our goal is 300 patients, 300 controls (people without the disease) and 100 patients with both their parents alive. The HEPHF will provide additional financial support to the project including consulting costs of the Principal Investigator, financial management and research administration. We motivate now for support for study echocardiography.

2.4. 2nd All-Africa Workshop on RF and RHD

This workshop, held under the auspices of the World Health Organization (WHO AFRO) and the Pan African Society of Cardiology (PASCAR) was held at Livingstone, Zambia, on 1-2 February 2014. Dr Hugo-Hamman was one of the co-chairman of the meeting and a rapporteur. There were business meetings of

the REMEDY and RHD GEN to coincide with the workshop. In view of her role as study doctor for REMEDY, the HEPHF supported Dr Liina Sikwaya to attend this workshop as an observer and participate in the REMEDY business meeting. The most significant output from this workshop was the publication in the Lancet in August 2014 of a “Rheumatic Heart Disease A.S.A.P. in Africa: the Mosi-o-Tunya Call to Action”. This “call to Action” has produced remarkable results in that it attracted the attention of the African Union and as a result, under the auspices of the African Union, the third All Africa workshop on RF and RHD was held in on 21 and 22 February 2015 where the goal was to develop “A Roadmap Towards the Eradication of Rheumatic Heart Disease in Africa”.

2.5. The third All Africa workshop on RF and RHD.

The African Union, assisted by WHO AFRO, held the third All Africa workshop on RF and RHD in Ethiopia on 21 and 22 February 2015 where the goal was to develop “A Roadmap Towards the Eradication of Rheumatic Heart Disease in Africa”. This was the most significant public health breakthrough in RHD and NCD Africa thus far. Recommendations for Prevention and Control were tabled at the meeting of African Health Ministers in May 2015. None of this would have been possible without the work done in REMEDY and the country registry’s (Namibia). Dr Hugo-Hamman was a co-chairman and contributor and attended, with HEPHF support the two business meetings of the REMEDY study and the RHD GEN study held to coincide with the workshop.

2.6. National Advisory Committee for Prevention and Control of RF/RHD

On the 24th of March 2014 The Hon Dr Richard Kamwi, Minister of Health, announced the launch of a National programme for the Prevention and control of rheumatic fever and rheumatic heart disease in Namibia. This followed a period of advocacy beginning with the submission of a Cabinet Memorandum in November 2010. Minister Kamwi directed the first step to implementing a National A.S.A.P. Program should be the formation a National Advisory Committee on RF/RHD in the Ministry of Health. Our advocacy finally proved successful when under the leadership of Minister of Health, the Hon Dr Haufiku, the first meeting of the Advisory Committee was held on 23 April 2015.

The Committee will serve as the primary decision-making body of the program and be responsible for designing, implementing and adapting the A.S.A.P. for Namibia. Members of the inter-sectoral committee consist of key stakeholders in the program such as cardiologists, paediatricians, physicians, nurses and epidemiologists. The committee will advise and report to the

Minister of Health. The initial task for the National Advisory Committee will be an assessment of the current state of RF/RHD control in the country, review the current epidemiology of RF/RHD, identify specific barriers to control efforts, review investment and resource allocation for RF/RHD control and examine the health infrastructure available to support program activities. This national programme will follow the “Stop RHD ASAP” guidelines for national programmes which are endorsed by the Pan African Society of Cardiology (PASCAR) and the World Heart Federation.

The Committee will design and implement the 4 specific elements of the “StopRHD A.S.A.P.” program namely, Awareness, Surveillance, Advocacy and Prevention. A timeline for the progressive implementation of program activities will be an essential element to ensure an objective-led plan for RF/RHD control. Dr Hugo-Hamman won N\$ 20 000 on behalf of HEPHF in a competitive application to PASCAR/World Heart Federation for funds to support advocacy projects. This was put to use for the National Advisory Committee.

2.7. Adults with native congenital heart disease

Prior to 2009 there were no services in Namibia. Amongst the indigent, poor, non-insured population (85%), all children with critical congenital heart disease would have perished. Amongst the survivors there is an interesting group of children now over 13 years or in adulthood, without medical or surgical intervention. We believe they have important lessons for our health service. After approval from the Permanent Secretary and with the assistance of study nurse Mr Paul Barno and Dr du Toit, Dr Hugo-Hamman has collected data on adolescents and young adults born with congenital heart disease. We have described 104 patients over 13 years of age presenting with congenital heart disease (CHD) and no previous treatment. They have reported this data to the annual meeting of the Association of European Paediatric Cardiology on 21 May 2015 and do in an African forum at the South African Heart Association in October 2015.

2.8. The Namibian Children’s Heart Project

This project was initiated with the help of Dr Amadhila and Mr Pupkewitz in 2009. To date over 5 years more than 170 Namibians have been referred for heart surgery in Cape Town. The outcomes from this project are currently being audited by Dr Fenny Shidhika under direction of Dr Hugo-Hamman. Dr Shidhika will present these results at the annual meeting of the Pan African Society of Cardiology in Tunisia this year (abstract attached) and will submit

the paper for her MMed thesis in the University of Cape Town. The HEPHF will support Dr Shidhika to attend this meeting.

3. Capacity Building

The terms of reference and founding documents of the HEPHF state that capacity building in research and clinical science is an imperative. To date the HEPHF has supported the following researchers,

- Dr Brenda Kaaya
- Dr Liina Sikwaya
- Mrs A Awases
- Mrs A Bock
- Mr P Barno
- Dr T Auala
- Dr F Shidhika

4. Annual Financial Statements

1. The draft annual financial statement ending 28 February 2015 prepared by SGA Chartered Accountants are presented for approval. Total assets and retained income is N\$ 986 160.
2. Balances as at 10 June 2015 N\$ 147 742 in our current account and N\$ 728 070 in a money market account at First National Bank Namibia (total N\$ 875 812)
3. A draft budget for the year ending 28 February 2016 is presented for approval.

2. Fund raising

2.1. To date a summary of our "income" is as follows

1. The Pupkewitz Family Foundation (N\$ 1 million).
2. Mediclinic donation NS 148 834.75.
3. REMEDY grant via PI Dr CHH and Canada N\$ 76 001
4. RHD GEN grant via PI Dr CHH ex Welcome Trust/UCT N\$ 848 369 (over 4 years)
5. PASCAR/WHF N\$ 20 000 via PO Dr CHH

2. Future

Cash flow has been greatly boosted through grant funding (two RHD research projects). However, we must guard against complacency and prevent the Foundation being depleted at the end of RHD GEN! If we are to grow as a principal research funding agency we need to;

- request the Pupkewitz Foundation make good on N\$ 700 000
- continue to write grant applications to fund research projects
- raise finance from industry, philanthropists and foreign governments

It is proposed that we form a fund-raising sub-committee under the Chair of Mrs Barry.

6. Conclusion

1. HEPHF continues to make an invaluable contribution to heart disease research in children in Namibia.
2. However, the contribution from the research goes far beyond clinical research and empowers our advocacy responsibilities and activities into public health and health policy development.
3. Without research into RHD the national programme for prevention and control would never have been launched. and the National Advisory Committee would not have been constituted.
4. We are in fulfillment of the HEPHF mandate namely, supporting heart research in Namibia and building research capacity.

Dr C Hugo-Hamman
Principal Officer

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