



Namibian Children's  
Heart Foundation

(NON-PROFIT ASSOCIATION INCORPORATED UNDER SECTION 21)  
(Reg No: 21/2012/0013)

## **DRAFT ANNUAL REPORT 2017/2018**

### **I. Introduction**

The Harold and Ethel Pupkewitz Heart Foundation (HEPHF) was established in 2011 by the late Mr Harold Pupkewitz. The purpose being to support research into heart disease in Namibian children. In 2017 the name changed to the Namibian Children's Heart Foundation (NCHF). This is the annual report of the NCHF for 2018.

### **II. Annual Financial Statements**

A. The annual financial statement ending 28 February 2018 is presented for approval. The financial affairs of the Foundation are sound. With donations received through 2018 (N\$ 802 259.00), current assets are N\$ 1 426 761.

### **III. Research supported by and through the NCHF**

#### **A. *Namibian Register for Rheumatic Heart Disease***

1. The Namibian National Registry for RHD has been supported and funded by the Foundation since inception in 2010. Patients are recruited at Windhoek Central Hospital and since 2013, on outreach visits to Oshakati and Rundu Intermediate Hospitals. There are now 683 patients in the national RHD Register.
2. Baseline results on the 3343 patients enrolled in REMEDY *globally* were published in the European Heart Journal in November 2014.
3. The 24 month follow-up data on those 3343 patients were published in the journal of the American Heart Association, "Circulation", in 2016.
4. The baseline results of the *Namibian sub-study* of 266 patients were presented at the Pan African Society of Cardiology (PASCAR) in Mauritius and the Annual Congress of the South African Heart Association in 2015. Publication of the baseline and follow-up data in, "Cardiology in the Young", is in press.
5. The Registry is the surveillance tool used by the National Programme for prevention and control of RHD in the Ministry of Health (MHSS). In the last year the Registry has moved to an App based system called COMM CARE maintained by Administrator, Ms Gonda Olivier.



Namibian Children's  
Heart Foundation

### *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 in a study of 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 study was formally closed in Johannesburg in 2017. Analysis of the DNA is now taking place in Canada and the results of this investigation are much anticipated.

### *C. Surgery for rheumatic heart disease in Namibia.*

1. Since the unit was commissioned in 2010, over 300 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 outcomes of surgery in the first 200 patients.
2. On behalf of the investigators, Dr Auala presented 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 World Congress of Paediatric Cardiology and Cardiac Surgery in Barcelona, Spain in July 2017.
3. The NCHF supported this research and enabled Dr Auala attend this meeting. Publication of results will follow later as part of Dr Auala's MPhil in Cardiology at the University of Cape Town.

### *D. 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) through a complication known as *atrial fibrillation*, is a major cause of stroke.
2. INVICTUS will perform two simple, 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



Namibian Children's  
Heart Foundation

- (20,000) to help understand the natural history of the condition, factors that affect outcomes and barriers to appropriate care.
3. With Dr Hugo-Hamman as the Principal Investigator, in 2015 the Namibian research team was invited to participate INVICTUS.
  4. A clinical trial has never been conducted in Namibia. Whilst this was an important opportunity for the country and the protocol was submitted to the MHSS on 1 June 2016, permission to proceed with the study had still not been given by the MHSS, in fact the application had not even been considered, by October 2017.
  5. Unfortunately, at great cost to the Foundation and to research in Namibia, in December 2017 we were formally relieved of our status as co-investigators in INVICTUS.

#### *E. 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 8 years, more than 380 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 to December 2015 have been analysed. On behalf of the investigators, Dr Shidhika presented a paper, "*the Namibian Children's Heart Project: A 6 year review of patients and outcomes*", at the World Congress of Paediatric Cardiology and Cardiac Surgery in Barcelona Spain in July 2017.
3. The Foundation supported this research and enabled Dr Shidhika attend the Congress.
4. Dr Shidhika will submit the paper for her MPhil thesis in the University of Cape Town and it will be submitted for publication in the prestigious journal, "Cardiology in the Young", this year.

## **IV. The Eradication of RHD**

### *A. Global Resolution on Rheumatic Fever and 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.
- c) A working group, led by New Zealand but with participation from Namibia, was established to write this resolution for presentation to the Executive Board of the WHO. As a result a resolution adopted by the Board of the WHO in May 2017 for adoption by the Assembly, in 2018.



Namibian Children's  
Heart Foundation

- d) Following years of campaigning and advocacy from the global RHD community, on Friday 25 May 2018 Member States of the WHO unanimously adopted a “*Global Resolution of Rheumatic Fever and Rheumatic Heart Disease*” at the World Health Assembly in Geneva Switzerland. The historic decision marks the first time that RF and RHD have been recognised as a global health priority. The Resolution was co-sponsored by countries from all 6 regions, including Namibia, demonstrating the urgent need for a global response.
- e) None of this would have been accomplished without the work done in REMEDY, the Namibian and other registries in Africa.

## B. Eradication of Rheumatic Heart Disease in Namibia

- a) The 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. 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.
- b) In 2017 the Pan-African Society of Cardiology (PASCAR) partnered with the World Heart Federation (WHF) to offer funding for up to five projects/activities (\$ 2000 each) to advance implementation of the “African Union Communiqué on the Eradication of RHD in Africa”. The Namibian RHD team applied for this grant and was one of the successful applicants. The award was used primarily to to fund the activities of the *National Penicillin Task Force* which met in September 2017 to attempt to plug the substantial gaps in the supply chain for oral and injectable penicillin.
- c) Furthermore, RHD Action provided funding for 5 projects (\$ 2000 each) which supported advocacy around RHD in Africa. The Namibian RHD team, also applied for this small grant and was again one of the successful applicants. The award was used to support the novel “*Namibian RHD Ambassador programme*”.
- d) The NCHF supported the marketing and publicity around World Heart Day in Namibia the focus of which, was RHD prevention. The NCHF again sponsored RHD T shirts and posters for World Heart Day and pamphlets for distribution to health centres and hospitals in Namibia.

## V. Capacity Building

- A. An important objective of the Foundation is, “*to identify young medical scientists and build research capacity in our country*”.



Namibian Children's  
Heart Foundation

- 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 2017;
  - 1. NCHF supported Dr Ndati Agapitus to attend the 49th Ten Day International Teaching Seminar on Cardiovascular Disease Epidemiology and Prevention June 3 - 16, 2017 in Kuala Lumpur, Malaysia.
  - 2. NCHF supported Dr Auala and Dr Shidhika's attendance at the 7th World Congress of Paediatric Cardiology and Cardiac Surgery in Barcelona.
  - 3. NCHF supported Dr Monika Kakololo attend the Congress of the South African Heart Association in Johannesburg, South Africa.

## VI. Grants and Donations

- A. Historically the Foundation has received the following *donations*;
  - 1. Mr H Pupkewitz N\$ 1.7 million.
  - 2. Mediclinic Hospital Group NS 148 834.75.
  - 3. Mr Richard Hugo-Hamman N\$ 100 000.00
- B. Dr Hugo-Hamman received the following *research grants*
  - 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 (but this has been lost to the NCHF and to research in Namibia).
- C. In the current financial year the following donations and grants were received;
  - 1. Mr Richard Hugo-Hamman N\$ 430,843.14 donation.
  - 2. Leap Software Solutions N\$ 192,094.00 donation.
  - 3. The Pupkewitz Foundation N\$ 100 000.00 donation.
  - 4. World Heart Federation grant N\$ 23 978.57.
  - 5. Pan African Society of Cardiology (PASCAR) grant N\$ 31 874.50.
  - 6. RHD GEN grant N\$ 23 469.00.
- D. LEAP Software also carried the development cost for the NCHF webpage - a grant in aid valued at N\$ 53 000.00.
- E. The total income for the year was N\$ 802,629.04.

## 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



Namibian Children's  
Heart Foundation

specialists and scientists is currently being trained and the Foundation has been actively promoting their development.

The highlights for the year were the successes achieved internationally through evidence based advocacy, the international presentation of our research, the investments in people living with RHD (The Ambassadors) and the work done in the Penicillin Task Force. On the other hand, the failure by the MHSS to consider the application to proceed with INVICTUS has been a massive setback to the national research team. The core research group had achieved so much and promised so much more in a four year project which would have taken them through 2020.

The Foundation managed to solicit generous financial support over the last year. However, it is unlikely to continue to attract funding without the energy provided by research. The challenge to the Foundation is to move quickly beyond the INVICTUS disappointment. The NCHF will continue to support the the new generation of young researchers we have helped develop. The challenge to them is to come forwards with innovative projects deserving funding from the NCHF.

THE HON MINISTER T ALWEENDO  
CHAIRMAN

30 June 2018