this is a small story about life and death

[unfortunately, it's not a fairy tale]

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FOREWORD

Newborns with Spina Bifida or Hydrocephalus are children with similar life aspirations as any other child A child who developed Hydrocephalus needs proper treatment to preserve chances for a meaningful life. As treatment is easily available, we should never see images of small children with enormous heads, children who have become blind and intellectually impaired due to this accumulation of fluid in their heads; children who suffer terrible pain before they die a slow, excruciating death.

But unfortunately there still are such children, even in some places in Europe.

If timely and adequate treatment is provided for them, children born with Spina Bifida and Hydrocephalus may still have to cope with a lifelong disability, but they can generally have normal intellectual development and a full, active life. That makes for a huge difference in ethical terms. The suffering of untreated children is entirely preventable, and the solution is well within the technical and financial means of all European countries.

This is not, however, just a question of ethics; it is also a question of rights. In Article 10 of the new UN Convention on the Rights of Persons with Disabilities "States Parties reaffirm that every human being has the inherent right to life, and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others". Further, Article 25 lays down that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disabilities. As the individual countries embark upon ratification of this Convention, they should not see it as a mere legal exercise, but as a powerful impetus to change realities on the ground. The lack of treatment for children with Spina Bifida and Hydrocephalus in some countries is certainly among those issues where change is needed most urgently.

Jan Jařab
Regional Representative for Europe
of the United Nations High Commissioner for Human Rights

ONCE UPON A TIME IN THE WOMB…

Once there was an embryo. It was in the first few weeks of pregnancy, **BEFORE THE MOTHER EVEN KNEW SHE WAS GOING TO HAVE A BABY.**

The spine of the embryo did not develop into a closed tube as it should and when this happened, a sac of fluid came through an opening in the baby's back. As happens very often in such cases, a part of the spinal cord was contained in this sac and became damaged.

This malformation is called **SPINA BIFIDA.**
A related and often accompanying developmental disorder is **HYDROCEPHALUS.** It occurs when fluid accumulates in the head, creating potentially harmful pressure on the brain.

VERY FREQUENT & LITTLE KNOWN

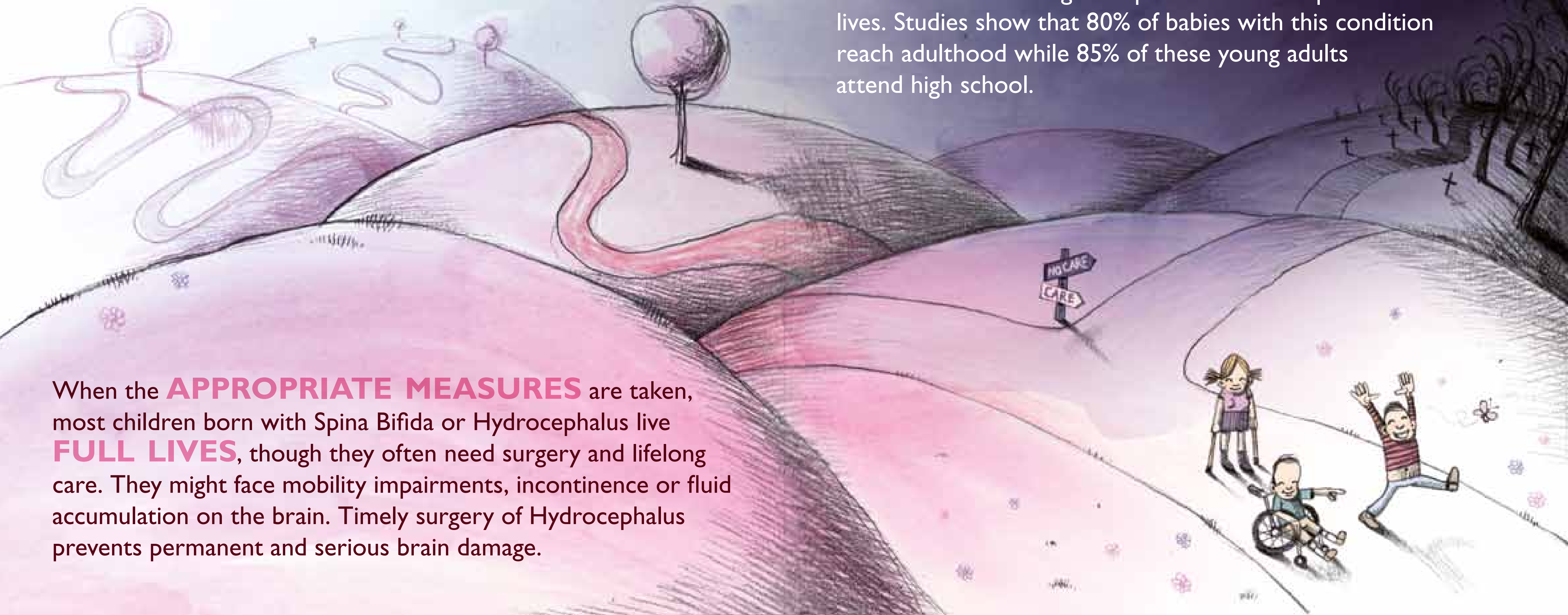
SPINA BIFIDA & HYDROCEPHALUS are no phantasmagorical dragons in a fairy tale. They are real and found throughout the world.

They are two of the most common, permanently disabling birth defects in the world. Worldwide, **ONE IN A THOUSAND BABIES** is born with Spina Bifida. Another one in a thousand develops Hydrocephalus. Without preventive measures, they affect 2 in every 1000 newborns.

In some countries this natural phenomenon remains unseen as people with these conditions are **HIDDEN IN STIGMA** and often die in pain and solitude.

A LONG AND WINDING ROAD

Not all these children have the same needs. Some children have problems that are much more severe than others. Even so, with the right **CARE**, most of these children will grow up to lead full and productive lives. Studies show that 80% of babies with this condition reach adulthood while 85% of these young adults attend high school.



When the **APPROPRIATE MEASURES** are taken, most children born with Spina Bifida or Hydrocephalus live **FULL LIVES**, though they often need surgery and lifelong care. They might face mobility impairments, incontinence or fluid accumulation on the brain. Timely surgery of Hydrocephalus prevents permanent and serious brain damage.

ALEXANDRA, SWEDEN

Eight years ago, Alexandra was born with Spina Bifida. After some surgery and the appropriate care, she walks or wheels (depending on her mood) to the school in the neighbourhood.

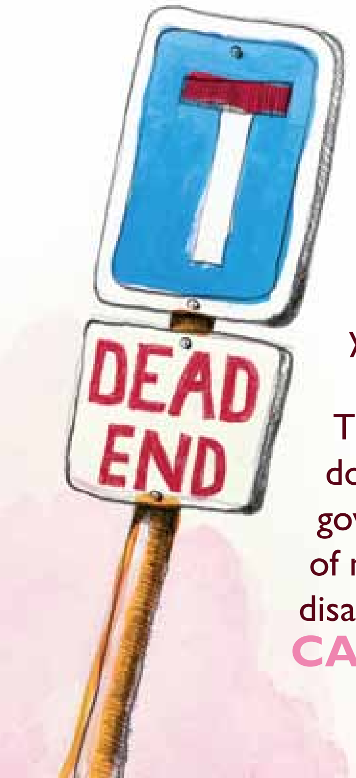
When she was born her mother had many worries, not knowing how it would be to raise a child with a disability. Thanks to the Spina Bifida and Hydrocephalus-network and the excellent facilities provided by the state, she now knows that although Spina Bifida will not go away, **EVERYTHING IS STILL POSSIBLE**, albeit in different ways.

SIMON, KENYA

Two hours walking took Simon's mother and her newborn son with this strange open back from their Masai village to the bus that brought them to the hospital. There Simon was helped surgically. He was lucky that his parents got in contact with the IF project in the nearby town.

The social worker there is now taking care of repairing his wheelchair. Simon is scheduled for continence training and his father will get the necessary support to pay the school fees. **SIMON DREAMS** of becoming an engineer or a doctor.

WHERE THE TALE TURNS SOUR



In many countries in **EASTERN EUROPE** parents of a child with Spina Bifida and/or Hydrocephalus lack access to information and care. They are faced with outdated knowledge and policies, prejudice and a lack of facilities, equipment and supplies.

It seems that the right to treatment of children with a disability - and specifically with Spina Bifida or Hydrocephalus - doesn't yet exist.

The adoption of international conventions doesn't mean anything if it isn't followed by government actions. The result is a sad story of neglect, pain and stigma, turning people with disabilities into outcasts **IN NEED OF CARE.**

ANDREÏ, ROMANIA

Andreï was born prematurely. He got meningitis which developed into Hydrocephalus. In Romania **NOBODY WOULD HELP HIM** though his desperate parents tried everything they could think of. Not even the Red Cross was able to help. By sheer luck they met a woman who helped them to get the crucial medical care in Vienna. The Viennese City Council paid for the operation and follow-up. Andreï is now a bright ten-year-old who is doing very well at school.

Andreï has been extremely lucky. In Romania, each year an estimated 600 children are born with Spina Bifida and Hydrocephalus. Many become blind because of **LACK OF TREATMENT OR CARE** or are left dying from infections, neglect and complications. The Romanian authorities keep the exact figures secret and hide the problem behind closed doors.

For a detailed story of these children's' lives, see: ***www.ifglobal.org/story***.

A DIAGNOSIS SHOULDN'T BE A DEATH SENTENCE

Old-fashioned opinions on the prognosis and the fate of people born with Spina Bifida or Hydrocephalus deprive them of their **RIGHT TO TREATMENT**, their right to a worthy life. Still, the proof is there that with the dedicated efforts at the right places in the command chain of medical and social care, so much can be done. If not, chances are high that in many eastern European countries the end result will be high tech for a few and no care for most, while **UNIVERSAL LOW TECH** but **HIGH CARE** is within realistic reach. The active involvement of persons with disabilities and the empowerment of parents is the single most effective and efficient method to plan the strategies and policies that in the end will be affecting their lives in the first place. IF has shown that it can work south of the Sahel, why wouldn't it work east of the Oder?

ONLY ACTION CAN BRING THIS TALE TO A HAPPY END

International human rights instruments set the standards for legal and humane medical treatment recommendations for all people. Giving parents accurate multi-disciplinary information about the medical, social and life prospects of their newborn child in a non-directive and non-judgmental manner costs little and goes a long way to attain those goals.

Stereotyped negative judgments about the worthlessness of life with a disability steer too many of our opinions, habits and regulations. With an open mind, small but dedicated budgets and back-to-basics tactics, people with Spina Bifida and Hydrocephalus may **LIVE HAPPILY EVER AFTER.**

KNOWLEDGE IS THE KEY TO CHANGE.

Knowledge turns people with Spina Bifida and Hydrocephalus, their next of kin, their carers and all professionals involved, into full partners in decision-making. Knowledge is the only low budget tool that can achieve so much. The knowledge network of IF connects all people involved into a global network.

More information is only one mouse click away on
WWW.IFGLOBAL.ORG.

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The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA and EU candidate and pre-candidate countries.

To that effect, PROGRESS purports at:

- providing analysis and policy advice on employment, social solidarity and gender equality policy areas;
- monitoring and reporting on the implementation of EU legislation and policies in employment, social solidarity and gender equality policy areas;
- promoting policy transfer, learning and support among Member States on EU objectives and priorities;
- and relaying the views of the stakeholders and society at large.

European Commission
Directorate-General Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3

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