Fighting for Accessible Education and Care with Parkinson’s Si Buko

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Mission

Parkinson’s Si Buko in Uganda is an organization privately founded and run with the mission to provide education about this debilitating neurodegenerative disease, Parkinson’s Disease, and remove the stigma surrounding it. In addition to this, they also strive to provide access to proper medical care and resources to those affected. As such, it will be our mission to provide support to this organization by helping organize medical camps, providing care for patients and their loved ones, organizing and facilitating awareness campaigns, and seeking out connections with other similar organizations globally.

Background

In a world where people are living longer than ever, the prevalence of debilitating neurodegenerative diseases, such as Parkinson’s, is on the rise. Globally, an estimated 9.4 million individuals were living with this disease in 2020 and each year, hundreds of thousands die from it (Maserejian, 2020). Individuals with this disease need proper treatment and long-term care to improve their quality of life. Unfortunately, there are some places around the world where a lack of proper education and funding have left those with Parkinson’s Disease alone and without the care they need. A lack of proper medical infrastructure, cultural misinterpretations, and a lack of awareness have led to the needless suffering of millions of individuals around the world. Luckily, with the help of volunteers and donations, there are many organizations that are fighting to better the lives and futures of those with this disease. One such organization, Parkinson’s Si Buko in Uganda, is working to end the stigma surrounding Parkinson’s and provide the proper care facilities for those in need.

Partnering Organization

Parkinson’s Si Buko was created in 2017 and continues to be run by Kabugo Hannington in Uganda. This organization was founded after Hannington watched his own mother suffer and unfortunately pass away from this disease. He told us the heart-wrenching story of watching his face not only the physical and mental challenges of Parkinson’s, but also the social isolation and abandonment due to the stigma surrounding this disease. In collaboration with Sherryl Klingelhofer and Gavin Mogan, both of whom have been personally affected by Parkinson’s Disease, Hannington has dedicated his life to ensuring that the suffering his mother faced is not experienced by anyone else.

As an organization, Parkinson’s Si Buko has accomplished many incredible things in the short time they’ve been established. A few of their many accomplishments include launching awareness campaigns through social media, community messaging, and taxicab banners; facilitating an awareness run (2019); organizing the first Fun Run for Parkinson’s Disease awareness and support in sub-Saharan Africa (2021); receiving national media coverage; securing dedicated hospital space exclusively for the care of Parkinson’s patients; and creating a library of books and educational resources for patient reference. Their primary initiatives are to: dispel myths/inform facts, train health care professionals, and secure access to resources for patients.

Project Details

Partnership with the Parkinson’s Si Buko organization will promote peace by providing access to education, medical treatments, and long-term changes to the way this disease is thought about. Currently, Parkinson’s Si Buko is struggling to help the many individuals seeking out desperately needed care. With a lack of funding and limited help from outside the organization, the impact Parkinson’s Si Buko can have is limited. Without additional funds, they struggle to afford the medical equipment, medications, staff, and facilities that are needed to give those suffering from Parkinson’s Disease a chance at a better and more comfortable life with this disease.

In addition to this, Parkinson’s Si Buko is also working towards the bigger picture of preventing the continued needless suffering of those with this disease. As aforementioned, one of the biggest problems that those with Parkinson’s face globally is the stigmatization of this disease. Without an understanding of the neurological basis of Parkinson’s, many cultures attribute the symptomatology to witchcraft. This misinterpretation is then passed down through generations and the problem persists. By providing accessible education, Parkinson’s Si Buko is taking the first step in the fight against the misinformed stigma surrounding this disease. As more people become educated, more resources become available to help provide the necessary treatments and more funding becomes available to research possible treatments and even cures for Parkinson’s.

Parkinson’s Disease affects millions around the globe, but certain regions experience less support than others. This problem is not simply one of a lack of funding. It is a problem deeply rooted in a lack of education due to systematic health disparities particularly in many African countries. By partnering with this organization, we hope to fight against this disparity by helping to provide the education and resources needed for the long-term battle against Parkinson’s Disease.

Project Plan & Timeline

We have personally met with Kabugo Hannington in order to better understand what this organization needs and what we would be able to help with to further contribute to their mission of peaceful education. When we met, he expressed great interest in this collaboration and we worked together to come up with several possibilities for global outreach and local educational and fundraising campaigns.

The project will occur over 6 weeks from July to August. We will be in direct collaboration with the local leaders of Parkinson’s Si Buko as well as community members and patients. Our main responsibility will be to further community education and understandings of this disease to provide a longer lasting impact on society as a whole, beyond our short time there. Additionally, we will assist medical personnel in providing patient care and companionship. As such, we will primarily be serving as volunteers and assisting with the following:

- Facilitating fundraisers and awareness campaigns; leading the community education movement
- Organizing and setting up medical camps; obtaining medications/medical supplies
- Connecting with other organizations for possible partnerships
- Maintaining and contributing to the organization’s educational resources and library on Parkinson’s

Contingencies:

While Tracey Nassuna is familiar with the region, if the current pandemic results in unexpected delays or border closures we have several contingencies in place. If simply delayed, we will either extend our time in Uganda by as many days or we will remotely continue our agreed upon collaboration. If we are unable to enter the country, we will work with Parkinson’s Si Buko remotely. This will primarily entail virtual correspondence, communicating with possible partnering organizations, remotely purchasing medications and medical equipment, and remotely organizing campaigns and fundraisers.

Biography:

Amanda Grassel and Tracey Nassuna are both Neuroscience majors who conduct neurobiological research on Parkinson’s Disease in Dr. DebBurman’s lab. Tracey is also majoring in Psychology and was a Richter Scholar in Dr. Kelley’s research lab. She was born and raised in Kampala, Uganda and is fluent in one of the region’s dominant languages--Luganda. Tracey attended UWC Eswatini and spent a semester studying abroad in the UK. Amanda is a native English speaker and has spent many hours volunteering at the local hospital and has continued searching for ways to provide support beyond the United States. She is also an intern at the Lake Forest Acute Care clinic. Amanda has shown leadership in many areas, including as co-President of the neuroscience honor society; Nu Rho Psi.

References

Maserejian, N., Vinikoor-Imler, L., and Dilley A. (2020). Estimation of the 2020 Global Population of Parkinson’s Disease (PD). MDS Abstracts.