February 2016

TO WHOM IT MAY CONCERN

Re: FUNDING REQUIRED FOR SCLEROSTEOSIS RESEARCH PROJECT (A RARE GENETIC BONE DISORDER)

Sclerosteosis is a rare autosomal recessive genetic disorder, a debilitating condition that irrevocably alters the lives of the people who has it, as well as their families. The clinical features are uncontrolled bone formation that leads to thickening and sclerosis (hardening) of the skeleton, including the skull, resulting in widening of the jaw, distortion of the face, gigantism and entrapment of the cranial nerves as well as spinal nerves with consequential recurring facial paralysis, hearing loss, loss of smell and severe headache and back pain. The most dangerous feature is raised cranial pressure that can lead to sudden death due to impaction of the brain stem in the foramen magnum.

To this point, except for an immense effort by Dr Herman Hamersma (ENT), Dr Louis Hofmeyr (ENT) and Dr Jacques du Plessis (Neurosurgeon) to treat the patient symptomatically (to correct the effects of Sclerosteosis surgically), no effort has been made to find a possible preventative treatment or cure. When dealing with a condition like Sclerosteosis, where only approximately 130 cases have been documented, it is regrettable that the amount of people that have the condition are so few that it is not financially viable for pharmaceutical companies to invest large sums of money to find a possible cure. The individuals and families affected by this disease have therefore found it imperative to make a concerted effort themselves to raise funds for this project, as financing is the only obstacle in driving this project forward.

We would like to thank Prof. Vinny Naidoo at the University of Pretoria (*Deputy Dean: Research and Postgraduate studies at the faculty of Veterinary Science*), who has agreed to accommodate the Sclerosteosis research project at one of their research facilities. This project is already under way as from January 2016, with Timothy Dreyer, a PhD student who also suffers from the condition, participating in the project.

We humbly call on the community and individuals to assist us in our quest to find a cure for our children and fellow-sufferers, who are dealing with the condition on a daily basis. We have taken this project as far as we can on our own. For some of us, it has been years of tireless petition and searching, with new cases being diagnosed yearly. This study will contribute greatly to understanding sclerosteosis bone metabolism better to hopefully bring about a cure to a small group of patients that live with this debilitating and dangerous condition.

We are greatly indebted to the accountants of PSG Silverlakes & George Central who will manage the funds received in the trust account, as well as Cobus Goosen at Grant Thornton Auditors in George for assisting with the registration of this foundation.

Any funds received (once-off or as a montly contribution) will be greatly appreciated.

Yours sincerely

Theuns Botha
Rare Bone Disease Foundation Trustee
And father of Sclerosteosis patient

BANKING DETAILS:
BANKING INSTITUTION:Investec
ACCOUNT NAME:Rare Bone Disease Foundation
ELECTRONIC TRANSFER ACCOUNT NUMBER:500 1004 7858
BRANCH CODE:580 105
ACCOUNT TYPE:CURRENT (CCM call money fund)

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