

Layperson explanation of research project:

The Prevalence and Mutation Profile of Southern African Patients with Treatable Lysosomal Storage Disorders.

Ethics committee approval Number: UFS-HSD2018/0913

Lysosomal storage disorders (LSD's) are complex disorders that affect many organs in the body. They are progressive disorders leading to organ damage and frequently organ failure. Individually these disorders are rare. They are inherited and there may be more than 1 affected person in a family.

The purpose of the study is to determine the prevalence of selected LSD's in Southern Africa. If available, information about the genetic cause (mutation) will be obtained. This may help planning and development of genetic tests specific to our population. Demographic and clinical data will be analyzed to establish if the manner or age at presentation to healthcare workers is different in Southern Africa.

Participants are not obliged to participate and may withdraw their consent at any stage.

Yours sincerely



Dr. BD Henderson



Dr. BD Henderson
Div. Human Genetics
PO Box 339(G69)
Bloemfontein

Tel: 0514053046
Fax: 0862705512
e-mail: gnmgbdh@ufs.ac.za



UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA