



**HAROLD AND ETHEL PUPKEWITZ HEART FOUNDATION
(NON-PROFIT ASSOCIATION INCORPORATED UNDER SECTION 21)
(Reg No: 21/2012/0013)**

ANNUAL REPORT 2016/2017

- I. The Harold and Ethel Pupkewitz Heart Foundation (HEPHF) was established in 2011 by the late Mr Harold Pupkewitz. The purpose is to support of research into heart disease in Namibian children. This is the annual report for 2017.
- II. Annual Financial Statements
 - A. The annual financial statement ending 28 February 2017 is presented for approval.
- III. Activities and outputs supported by and through the HEPHF
 - A. Namibian Register for Rheumatic Heart Disease
 1. The national registry started with REMEDY in January 2010. Patients are recruited at Windhoek Central Hospital and from 2013, on outreach visits to Oshakati and Rundu Intermediate Hospitals. There are now 581 patients in the national RHD Register.
 2. The baseline results of the Namibian sub-study of 266 patients were presented at the meeting of the Pan African Society of Cardiology (PASCAR) in Mauritius and the Annual Congress of the South African Heart Association in 2015. Publication in “The Cardiovascular Journal of Africa”, in press and is pending approval from the Permanent Secretary.
 3. Baseline results on the 3343 patients enrolled in REMEDY *globally* were reported at the annual meeting of the European Cardiology Society in November 2014 and published in the European Heart Journal in November 2014.
 4. The 24 month follow-up data on those 3343 patients was presented at the World Congress of Cardiology in Mexico in June 2016 and then published in the prestigious journal of the American Heart Association “Circulation”, in October last year.
 - B. Genetics of Rheumatic Heart Disease (RHD GEN)
 1. Namibia were co-applicants (with the University of Cape Town and 7 other countries in Africa) to the Wellcome Foundation to study the genetics of RHD. Dr Hugo-Hamman was Principal Investigator with Dr Tangeni Auala, Dr Liina Sikwaya and Dr Camantha Brinkman Study Doctors.

2. Namibia recruited 334 patients living with RHD and 341 healthy controls. The target was reached and study recruitment concluded on 31 July 2016.
3. Funding from Wellcome has contributed £44 650 to funds under management by the HEPHF and this supported the study nurses, technologists, laboratory assistants and some administration costs.
4. The Foundation provided additional financial support to the project including travel costs of the Principal Investigator, financial management and research administration.
5. The Foundation will host the study closure meeting in Windhoek in June 2017.

C. Surgery for rheumatic valvular heart disease in Namibia.

1. Since the unit was commissioned in 2019, over 200 patients have received surgery for RHD in Windhoek. Dr Tangeni Auala, supervised by Dr Hugo-Hamman and assisted by Dr's Agapitus, du Toit and Nghaamwa, have investigated the outcomes of surgery in 200 patients.
2. On behalf of the investigators, Dr Auala will present a paper "A review of 5 years experience (2010 - 2015) of surgery for Rheumatic Heart Disease at the Windhoek Central Hospital, Republic of Namibia" at the forthcoming World Congress of Paediatric Cardiology and Cardiac Surgery in Barcelona, Spain in July 2017.
3. The Foundation supports this research and will enable Dr Auala attend this meeting.
4. Publication of the results will follow later in 2017.

D. The Namibian Children's Heart Project (NCHP)

1. This project was initiated by Dr du Toit and Hugo-Hamman, with the help of Dr Amadhila and Mr Pupkewitz, in 2009. To date, over 6 years, more than 280 babies and small children have been referred for heart surgery or intervention at the Christiaan Barnard Memorial Hospital in Cape Town.
2. The outcomes from this project have been analysed by Dr Fenny Shidhika and Dr Hugo-Hamman. On behalf of the investigators, Dr Shidhika will present a paper, "THE NAMIBIAN CHILDREN'S HEART PROJECT: A SIX YEAR REVIEW OF PATIENTS AND OUTCOMES", at the forthcoming World Congress of Paediatric Cardiology and Cardiac Surgery in Barcelona Spain in July 2017.
3. The Foundation supports this research and will enable Dr Shidhika to attend this meeting. Dr Shidhika will submit the paper for her MPhil thesis in the University of Cape Town.

E. Novel treatment for prevention of outcomes in rheumatic heart disease

1. INVICTUS is a large randomised trial investigating novel treatments for prevention of cardiovascular outcomes in rheumatic valvular heart disease. Rheumatic valvular heart disease (RVHD) is a major cause of stroke and heart failure.

2. INVICTUS will perform two simple and well-designed randomised clinical trials of a promising novel oral anticoagulant, rivaroxaban vs the standard treatment with a drug called warfarin. It will include a large registry (20,000) to help understand the natural history of the condition, factors that affect outcomes and barriers to appropriate care. So the national registry will continue under INVICTUS and will be the vehicle through which patients are enrolled in the clinical trial.
3. With Dr Hugo-Hamman as the Principal Investigator, in 2015 the Namibian research team was invited to participate in the international INVICTUS study.
4. A clinical trial has NEVER been conducted in Namibia. Whilst this is an important opportunity for the country and the protocol was submitted to the Permanent Secretary on 1 June 2016, permission to proceed with the study has still not been given by the Ministry of Health and Social Services. Directors are able to assist with this challenge.

F. The Eradication of RHD

1. Eradication of Rheumatic Heart Disease

- a) Heads of State of the African Union adopted the “Addis Ababa Communique on eradication of rheumatic heart disease in Africa” in 2015 (published in the Cardiovascular Journal of Africa in 2016).
- b) “RHD Action” and a number of countries including Namibia, sponsored a meeting held at the World Health Assembly in Geneva in May 2016 on a draft resolution for the WHO on RHD Eradication. This was attended by Dr Hugo-Hamman who accompanied Minister Haufiku to the meeting.
- c) A working group, led by New Zealand but with participation from Namibia, was established with the task to write this resolution for presentation to the Executive Board of the WHO. As a result a resolution will be put the Board of the WHO in May 2017 for adoption by the Assembly, in 2018.
- d) None of this would have been accomplished without the work done in REMEDY, the Namibian and other national registries in Africa.

2. Eradication of Rheumatic Heart Disease in Namibia

- a) The Namibia National Advisory Committee for Prevention and Control of RF/RHD was formed in 2015. Knowledge and evidence on RHD acquired through the Namibian National Registry is what enabled its formation and what supports its important agenda.
- b) The Committee serves as the primary decision-making body of the program and is responsible for designing and writing the “Beat RHD A.S.A.P.” national programme. The second meeting was on 1 June 2016 with Dr Auala and Dr Hugo-Hamman drafting the national programme for presentation to the Advisory Committee in June 2017.

IV. Capacity Building

- A. An important objective of the Foundation is, “to identify young medical scientists and *build research capacity* in our country”.
- B. To date the Foundation has engaged and supported the following clinician scientists and research assistants - Dr’s Brenda Kaaya, Liina Sikwaya, Johanna Shapaaka, Fenny Shidhika and Tangeni Auala.
- C. In addition we have engaged the assistance of RN’s Antoinette Awases, Angeline Bock, Anna Marie Amanyanga, Helvi Neumbo and Paul Barno.
- D. In 2016 Dr Auala participated in the annual training “Seminar on Cardiovascular Disease Epidemiology and Prevention in the West Indies and in June 2017 the Foundation will support Dr Agapitus to attend the same course in Kuala Lumpur, Malaysia.

V. Research system support

- A. Consistent with the budget, the Foundation purchased computer and audiovisual equipment for use by clinician scientists and educators in the Cardiac Unit at Windhoek Central Hospital. This has been installed in the Conference Room in 1 West.

VI. Fund raising

- A. Our vision is to be the principal heart research funding agency in Namibia.
- B. To date the Foundation has received the following *donations*;
 - 1. N\$ 1.7 million by Mr Pupkewitz and delivered through the Harold Pupkewitz Descendants Trust.
 - 2. Mediclinic Hospital Group NS 148 834.75 in 2013.
- C. Dr Hugo-Hamman was awarded the following *research grants* (worth a total of N\$ 2 059 685) which have more than doubled funds under management.
 - 1. N\$ 76 001 towards REMEDY from PPI Canada.
 - 2. N\$ 1 021 380 towards RHD GEN from the Wellcome Trust, UK
 - 3. N\$ 20 000 from PASCAR/World Heart Federation.
 - 4. N\$ 942 304 from BAYER PHARMA for the INVICTUS clinical trial
- D. Mr Richard Hugo-Hamman has donated N\$ 100 000.00 in his personal capacity. He has submitted a guarantee for N\$ 200 000 from his company LEAP Software Solutions and a further N\$ 50 000 per annum pending outcomes from the Annual General Meeting.
- E. Dr Hugo-Hamman will continue to write grant applications. However, to reach our vision as a research institution and hub which promotes, solicits and invites research proposals from the broader scientific community, the added impetus of external donations is an imperative.

VII. Conclusion

The Foundation has made an invaluable contribution to heart disease research in children and research capacity development in Namibia. The impact of that research is best measured by its relevance to and influence on health policy in Namibia and Africa. Without our 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. We are fulfilling our mandate namely, supporting heart research in Namibia and building research capacity. A new generation of heart specialists and scientists is currently being trained and the Foundation has been actively promoting their development. The 9 months delay in approval from the MHSS for INVICTUS is a setback for the programme and the Foundation. The Foundation and its Directors need to assist the MHSS with the challenging questions relating to clinical trials and work to facilitate the projects approval without further delay.

DR C HUGO-HAMMAN
PRINCIPAL OFFICER

THE HON MINISTER T ALWEENDO
CHAIRMAN

5 APRIL 2017