



## UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY



### COMMEMORATION OF WORLD CEREBRAL PALSY DAY HELD ON 5<sup>TH</sup> /10/2019 BUKEERERE PLAY GROUND –GOMA DIVISION MUKONO DISTRICT REPORT

## **1.0 Introduction:**

UNAC is a non-governmental organization established in 2013 to advocate for the rights of people with Cerebral palsy (CP). The organization was established by a group of people with Cerebral palsy after realizing that their rights were being violated and not respected from the government communities and not benefiting from mainstream NGOs programs.

World Cerebral Palsy Day is a movement of people with cerebral palsy and their families, and the organisations that support them, in more than 65 countries. The purpose of this event is to ensure that children and adults with cerebral palsy (CP) have the same rights, access and opportunities as anyone else in our society. It is only together, that we can make that happen.

Cerebral palsy is the most common physical disability in childhood. It affects 17 million people globally and 350 million family members and caretakers.

On the 5<sup>th</sup>, October 2019 UNAC joined the rest of the world to commemorate the cerebral palsy day aimed at raising awareness about cerebral palsy as well as create an enabling environment for Persons with CP to participate “In inclusive development and decision making process at all levels”, and share their concerns as citizens of the country, reflections on achievements and existing gap in improving the living standards persons with cerebral palsy. This year’s celebration was guided by the theme “**Let’s Move As One**”.

The climax of world cerebral palsy day started with a marching band in Bukeerere trading centre and coverage communities of Namasiga village up to Bukeerere Playground. After the Uganda national anthem and traditional Buganda anthem were sung.

## **2.0 Purpose of the world CP-day cerebation.**

The main aim of the commemoration world CP day is to raise awareness on key concerns of persons living with cerebral palsy disability and show case on organisation achievements, share the existing gaps and best practices which will help to contribute to the creation of an enabling environment that will allow persons with cerebral palsy enjoy productive lives like any other citizen in the country.

## **2.1 Appreciation**

UNAC would like to appreciate the following Partners and stakeholders for the generous contribution support towards our commemoration of world CP day. This include; Katalamwa Cheshire Home, Spastiker, Heart Extended Uganda, Motivation Charitable trust, COMBRA , and the media fraternity (Bukedde TV, NBS TV and Dream TV, Mama FM Radio).

UNAC appreciate the massive turn up of over 250 people including; persons with cerebral palsy, parents/caretakers of children with cerebral palsy, Partners (DHF staff), Heart Extended staff, UNAC Board members, Pupils and teachers of St. Charles Lwanga primary school, Local leaders in Goma Division, Police security of Uganda and religious leaders for honoring invitation and turned up in big number to join UNAC in the commemoration of world CP day.

## **2.2 Special Remarks from invited guests.**

### **2.2.1 Opening Remarks from LCI Bukeerere (Namasiga village)**

The chairman LCI opened the celebration of world cerebral palsy by recognizing the presence of the distinguished guests, Parents of children with cerebral palsy and all protocols. He thanked all partners, UNAC for the mobilization and supporting service given to persons with Cerebral palsy especially in Goma communities and country at large. The chairman thanked St. Charles Lwanga primary school administration for offering a free space to construct the inclusive Day care centre for children with disabilities and encourage parents of children with disabilities Bukeerere and Mukono to take up this opportunity and bring their children in the day care centre after accomplishment of the construction. The man mentioned that parents should make birth day parties for their children as a sign of parental love and care, enjoyment of their equal rights as citizens of this country. Therefore informed them to take their children for measles vaccination on 6<sup>th</sup>, October 2019 at Mukono Health centre V.

Finally he thanked UNAC and Katalemwa Cheshire home for making a name and commemorate the world cerebral palsy in Bukeerere.

### **2.2.2 Community Development Officer Goma Division. (Madam Caroline)**

The CDO started by recognizing the presence of all protocols, parents of children with cerebral palsy and thanking UNAC for the great work it has done in the communities surrounding Goma Division, Mukono Municipality and other parts of the country in changing the lives of persons with cerebral palsy. Furthermore thank parents of children with cerebral palsy for taking good care and supporting them.

She mentioned on the available government opportunities at Goma Division which persons with cerebral palsy and parents/care takers can apply for and be supported through group formation in their communities; these include Youth livelihood, Women Entrepreneurship Fund and encouraged parents of children with cerebral palsy to form or join other formed group so that they can benefit from these grants. For example Lulemu group and Jogo groups received the Community Development grant (CDD-grant) this year. However she gave a challenge that most parents don't want to form groups or apply for these grants for instance she worked with one of UNAC board Vice chairperson in advising parents in communities surrounding Goma division but only a few groups were formed. The office of CDO is working together with Town clerk to ensure the government building facilities are accessible for instance National Union of Disabled persons of Uganda (NUDIPU) visited Goma Division and advised us to construct ramps on our office premises and modify the current ramp at entrance of Sub-county hall because it was high. She also highlighted that the issue of negative attitude in communities and health service centres has reduced compared in the last years. And Goma division has supported a number of persons with disabilities through giving the assistive devices like wheel chairs and crutches. She also appreciated Abimanya centre in Seeta (a child centre) which works with a medical team from Mulago hospital to give support to Children with CP. Also thanked the social workers (Madam Rose and Shilah) in Bukeerere community and Goma division who provide services to persons with disabilities. Final she took honor to commission the construction of UNAC inclusive Day care Centre) at St. Charles Lwanga primary school.

### **2.2.3 Relevant achievements of UNAC extracted from Chairman Board Remarks (Mr. Kalule Rashid)**

1. Increased number of UNAC membership from (500 to 850) people through mobilization and group formation of Parent support groups and registered number of Association of persons with cerebral palsy both national and local structures. With 75% (Percent) being children with cerebral palsy.
2. Building the capacities of UNAC leaders of persons with cerebral palsy in the local structures through leadership trainings and mentorship programs and this has increased UNAC membership in the local structures.
3. UNAC has been able to promote inclusive education for learners with cerebral palsy in and round Mukono and we thank all school teachers, parents, local leaders who participated in promoting inclusive education for learners with cerebral palsy.
4. Increased Partners and a funding opportunities. Many partners have come on board to support our organisations programs.
5. With support from our dear partners, UNAC has been to train over 100 Parents/caregiver in homebased rehabilitation basic skills in physiotherapy to reduce the burden of parents from travelling long distances in accessing rehabilitative services in the referral centre.
6. UNAC has held a number awareness and sensitization programs in Radios, TV-talk shows and community out reaches. This is to introduce the concept of cerebral palsy and raise the concern needs and the rights of persons with Cerebral palsy and their caretakers.
7. Increased networking and partnership with different supportive agencies. This has enabled us to run activities of our organisation.
8. Increased Human Resource labour to run day to day programs of our organisation work at the secretariat.

Despite the above achievements UNAC still faces a number of challenges of ensuring effective management of the organisation so that the voices of persons with CP are effectively respected.

1. In Uganda the rights, responsibilities and potential needs of persons with cerebral palsy is still not recognised at national and local levels
2. Persons with cerebral palsy have found it had to penetrate into employment opportunities due to severity of disability and negative attitudes by employers.
3. There is more demand on the issue of health improvement to children with cerebral palsy especially in areas of nutrition, Feeding the children, physiotherapy and psychosocial support.
4. There is increased number of children with Cerebral palsy school dropout due to lack of reasonable accommodation given to them. And most teachers needs sensitization on the needs of children with cerebral palsy while at school.
5. Lack of supportive assistive devices like wheel chairs to support the mobility of persons with Cerebral palsy.
6. Expensive treatment services for persons with cerebral palsy that is physiotherapy and drugs in hospitals and most of parents/caregivers live extreme poverty especially mothers.
7. Lack of access to better health services or inadequate quality of health services provide for children. There few medical personnel in most of health centres who understands proper medication and rehabilitative service needs for persons with cerebral palsy disability.

8. Person with cerebral palsy are among the people who live under the poverty line at grass root and isolated in economic development activities in Uganda.
9. Inadequate resource to strengthen the work of secretariat towards improving the livelihood of persons with cerebral palsy at national and regional levels.

### 3.0 Proceedings of event celebration in pictorial and message information.



Preparing for the match to raise awareness on cerebral palsy day at Bukeerere



The Chairman UNAC Board and Executive Director lead the delegation on the match



Massive turn up as Parents/caretakers of persons with CP joins the commemoration of world Cerebral palsy #CreateAwarenessCp.



Children with Cerebral palsy day having fun on celebration the CP day in a Picture



UNAC Partners from Katalamwa Cheshire Home giving Remarks. Promised to build stronger partnership and provide more support on child empowerment program with UNAC.



The Media moments with Mutabazi Ali (Youth leader with Cerebral palsy)



Executive Director delivering her speech on the world Cerebral palsy, Argues Parents not to give up “You are our Heros”



**Namuga Ashman**(Youth with CP): Advices parents to give hand support to children with Cerebral palsy “Please stop keeping child with Cerebral palsy inside house”



Katalamwa Cheshire Home children and their caretakers arrived to join the commemoration of world Cerebral palsy day.



Children with CP showing their abilities in a play game.





Pupils of St. Charles Lwanga primary school lead the marching Band.



Massive turn up as Parents/caretakers join the commemoration of world cerebral palsy #CreatAwarenessCP. “Let’s Move As One”.



Community Development Officer (CDO) at the Centre with Executive Director and UNAC Board members commissioning the construction of UNAC inclusive Day care centre for children with disabilities at St.Charles Lwanga Primary school during the commemoration of world CP-day.



UNAC advisory technical Board and Chairman Board putting a brick on the construction site of UNAC inclusive Day care centre as Executive director, CDO and Parents sees.

#### **4.0 Conclusion.**

Without different people UNAC can't achieve its objectives. Therefore UNAC acknowledge all its members, partners, Local leaders from Goma Division, different development actors and journalists from media houses with all your commitment to join us in commemoration of world CP day. Therefore we encourage more of your contribution support in all kind of form to mainstream and support inclusion interventions for persons with Cerebral palsy.