

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY CELEBRATIONS

2014.

Juliana's Speech.

The chief guest Hon. Mercy Kamau, County executive member for health, County director public health, Dr. Lucy Musyoka, County health management team, distinguished guests, ladies and gentlemen, boys and girls. All protocols observed. Good morning, God is good all the time and all the time God is good and He remains good.

My name is Juliana, mother of two, my son Joshua is 3 and my daughter Phoebe is 19 turning 20 November 1st. Phoebe is the reason I am here today. My Phoebe was born with Spina bifida and Hydrocephalus and when she was born I was told her head is full of water she doesn't have a brain and that she will not live to celebrate her first birthday. Very cruel words for a young first time mum. These words killed my hope, the little hope I had in my Phoebe growing up and in me enjoying motherhood as I was just a new young mum to a beautiful daughter. My Phoebe has grown to a beautiful young lady who is helping us at our SHAK parent's guesthouse Kijabe where we accommodate parents as they come from or to Bethany Kids for medical care. My Phoebe has undergone 9 major surgical procedures and we thank God for her life.

But as I said earlier God is good and since He remains good, today 25th October we celebrate our children and persons living with Spina Bifida and Hydrocephalus. We celebrate the parents, caregivers, family, friends, teachers and all service providers as we mark the 3rd international day for spina bifida and hydrocephalus. We can never overlook the efforts; courage and sacrifice of our dear parents who have fought to ensure their children undergo surgical care, rehabilitation, therapy, bowel and bladder training, attend school and grow up to be very useful persons in our society. It is this effort that gave birth to SHAK a parent support group that seeks to give hope to like parents and advocate for the rights of these very dear children with very special abilities as we have seen and heard from our Joytown school choir.

It is in this regard madam minister that we (parents) uphold the efforts of our partners specifically GAIN – Global Alliance for Improved Nutrition and the ministry of health in their quest to ensure our nutritional needs are met through mandatory fortification. Your Excellency it is our humble yet very honest appeal that all staple foods be fortified with the right amounts of iron and folic acid to ensure we see a major decline in the number of children born with these conditions. Bringing up a child with spina bifida and or hydrocephalus is very expensive because sadly disability is associated with poverty in our society.

We (parents) also call upon the county government, public health department to ensure all health workers at community level (country wide), are sensitized on the causes, primary prevention and early intervention of these neural tube conditions. Spina bifida can be prevented by 78% due to regular intake of folic acid by women of childbearing age. Unfortunately, women me included attend

clinic when they already know they are pregnant which is a little too late because spina bifida occurs 21 days after conception, note that the neural tube closes on the 28th day after conception. After this day we cannot do much to prevent spina bifida.

In a bid to ensure early intervention is achieved, madam minister we request your good office to ensure that children with these conditions are treated early in their lives. With early treatment our children have a good survival chance and can compete with fellow able or normal children. We therefore request your good office to allocate us land where we can build a holistic center for our children. A center where they can access specialized surgical healthcare, rehabilitation, education, vocational training and life skills all in one unit. A van would be and is a necessity due to the barriers in our transport system. Our education system and curriculum should be reviewed to suit and accommodate our children with spinabifida who have to wash their hands every 3 hourly due to lack of bladder function. Our children have to empty their bladder every 3 hourly using a disposable catheter. Our children waste a lot of time yet we only have 40 minutes per lesson in a regular school timetable, I am glad am addressing teachers and policy makers who are in attendance.

Collectively we can do so much and this world will be a better place for each one of us. Just as the cathedral under the guidance of Rev. Ikucha has embraced us and shown us their love in action, we are requesting the county government to follow suit and always keep us close to their hearts as they formulate policies touching on our lives and those of our very dear children with spina bifida and hydrocephalus.

Sensitization and capacity building are both very key, we want to see a Kenya whereby all district, general and referral hospitals are able to handle these cases and we do not want to depend entirely on Kijabe's Bethany Kids for all neurological surgeries. It will be a great relief and joy when a family is able to access specialized healthcare at their community level.

With those few remarks I want to thank for you this partnership and we hope and pray that it gives our parents and children at SHAK a brighter future full of hope. Thank you and God bless you all.