

# GladAfrica Epilepsy Research Project (GERP): Initiation, Launch and Community Interest Report

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The University of Venda and the GladAfrica Foundation Trust hosted an event to launch the GladAfrica Epilepsy Research Project on 12 February 2020 at the Sports Hall, University of Venda, Limpopo, South Africa. The official signing of the Memorandum of Agreement between the School of Health Sciences, University of Venda and the GladAfrica Foundation Trust took place on the occasion. The delegates who attended the conference included University of Venda staff members and students, GladAfrica Group and GladAfrica Foundation Trust executives, trustees and teams, Vhembe District Municipality representatives, community leaders, traditional practitioners and members of the community.

A holistic understanding of epilepsy is key given that it has been found and understood to exist within two parallel worlds: the first is based on the scientific advances in the management and treatment of epilepsy where enormous scientific progress has been



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witnessed; the other concerns a religious and traditional world characterised by beliefs, superstitions and prejudice related to epilepsy that remain quite resistant to the numerous Western initiatives for people living with epilepsy (PLWE). Strong traditional values, practices and beliefs contribute to delays in the presentation and diagnosis of epilepsy in the available healthcare systems of people in the rural communities of South Africa. Moreover, religious and sociocultural beliefs influence the nature of treatment and care received by PLWE. Many communities in South Africa (both urban and rural), as well as other African and developing countries, believe that epilepsy results from evil spirits and from being possessed, and thus treatment should comprise anointments with herbaceous plants from traditional practitioners and religious leadership. This has also perpetuated and promoted the stigmatisation of epilepsy within our African context, which has been promoted by the available media. Stigmatisation is mainly associated with poor knowledge and awareness regarding epilepsy.

Patient, parent/caregiver and community education is a necessity and of paramount importance in promoting the provision and maintenance of quality care. It is against the above-mentioned background that the University of Venda (UNIVEN) and the GladAfrica Foundation Trust (GFT) embarked on initiating the GladAfrica Epilepsy Research Project (GERP) (2020–2023) aimed at developing an Epilepsy Awareness Programme, a Cultural Congruent Intervention Programme, and an Epileptic Life Skills Manual for both primary and secondary schools. This will be achieved through a holistic community-based participatory action research approach, which will also provide awareness, knowledge and skills among families, communities, community health workers and professionals to ensure the prevention and management of epilepsy, and support, rehabilitation and advocacy for PLWE.

The GERP was launched during the national epilepsy week (10–16 February 2020). The project launch programme was directed by the Director of Communications, Dr T. Dzaga, and was honoured by the presence of the UNIVEN Deputy Vice-Chancellor Academic, Prof. J. E. Crafford, the Dean of the School of Health Sciences, Prof. M. T. Mulaudzi, the Director of Research and Innovation, Senior Prof. G. E. Ekosse, the Co-Chairperson of GFT, Mr N. Mashaba, the GladAfrica Group CEO, Mr K. Lebese, delegates from the Vhembe District Municipality, the GladAfrica Epilepsy Research Project Leader and Senior Lecturer in the Department of Public Health, Dr L. Makhado, Research Professor at the School of Health Sciences, Prof. R. T. Lebese, the Epilepsy South Africa representative, Ms K. R. Mashego, and UNIVEN staff members and students, community members and media delegates including Munghana Lonene FM, Capricorn FM and Choice FM who graced the occasion to launch the project.

Prof. Crafford provided a welcome address note in which he indicated that “as the University we are very proud that the School of Health Sciences has attracted this important funded project.” He further indicated that GERP is a very important project for the university because it has come at a time when the university is reviewing the new UNIVEN Strategic Plan 2021–2025. He added that he can assure the audience that

the GFT and UNIVEN partnership will fit well the strategic plan because it talks to research and the improvement of the lives of people in our communities. Prof. Crafford further thanked the GFT for trusting the UNIVEN to host, conduct and manage the project.

The guests were introduced by Dr Makhado, who acknowledged all dignitaries from different departments and representatives. Dr Makhado also introduced the GERP team members who are inclusive of the coinvestigators Prof. R. T. Lebese, Prof. M. S. Maputle, Dr A. Maphula, Dr J. T. Mabunda, Dr N. S. Mashau and the project administrator, Mrs T. G. Makhado. He further explained that seven postgraduate students are currently funded by GFT under the GERP, thus two doctoral (PhD) candidates (Ms M. Nemathaga and Ms O. Musekwa) and 4 master's degree candidates (Ms Q. Chabangu, Mr M. Ramanyaka, Ms M. Luvhengo and Ms M. Munyadziwa) with the other PhD candidate to be recruited in the subsequent year. The launch was also attended by several community leaders and members from some of the villages where the research project will be conducted.

The purpose of the launch was provided by Prof. Lebese, who described epilepsy as a chronic disorder that affects the brain and is characterised by recurring seizures, which are brief episodes of involuntary movement of the body, sometimes accompanied by loss of consciousness. She added that the disorder affects all age groups and in onlookers it can instil fear, prejudice, stigma and discrimination. It was further indicated that people who suffer from epilepsy are often ostracised by their families and communities due to a lack of understanding concerning epilepsy. There is, therefore, a need to destigmatise epilepsy, promote knowledge and raise awareness regarding causes and medication options applicable to different types of epilepsy, which is the reason for this project.

Mr Noel Mashaba, co-chairperson of the GFT who lives with epilepsy and has had the condition since his childhood, addressed the audience. In his touching speech, he described what growing up with epilepsy was like for him and said that he does not wish others living with epilepsy to go through the same experiences. He indicated that there is a need to explain epilepsy in the medical sense to dispel the myths and misconceptions that exist within our communities. He further indicated that to improve the quality of life of people living with epilepsy considerable efforts need to be made to educate all stakeholders and the general public, as well as the families of people living with epilepsy.

Mr Mashaba explained that “people with epilepsy are sometimes regarded as being chosen or being possessed, depending on the prevailing popular belief; this can delay treatment and worsen society's attitudes towards epileptic people. Despite the significant clinical and therapeutic progress of the last century, people with epilepsy continue to be stigmatised.” Mr Mashaba further expressed that people who are living with epilepsy do not feel free because a seizure can occur at any time and anywhere. He

indicated that the launch of the project was a dream come true because he has always wanted research to be conducted on epilepsy with helpful outcomes. Additionally, through this research project, the level of knowledge and awareness, cultural and religious practices, and attitudes concerning epilepsy in local communities and ways to reduce stigma can be explored to provide the necessary information from the grassroots, which can serve as the basis for future interventions.

The speech was further supported by Ms Mashego from Epilepsy South Africa who indicated that the GladAfrica Epilepsy Research Project could not have come at a better time as there is a dire need to uproot the causes of stigma, myths and misconceptions within our rural communities. She also stressed the importance of this research and indicated that as Epilepsy SA they will provide support where necessary. Senior Professor Ekosse indicated the importance of conducting research that explores real problems within our communities and provides real-life solutions. He urged the audience to continue making strong collaborative efforts and serving the communities tirelessly. Prof. M. T. Mulaudzi gave the vote of thanks and thanked all speakers, dignitaries, guests and attendees for their participation in the GERP's launch. The project launch was concluded by the signing of the Memorandum of Agreement (MOA) between the GFT and the UNIVEN.

The GERP launch attracted multiple media interviews, which were conducted by Radio South Africa (RSA) FM, Munghana Lonene FM, Choice FM and SABC 2 (*Morning Live*). The interviews stimulated several responses from all over the country from community members, parents and caregivers, academics and professionals affected by epilepsy. The following are a few extracts of responses based on the interviews conducted after the launch through the communication media created specifically for GERP (Epilepsyresearch@gladafoundation.com):

Thanks very much for the touching interview on SABC this morning. Grew up knowing several people who are affected by this condition, and the misconception that went with it was all about spirits, witchcraft or even being the chosen one. (Community Member)

I am not a researcher nor a doctor but an individual who has an interest [in epilepsy] as I also have been affected by the lack of knowledge on the matter. (Community Member)

Community members indicated that there are myths and misconceptions related to epilepsy as it is said to be associated with spirits, witchcraft, being possessed or even being the "chosen one." It was further indicated that there is a lack of knowledge about epilepsy, which was also emphasised by the mother of a child living with epilepsy:

My son who is now 14 years was diagnosed with epilepsy (absence seizures [Petit mal seizure]). Initially, I did not understand as I had no idea what this thing was. He would have episodes where he would go blank, stare into space, blink and mumble, but he will have no idea of that. When he comes to [recovers] he will have no idea where he was and what just happened. I did not even know if I will not sound crazy when I explain

the symptoms to the doctor but fortunate enough when I took him to X hospital, the attending doctor suspected that it was this type of epilepsy [absence seizures/Petit mal seizure] and never looked at me funny. I was very grateful. I do agree that more awareness, information and support is needed, like [epilepsy] centres that [can] offer support to parents and patients in communities.

The GERP launch not only attracted parents and caregivers of people living with epilepsy and community members but also academics and professionals who feel it is about time to attend to the stigma attached to epilepsy through measures that critically enlighten the general public about the disease and provide knowledge and awareness to all. Additionally, the willingness to share what has been done already, as well as the excitement about the research project and the need to be part of this journey, was portrayed:

I was so excited to hear of the above-mentioned research [GladAfrica Epilepsy Research Project] on combating epilepsy stigma in the country from Morning Live SABC 2 News this morning [13 February 2020]. I am [a] retired [academic] and have some [research] work that I have done on epilepsy and would like to check how best I can work with you to contribute to this exciting initiative. (Retired researcher/academic)

It was clear from the discussion during the project launch, the media interviews, and the feedback from the parents and caregivers of PLWE and community members who heard about the project on the radio, watched the interviews on TV and read about it on social media that there is a need for this epilepsy research project to be conducted. The feedback also satisfactorily increased our confidence that there is strong buy-in from the parents and caregivers of PLWE, community members, community leaders, academics, healthcare professionals and healthcare auxiliaries. The GERP launch was a success and stimulated genuine interest and excitement in various stakeholders in the country, which provides the GERP team with the understanding that this is one positive step toward providing solutions to real-life challenges faced by PLWE, parents and caregivers, and the community at large.

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