

11 April 2019

Dr M Molokomme
Chief Executive Officer
Universitas hospital
1 Logeman St
Universitas,
Bloemfontein, 9301

CC: Dr R Nathan Head Clinical Services, Universitas Hospital
Dr N Mofolo, Head: School of Medicine, University of the Free State
Mr D Motau, Head of Department: Health, Free State

Dear Dr Molokomme,

Letter of Support: Medical Genetic Registrar & Genetic Counsellor Posts

Genetic Alliance South Africa (GA-SA) is a non-profit membership organisation uniting patient support groups, healthcare professionals and other stakeholders relevant to the care and prevention of congenital disorders (CDs). Our vision is a united CD community that works towards a South Africa where those affected by CDs can readily access care and support – by uniting, supporting and building capacity through advocacy, networking, education, public awareness and research.

The purpose of this letter is to advocate for specific posts to be created to further develop and strengthen the medical genetic services in the Free State province.

The Clinical Genetics Unit operating out of Universitas Hospital provides a clinical genetics service for a minimum of 4.1m South Africans in both the Free State and Northern Cape Provinces, with patients from Lesotho and parts of the Eastern Cape also accessing these services. While collectively representing 7% of the population, these are two of the largest provinces by area, accounting for over 40% of the geographical area of the country. The capacity of the Clinical Genetics Unit is limited to two clinical medical geneticists - Dr Bertram Henderson, Head of Unit and Dr Maureen Conradie, Specialist Medical Geneticist. There are no genetic counsellors on staff, despite the national recommendation of the 2001 National Policy Guidelines of four genetic counsellors per medical geneticist. There are also no medical genetic registrar posts to ensure the sustainability of the service through capacity building and training.

With 6.8% of live births in South Africa affected by CDs, estimates indicate over 5 000 births are affected by CDs annually in the Free State and Northern Cape combined. However, in 2018 the Genetics Unit at Universitas saw a total of 1 029 patients, of which 545 were new and the remainder

were followup patients. This indicates that only a very small proportion of the population are able to access these services.

The creation and subsequent appointment of these posts would have a significant positive impact on both the surrounding locality, district, and the provinces as a whole. For those affected or at risk of CDs - which is 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. These posts are 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.

As infectious diseases are better controlled the proportion of patients affected by CDs is set to rise – making it an imperative that we implement comprehensive 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.

In the Free State the under-five mortality rate (U5MR) is 50 per 1 000 live births - meaning that 50 children die out of every 1 000 before they reach their 5th birthday. This is 60% higher than the national average of 32 per 1 000. If the Sustainable Development Goal 3 Target of an U5MR of 25 per 1 000 live births is to be met by 2030, CDs need to be prioritized as a health care priority by every province countrywide.

We urge you to consider the issues highlighted in this letter and would be happy to discuss things further with you in detail in person subject to your availability. We look forward to partnering with you going forward to achieve our common goal of ensuring 'Health for All' in the Free State.

Yours sincerely,



Dr Helen Malherbe
Chair Governing Board: Genetic Alliance South Africa
Email: helen@hmconsult.co.za
Tel: +27(0)83 399 4353