

30 March 2019

Prof S Risenga
Director: School of Medicine
Faculty of Health Sciences
University of Limpopo
Polokwane
Limpopo Province

Dear Prof Risenga,

Letter of Support for Genetic Counsellor Position

We are writing to motivate for the creation of a genetic counsellor post to service Pietersburg and Mankweng Hospitals as part of the establishment of medical genetic services in Limpopo Province.

As a non-profit membership organisation uniting patient support groups, healthcare professionals and other stakeholders relevant to the care and prevention of congenital disorders (CDs), Genetic Alliance South Africa (GA-SA) fully supports the establishment of this post, and any subsequent supporting positions relevant to the care and prevention of CDs.

The appointment of a genetic counsellor at the Pietersburg and Mankweng Hospital, ideally as a joint appointment between the University and the Department of Health as is the case for other provinces, will have a significant positive impact on both the surrounding locality and district, and the province as a whole. For those affected or at risk of CDs - which includes one in every 15 live births in South Africa, it will help gain understanding into the cause, management and the implications of the diagnosis for themselves, their children and family members. Genetic counselling also assists in managing the emotional impact of a genetic condition and enables well-informed decision making by patients about their health and wellbeing.

As you may know, there is currently no appointed genetic counsellor post in Limpopo, as is also the case for seven other provinces in South Africa. With the establishment of the genetic counsellor post, Limpopo would lead the way for these provinces by pioneering tertiary genetic services, and effectively provide a model for others to replicate. This is likely to provide a

significant return on investment in future, both in terms of minimising the socioeconomic impact represented by CDs, as well as easing the human and personal cost - particularly resulting from reoccurring genetic conditions and complex cases requiring referral out of province.

Currently, tertiary medical genetic services are only available at four academic centres in three of the nine provinces, with state employed genetic counsellors only available in two provinces. With only 12 full-time practising medical geneticists (1 per 5 million of the population) and 10 genetic counsellors in the public sector (1 per 7 million), capacity falls far short of recommended numbers. The appointment of a genetic counsellor at these hospitals would considerably strengthen the health capacity of the Province as a whole and contribute towards achieving a national target of 27 genetic counsellors by 2020.

With the increasing health need posed by CDs due to epidemiological transition – as infectious diseases are better controlled the proportion of patients affected by CDs is set to rise - it is now an imperative that we implement medical genetic services for their care and prevention. Like many middle and low income countries, South Africa is following the trend of industrialised countries where CDs emerged and remain the leading cause of death in infants and children – accounting for up to 28% of under-5 deaths in high income countries today.

At GA-SA, our vision is a united CD community that works towards a South Africa where those affected by CDs can readily access care and support – achieved through our mission to unite, support and build capacity in the CD community through advocacy, networking, education, public awareness and research.

We applaud you for your efforts to date in progress towards this genetic counselling post and urge you to finalise the appointment as soon as possible. We look forward to partnering with you going forward to achieve our common goal of ensuring 'Health for All'.

Yours sincerely,



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