JINJA ORGANISATION OF PARENTS WITH DEAF CHILDREN (JOPDC)

DETAILED REPORT ON THE OVERALL PERFORMANCE OF THE SIGHT RECOVERY PROJECT & EYE CAMP HELD AT RUBAGA HOSPITAL, KAMPALA

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Background

According to WHO, about 285 million people are visually impaired worldwide and one individual becomes blind in each minute and a child in each 5 minutes. The burden of visual impairment is not distributed uniformly throughout the world. About 90% of visually impaired people are living in developing countries. The poorest regions of Africa and Asia are where three quarters of the world's blind children live. Out of the 1.4 million blind children globally, about 300,000 live in Africa. The prevalence of blindness in children in a country is related to the nutritional, health, and socioeconomic status of that country.

Uganda, with a population estimated to be over 41 million and prevalence of blindness of about 1%, ophthalmology remains a neglected public health issue with limited data on the prevalence of visual impairment overall. There is approximately one ophthalmologist to a million plus of the population and one ophthalmic clinical officer to 205,000.00 of the population.

In Uganda 57.1% of blindness is caused by cataracts, while uncorrected refractive errors and trachomatous corneal opacity are the commonest cause of visual impairment. Major causes of low vision and blindness are either preventable or treatable.

Our Ministry of Health management information system indicates eye diseases as one of the top 10 causes of morbidity and Out Patients Department attendance.

Jinja Organisation of Parents with Deaf Children (JOPDC) was established in 2015 by a group of parents with deaf children. It is legally registered as a community based organisation with a mandate to operate in the whole of Jinja District.

Although it began by focusing only on children with hearing impairment, the organisation took a strategic move in 2016 to welcome all other children with different disabilities in addition to deafness like visually blind/ impaired, physically challenged, Spinabifida, cerebral palsy (CP), Intellectually disability, among others.

For this particular report I will indulge in stating that so far JOPDC has a total of four children this visual impairment (Amiru Musa at Primary School, Yudaya in lower Secondary, Rosemary currently in her final semester of High School and Yayeeri who is in her first year at the University) with visual blindness. All these children are being sponsored by Helping Uganda Schools (HUGS) UK. We are

very grateful to HUGS as it has expressed willingness to sponsor more two blind children (Ashirat for High School (Uganda Advanced Certificate of Education) and Yudaya for lower secondary Education (Uganda Certificate of Education) in 2020.

Later 2016, the management of JOPDC undertook the responsibility of conducting and assessing the real causes of blindness among these four children above.

The feedback informed management that the cause of blindness among these four children was as a result of their parents failing to take full details when their children started reporting to them that they were facing hardships in seeing and reading, taking long to take their children to health facilities for diagnosis and treatment, continued postponement to treatment from eye care professionals due to drug stock outs in government health facilities, self medication, use of herbal medicines like human urine, sheep's milk, ramming poverty among other factors.

These shocking findings prompted management of JOPDC in 2017 to take action so that some other children who were undergoing serious eye challenges can be saved from falling in trap of preventable blindness and impairment. The initial stage involved sharing these findings with one of the HUGS Trustee called Denise Elizabeth Ead (Mrs.).Denise like the JOPDC Management and staff got so much concerned with these findings prompting her to look of out the box to find a way to help the many other children we had earlier on identified and registered with eye related challenges.

The breakthrough came when her own mother (Denise's mother) took a bold decision to save all the funds she was meant to spend on celebrating her 80th birthday so that it is used to help our children undergo eye treatment/ surgeries.

It is this money and that of Denise's personal contribution that we used to organise the first eye camp in March, 2019 in which over 14 children were mobilized and invited for treatment at private facility Rana Medical Centre, Jinja. These were assessed and treated by a Volunteer Ophthalmologist of an Indian Origin called Priya Gupta (Ms).

With the complicated eye conditions that she could not manage, she could a referral system so that they can be treated in the big hospitals in Kampala like Mengo, Rubaga, Mulago Hospitals at a cost to be met by us.

In the year, 2018, Denise was able to link up with Primrose Magala (Ms), a Senior Nurse at Moorfields Eye Hospital London, UK. Primrose had started planning and conducting annual eye camps at Rubaga hospital, Kampala – Uganda in 2017. Primrose and Denise agreed to do a collaborating so that the Jinja children with visual challenges can be treated in the next annual camp 2018. The Eye camp provides care to a large patient population for various conditions including cataracts, refractive errors, glaucoma, eye infections, oncology conditions like retinoblastoma etc. Screening services for insidious eye conditions in the population like Retinopathy is also provided.

The eye camps are also being used raised awareness and advocacy for increased access to both preventative and therapeutic services in eye health care which are currently at a low scale in Uganda.

HOW ARE THE EYE CAMPS IN JINJA AND RUBAGA ARE ORGANISED BY JOPDC

Jinja Organisation of Parents with Deaf Children uses a bottom – Top approach in identifying and registering of all children with disabilities including those with visual impairment.

We routinely conduct community visits in the remote communities in Jinja and other surrounding districts to identify and register such children. Why this approach? Unlike in the developed countries, where the issues of disability is brought on the front, children with disabilities (CwDs) in Uganda are kept behind by their parents and even the community members and local leaders are not bothered to save the situation. Therefore to be able for us to get in contact with CwDs, we normally take ***a house to house approach and also taking vital tips given to us any member of the communities.***

Before HUGS funded the purchase of the one Motorcycle in 2018, were used to move on foot and sometimes we could hire a motor cycle or use public means to travel to these communities. This would result into identifying very few children because of the low coverage. Thanks to HUGS as the number of children being identified and helped to date has to a greater extent increased.

After identifying and registering the children with visual challenges, we organize them into groups of between 10 -15 for the eye camp in Rana Medical Centre in Jinja. These are invited and given the dates to come and be assessed and treated. Those who are able to be treated at this stage, are given return dates for reviews and additional treatment if required. Those with difficult and completed conditions like Glaucoma, Corneal Opacity, Cataracts, Squints, Retino Detachment, among others are put on a list for referral to Kampala for further specialized treatment and support.

The just concluded eye camp in Rubaga hospital that took place between 7th & 8th October, 2019 so 30 patients from Jinja benefit.

Of the 30 patients we took, 09 children (eight boys) were diagnosed with Cataracts and surgeries were successfully done free of charge. These were discharged the following day 8th/10/2019. Four of them were found to have cataracts in both eyes and they were from the same family. Therefore one eye for each was worked on waiting for the other in the near future if such opportunity comes around.



Two of the four children who had Cataract in both eye. Here they were out of the theater

Three patients were diagnosed with Myopia and given spectacles free of charge.

Two adults (1 female and 1 male) were found to have cataracts but because their pressure was high, they were advised to start on the treatment to manage the pressure and after which they could plan to go for the surgeries elsewhere.

One young girl was diagnosed with Retino Detachment and she was referred to Mengo hospital for surgery. The costs involved are yet to be established.




Ms. Madinah with Retino Detachment on the left being assessed by Prof. Cruz from UK

Four girls were diagnosed and referred for Contact Lens (CL) at Mulago Hospital or Rubaga hospital. The costs for these CL are yet to be established by Dr. Patel of Mulago Hospital.

One girl child (Perudasi) was found to have Corneal Opacity in the left eye according to Dr. Grace Ssali and there is a fear that this condition if left untreated may result into Intra Ocular Tumor any time which may result into danger. The doctors advised the parent to consider removing it and maybe acquire an Artificial Eye at a cost yet to be established at Rubaga Hospital.

Nine patients (6 females) were diagnosed with Conjunctivitis Allergies and they were all given eye drops to manage and treat their conditions.

Two children both boys from the same family were found to have lost sight completely in one eye each while the other eye of each had some sight. The mother was encouraged to enroll these children in a blind school as the little sight left cannot be improved.

We are so grateful to Primrose and her tire UK team for the kind care and support that our children continue to receive every year. We know that without such support these children would progress into blindness hence making them very vulnerable throughout their lives.

We are also very certain that without the financial support from Helping Uganda Schools (HUGS) UK to meet some of the inevitable expenses like lodging the parents and their children a day before the travel to Rubaga and in Kampala, Vehicle hire, and the general welfare while going and during the stay in Kampala would not have possible. Thank you HUGS Trustees for making JOPDC work easy.



The Patients being served with some soft drinks and a bit on arrive at Rubaga Hospital by JOPDC staff in a black Jacket



The patients in 36 seater vehicle being transported to Rubaga Hospital

ACHIEVEMENTS SO FAR

So far since 2017 to date a total of 164 children with eye related problems have benefited from our ***Sight Recovery Project.*** These have been treated through the eye camps held in Jinja, Referrals made to Mengo, Dr. Argawal Eye Hospital, Mulago and Rubaga Hospital the venue for Primrose's eye camps.

The common eye conditions treated in these camps include; Conjunctivitis Allergies, Cataracts, Squints, Glaucoma etc.

Four of the project beneficiaries especially the children have started formal education and those who had dropped out of school due visual challenges have rejoined the schools. All these are being funded by HUGS UK while the others their parents/ guardians are paying. It should be noted that a handful of other children have not yet got a chance to be go to school as their parents cannot afford the school requirements.

Many parents of the children who have benefited in the project have been sensitized and educated on how to take care and prevent eye related diseases in their homes and communities.

The project news has also reached distant places beyond Jinja district and this has resulted into increased number of children and adults coming to our offices to seek for help.

CHALLENGES FACING THE PROJECT

Inadequate funding to fully meet all the costs like surgeries for children and adults whose conditions cannot be handled once say during the Rubaga Eye camp. The case in point is of the four mentioned children who still will need to undergo the cataract surgeries of their other eyes and five are in dire need for corneal transplant, one for Retino Detachment. Those with corneal graft have been on the waiting list for close to three years and the situation is escalating.

High Transport costs especially where there is a need and opportunity to transport some of the children to other places for help like in Kampala hospitals. We solely depend of hiring vehicles for one or two days which is expensive for us when compared to having our own vehicle especially as the project continues to attract more beneficiaries.

Some of the surgeries require long term treatment and extremely expensive especially for the case of Corneal Transplant.

About five children who need corneal transplant have been on the waiting list for a quite a long time. There is a few that such children might completely become blind as their conditions worsens every minute that passes. Many have lost hope of being helped.

OUR HUMBLE APPEAL

We wish to scale up this life transforming project for more years. However, to enable do this, we kindly for more support in the following areas;

Increased funding to cater for the growing costs of doing the assessment and treatment/ surgeries especially for Retino Detachment, Corneal Transplant, and Contact Lens among others.

Call for any qualified Local or International Ophthalmologist/s, Optometrists Volunteers to join us so that we can continue with this amazing work of saving the sight among the most vulnerable.

Vehicle Acquisition for the project. This will lessen the challenges of hiring a vehicle/s to transport the children and their parents either to our Monthly Jinja based eye camps, make routine monitoring on the progress of who have been treated or when referrals are made for Kampala hospitals.

Funds to build our own eye care facility. This will ensure that the children are assessed and treated as soon as they are identified and registered by the staff/ volunteers. The current model of mobilizing a certain number of (10 -15) is good

but its major setback is that it keeps many children waiting as the eye clinic is determined by the availability of the Ophthalmologist at Rana Medical Centre

There is need for financial support to help those children who have been confirmed as blind with school fees and other school requirements in the specialized blind schools. Such schools are few in the country and the charges are relatively high for an ordinary and peasant parents/ guardians.

Thank you once again for reading this report and choosing to support us in this Noble cause.

Sebastian Waiswa,

Executive Director,

Jinja Organisation of Parents with Deaf Children (JOPDC)