



## Invitation to participate in a research project

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

Ethics committee approval Number: UFS-HSD2018/0913

Dear Dr.

I am attempting to determine the prevalence of selected lysosomal storage diseases (LSD's) in Southern Africa. This invitation has been sent to you via the professional medical society for your speciality or directly to you if I obtained your name from the laboratory providing a diagnostic service for LSD's. I apologize if you receive more than one invitation to participate, I am using many different avenues to get as much data as possible. The study is a retrospective collection of information on your files and as such there is no requirement for you to obtain additional information.

If you have any patients diagnosed with Fabry, Gaucher, Pompe, Hurler/Scheie, Hunter, Morquio A or Maroteaux-Lamy disease, please consider completing the information requested as completely as possible. Please complete the consent form and return it with the data to me at [gnmgbdh@ufs.ac.za](mailto:gnmgbdh@ufs.ac.za). If you want any further information, you can contact me or the HSREC at 051 4017795 or e-mail [ethics@ufs.ac.za](mailto:ethics@ufs.ac.za).

I am attaching the protocol, consent forms, data collection sheets and ethics approval for you to peruse and decide if you wish to participate. As you will note there is only a single page of information requested per patient. The protocol explains why I am requesting patients' names and date of birth, in order to prevent duplication. If you wish to add more information, please feel to do so.

Thanking you in anticipation  
Yours sincerely

Dr. Bertram Henderson

