The PROTEA Study

Partnerships in Congenital Heart Disease in Africa

Liesl Zühlke, Thomas Aldersley, Inge Smit, Rik DeDecker, John Lawrenson, George Comitis, Barend Fourie, Blanche Cupido, Bernard Keavney, Gasnat Shaboodien, Raj Ramaesar, Paul Human, Bongani M Mayosi for the PROTEA Investigators

1 Department of Paediatric Cardiology, Department of Paediatrics and Child Health, UCT and Red Cross War Memorial Children’s Hospital, Cape Town, SA
2 Division of Cardiology, Department of Medicine, University of Cape Town (UCT) and Groote Schuur Hospital, Cape Town, South Africa (SA);
3 Department of Paediatric Cardiology, Department of Paediatrics and Child Health, Stellenbosch University and Tygerberg Hospital, Cape Town, SA;
4 Division of Cardiovascular Sciences, University of Manchester, Manchester, UK
5 Hatter Institute of Cardiovascular Research, University of Cape Town (UCT) and Groote Schuur Hospital, Cape Town, South Africa (SA);
6 Division of Human Genetics, Department of Pathology, UCT, Cape Town, SA
In the language of flowers, the Protea symbolizes hope, diversity and courage.

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Congenital heart disease (CHD) is the most common birth defect, with a birth prevalence of 8:1000 births.

Yet, the epidemiology of CHD in Africa is poorly defined with a dearth of data on prevalence and predictors of mortality.
The population of adults with CHD is steadily increasing, and incorrect or inadequate management of this critical transition period has direct influence on maternal mortality.
Research to identify predictors of mortality and morbidity highlight gaps in implementation and provide evidence for interventions for children with heart disease is urgently needed.
Improving knowledge about CHD epidemiology in sub-Saharan Africa by the establishment of a densely phenotyped and prospectively followed CHD cohort in Africa can significantly impact the efficacy of care and ultimately improve the outcome for CHD patients.
Aims

- To establish a registry of CHD patients (children and adults), in Cape Town.
- To develop a comprehensive clinical, genotypic/phenotypic, demographic, and outcomes.
- To develop a biobank of samples for DNA extraction and genetic analysis.
- To train junior African researchers in advanced statistical genetic and bioinformatics methodology, developing local expertise.
- To develop a multidisciplinary collaboration in computational fluid dynamics, focused on novel functional assessment and treatment modalities in CHD.
Design

- Prospective cohort of CHD in both children and adults in South Africa commencing 1 September 2017.
- Ethics approval for a register and repository.
- Informed consent from all patients and guardians to be in registry.
- The study will be conducted at three sites: Red Cross War Memorial Children’s Hospital, Tygerberg Hospital and Groote Schuur Hospital. At Groote Schuur Hospital, the register will encompass two clinics: the GUCH clinic and the combined cardio-obstetric clinic.
- Focus on the life course approach.
Flow and opportunity

Antenatal diagnosis
First presentation: Acute->Surgery
First presentation: Elective Clinic
Grown-Up Congenital (GUCH)
Combined Cardio-Obstetric (CCOC) clinic

Echo and cath database
Echo and cath database
ESC database

Database for clinical, echo and cath data
Surgical Data Surgical outcomes/F-U
Outcomes and FU for stable patients
GUCH and CCOC database Adult surgical outcomes
The Protea Study

PARTNERSHIPS IN CONGENITAL HEART DISEASE IN AFRICA

Genetics Genomics
Cardiac MRI Cardiac CT
Computational Modelling
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### Cardiologists Data

<table>
<thead>
<tr>
<th>General</th>
<th>Structure</th>
<th>Measurements</th>
<th>Methods</th>
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<tbody>
<tr>
<td>Situs</td>
<td>Pulmonary veins</td>
<td>Atria</td>
<td>AV conn.</td>
</tr>
<tr>
<td>Abdominal Ao pulsatility</td>
<td>□ Good □ Reduced □ Absent</td>
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<tr>
<td>Retro-aortic innominate vein</td>
<td>□ Absent □ Present</td>
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### Conclusions

**IVC**
- □ Normal
- □ Interrupted with azygous continuation
- □ Dilated
- □ Interrupted with hemi-azygous continuation

**SVC**
- □ Normal
- □ Dilated
- □ Stenosed

**Hepatic veins**
- □ Normal
- □ Dilated

**Coronary sinus**
- □ Normal
- □ Unroofed
- □ Dilated
- □ Absent
PartneRships in COngeniTaL HEart Disease in Africa

Implications and Dissemination

Bespoke database for clinical management and research.

Pilots planned with Aswan, Egypt and Accra, Ghana.

Comprehensive, contemporary data on CHD in Africa.

Patient and Family Advisory group
In the language of flowers, the Protea symbolizes hope, diversity and courage.

Thank you to the Protea team
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Principal Investigators and collaborators
Professor Bongani Mayosi
Professor Bernard Kheavney
Professor Raj Ramasar
Professor Alistair Revell