

## Fighting the Stigma: Parkinson's Disease

Uganda | Lake Forest College

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<https://parkinsonssibuko.org>

### Summary

Our collaboration with the organization—Parkinson's Si Buko—focused on education, empowerment, and service. To do this, we organized and ran awareness campaigns to help provide educational materials, we helped to empower health care workers and village representatives to teach their communities about this disease, and we helped deliver medical and emotional support to those afflicted.

### Project Description

We work in a Parkinson's Disease lab on campus where we carry out research on the molecular basis of the disease. When joining the lab, we were motivated by the hope that our findings might lead to more information about the disease and possible treatments to help those suffering from this debilitating disease. However, research is a slow process, often taking years before conclusions can be made. We wanted to offer help to patients who need it most in a more tangible way.

Fortunately, in many areas around the world these patients have secure access to medication, physical therapy, and the much needed emotional support from family and friends. Despite this, there are still many regions in which this security is not guaranteed. One of these places is Uganda where there is often very little awareness about Parkinson's Disease. Instead, there is a damaging myth that the disease is caused by witchcraft. This creates stigma around the disease and discourages patients from seeking help. Additionally, those diagnosed with it often have little or no access to medication or the resources desperately needed to help them manage with the condition. Through some research on the internet, we found an organization in Uganda called *Parkinson's Si Buko* that strives to spread awareness about this disease and provide medication to those with it. We reached out and expressed interest in partnering with them as their mission deeply resonated with ours. The leader of the organization had identified an area in Uganda called Kisoro that had particularly low literacy levels and a high stigma around the disease. We organized training sessions with medical professionals in the local Village Health Centers, where a doctor with whom we had traveled explained the neuroscience behind the disease. The second part of the awareness campaign involved village health workers. These are the people within each small community in Kisoro that volunteer to look out for the health and wellbeing of those more vulnerable within that community. We taught them how to identify the symptoms of PD according to the Stanford Diagnostic Manual and encouraged those suspected to have it to seek medical attention. Initially, we had hoped to stay in Kisoro for two weeks, however, because of the fuel crisis we had to adjust our budget to accommodate the rapidly increasing travel costs. Additionally, the medications that these patients depend on are immensely expensive, and so we felt that more of our funds should be directed towards medical support.

*Parkinson's Si Buko Uganda* is supported by *Parkinson's Si Buko USA* which is another non-profit organization through which donations towards the cause are made. When we joined, the monthly donation received by the organization was \$300. In continuation of the work, we shared the link to this organization with our families and friends in the hopes of spreading it even further as a means of providing continued support for all of the work that this organization does. In addition to this, we both hope to be able to collaborate with this organization again in the future whether it be traveling there again or connecting virtually. The individuals involved in this organization will continue to provide education and patient support and hope to be able to have a greater impact in other regions besides Kisoro. In addition to this, the organization's founder was invited to speak on the impacts of this stigma at a global conference later this year.

### Reflection

We define peace as the ability for all people to have equal access to life-sustaining resources; whether it be food, shelter, or the support of their loved ones. We believe our project contributed to this by extending both educational and medical resources to the people of Kisoro who otherwise may not have had access to. In terms of short-term changes, we were able to provide medication for approximately a month to patients that had been diagnosed in addition to providing comfort and support to patients who had no one to care for them. Long term, through the medical training and workshops carried out with the medical health professionals and village health representatives in the local health centers, we were able to spread the understanding that PD is a neurodegenerative disease that has no cure but whose symptoms can be managed to live a better quality life. We also taught them how to identify symptoms of PD so that if they observed members within the community who exhibited such symptoms, they could refer them to the medical health professionals to receive the appropriate diagnosis and medication. Additionally, we taught the village representatives exercises to teach and help patients manage their symptoms as well as provided shoes to enable them to do so. By teaching community members how to understand and identify the symptoms of this disease, we have helped to empower these communities to pass down this knowledge and fight the stigma of this disease, generation after generation.

While we were working with patients and community members in Kisoro, we experienced a few challenges. Perhaps the greatest challenge was the language barrier that we experienced between our team and the community members. While we were fortunately able to get the help of a translator, certain medical terms in English did not have a direct translation, therefore some information may not have been passed on as effectively as we would have wished. This brings to light one of the major dilemmas of fighting the stigma of this disease through education: communication issues foster misunderstandings and may actually further contribute to the stigma surrounding Parkinson's Disease. We were incredibly fortunate to have translators working very closely with us so that we could ensure that we did not develop misunderstandings of this disease with the community members. An additional challenge that we discovered was the incredibly high cost of the medications these patients depended on. The lack of accessibility of this medication underlies one of the many challenges that those with this disease face every day.

Before we began this project, Parkinson's Disease was an abstract idea. It was only something that we studied in a lab and read research articles about. This project challenged all of the preconceived notions that we had about this disease and the people suffering from it. It has inspired us to continue to fight for peace and accessibility to resources. We have seen the way that the stigma and systemic obstacles around seeking treatment and education have been harming these individuals and the greater communities. Rather than seeing the world as a collection of separate countries, we need to work together as *humans* to ensure continued peace and support for those in need around the globe.

### Personal Statement

This project has challenged me to always consider the bigger picture in any research and to seek out opportunities for a more personal and tangible approach to contribute to the wellbeing of those in need (Tracey Nassuna).