

# Fighting disease with education

**Diana Dodds** explains why education and awareness are the most effective tools for preventing diseases like spina bifida

**T**he first official 'World spina bifida and hydrocephalus day will be on 25 October 2012 and I am honoured to be a patron of this momentous global event.

For over two decades, I have been heavily involved in campaigning to prevent spina bifida and hydrocephalus and supporting families who have been affected by these conditions.

My interest in this issue arises not only through my role in politics but also through my own personal experience.

In 1989, I fell pregnant with my second child. I had a healthy, normal pregnancy and therefore when my son Andrew was born we were shocked to learn he had spina bifida and hydrocephalus.

Spina Bifida is a birth defect caused by a fault in the development of the spinal cord within the first 28 days of pregnancy, each case differing in severity from the next.

Needless to say my family and I were initially devastated by this diagnosis, and having a limited knowledge of the condition we worried about the impact on Andrew's quality of life. Would he be able to play in the park with other children? Would he be able to go to the local primary school? Would he have the opportunity to see the world?

Over the years, I learned that the answer to all these questions was yes. Although Andrew was confined to a wheelchair

it did not stop him from playing (and fighting) with his older brother, travelling to various places across the globe with his family and eventually going to a local primary school with all his childhood friends.

Andrew never once let his disability define him. As a child he was extreme-

ly bright, funny and mischievous. As his mother, I felt it was my role to make sure he availed of every opportunity open to any other child of his age.

I am proud to say that Andrew was able to do the majority of things his peers could do, even if he had to do them in a slightly different way.

There are many children who are born with spina bifida and hydrocephalus who go on to lead extremely full and happy adult lives in spite of their condition. Unfortunately my own story did not end that way. After a short illness Andrew sadly passed away in 1998. He was nine years old.

I feel extremely blessed and grateful to have had such a wonderful, independent, loving and outgoing son who enriched my life so immeasurably.

In Europe today it is estimated that every year there are more than 4,500 pregnancies affected by a neural tube defect such as spina bifida.

Therefore, it is vitally important that we educate women on the importance of taking folic acid. In the United Kingdom alone up to 72 per cent of these defects could be prevented through women taking folic acid at the right time, ideally three months prior to pregnancy, and at the correct dosage.

Although women are becoming more aware of the benefits of folic acid, approximately half of all pregnancies across

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Europe are unplanned and therefore such pre-conceptual medical advice is rendered ineffective.

In response in part to this statistic, over 70 countries practice mandatory folic acid fortification of flour. However, no European country has implemented this mandatory practice of fortification.

The United Kingdom, the Irish Republic and the Netherlands are currently considering doing so following recommendations by their national expert committees.

Whilst raising awareness of prevention of spina bifida and hydrocephalus is a key priority, policy makers also need to take into consideration those who are currently living and aging with spina bifida across the EU.

In my own constituency of Northern Ireland there are those with spina bifida and other neural tube defects living into their sixties and seventies. However, in most member states appropriate policies and measures are not in place to help those who live past childhood.

We must do all in our power to ensure that adults and children across the EU suffering from spina bifida and hydrocephalus, or any other form of impairment, have equal access to the correct treatment and care services.

Through my own experiences of having a child who was born with spina bifida, and caring for him throughout his life, I have been given a rare insight into this condition.

It is my hope that 'World spina bifida and hydrocephalus day' will give us the opportunity to highlight all of these issues and hopefully to provide a better understanding and insight into the lives of those who are born with these conditions. ★

Diane Dodds is a non-attached member of the European parliament

# Unfolding potential

Despite improvements, many people with spina bifida and hydrocephalus still face significant challenges, writes **Pierre Mertens**

**T**he first 'World spina bifida and hydrocephalus day' will be celebrated on 25 October 2012 under the theme, 'Unfold their potential, (y)our return on investment'. The main event is a photography exhibition organised by the international federation for spina bifida and hydrocephalus (IF) and its member associations in collaboration with Northern Irish MEP Diane Dodds. The exhibition takes place from 22-25 October 2012 in the European parliament in Strasbourg.

The first world spina bifida and hydrocephalus day and the exhibition show the dedication, courage and hard work of people with spina bifida and hydrocephalus (SB-H), their families, doctors, friends and associations, fighting everyday for the rights of people with SB-H. The events aim to shape political agendas to promote accessible healthcare, social inclusion and participation in the labour force for people with these disabilities.

While medical and healthcare advances have greatly improved the lives of people with SB-H, there are still significant chal-

lenges and issues that must be tackled. Many children and adults living with SB-H don't have access to the right treatment and care services. The situation is worse once a person with complex needs turns 18. Hardly any coordinated health care for adults is available, putting a huge burden on these individuals. Stigma and discrimination remain a reality in many countries even within the European Union, which create obstacles in access to healthcare, education and employment.

The exhibition 'Unfold their potential, (y)our return on investment' aims to deliver powerful worldwide messages. The right to proper health care and treatments for children with SB-H should be respected. Newborns with SB-H will grow into children who have the same aspirations for their lives as other children do. Children with these disabilities need proper treatment to preserve their chances of ever having a meaningful life.

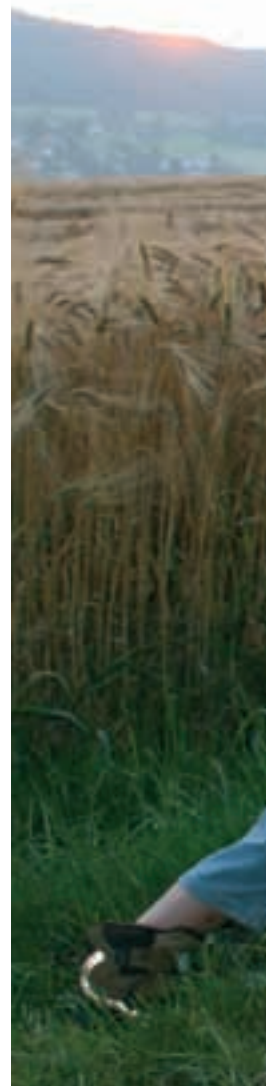
In most cases, treatment can be made easily available. We should never see images of small children with enormous heads, or children who become blind and intellectually impaired and eventually die due to the accumulation of cerebrospinal fluid in their brains. Unfortunately there are still such children all over the world and even in some parts of the European Union. Children with SB-H have the right to proper healthcare and to be treated in line with the best knowledge and expertise available.

Adults with SB-H should be provided with specialised and comprehensive healthcare. The vast knowledge and experience of professionals working with

**Ambrose - Spina bifida coordinator for western Uganda, checks on the progress of justice, a nine-month old girl with spina bifida who was abandoned by her mother**



*"Many people with spina bifida and/or hydrocephalus fear that potential employers struggle to see beyond their disability"*





children with SB-H need to be developed into coordinated and holistic health services for adults. Adults with SB-H often find that appropriate multidisciplinary healthcare is not available and they have to bear the additional costs necessary for their basic health. In 2012, only a small number of countries worldwide offer adults with SB-H the multidisciplinary care necessary for the maintenance of health.

Workplaces need to be disability-friendly to facilitate participation in the labour force and independent living. Many people with SB-H fear that potential employers struggle to see beyond their disability, putting them at a disadvantage when applying for work. They face difficulties in finding and maintaining work, a situation which is exacerbated as they grow older. There is a huge need for a cultural change towards disability friendly measures in the workplace.

Accessibility, both in the workplace and in getting to

and from work remains a priority. People with SB-H have the right to perform a job that caters to their specific needs, to live independently and make autonomous decisions concerning their lives.

The aim of our member's pictures at the exhibition show that people with SB-H can have fulfilled and active lives if society invests in them. Governments have committed to this investment by ratifying the United Nations convention on the rights of persons with disabilities. Now they should respect this commitment. ★

#### Spina bifida:

Spina bifida is one of the most common birth defects, and occurs within the first 28 days of pregnancy. The spinal column does not develop properly, resulting in varying degrees of permanent damage to the spinal cord and nervous system. The estimated incidence of spina bifida is one in 1000 people worldwide, with certain populations having a significantly greater risk. Approximately, two-thirds of people with spina bifida develop hydrocephalus.

Primary prevention of spina bifida with folic acid:

Over 70 per cent of pregnancies affected with spina bifida can be prevented if women of child bearing age take 0.4 mg of folic acid (vitamin B9) per day two months before conception and during the first three months of pregnancy. Despite this existing knowledge prevalence still remains too high. Governments need to ensure national recommendations on folic acid intake to prevent spina bifida are updated and that their implementation by healthcare professionals is monitored.

#### Hydrocephalus:

The primary characteristic of hydrocephalus is an excessive accumulation of cerebrospinal fluid in the brain resulting in an abnormal dilation of the ventricles and causing potentially harmful pressure on brain tissue. Hydrocephalus is treated surgically either by the insertion of a shunt or by an endoscopic third ventriculostomy which creates a natural bypass for the cerebrospinal fluid. The estimated incidence of Hydrocephalus is one in 500 newborns.

Pierre Mertens is president of the spina bifida and hydrocephalus international federation