

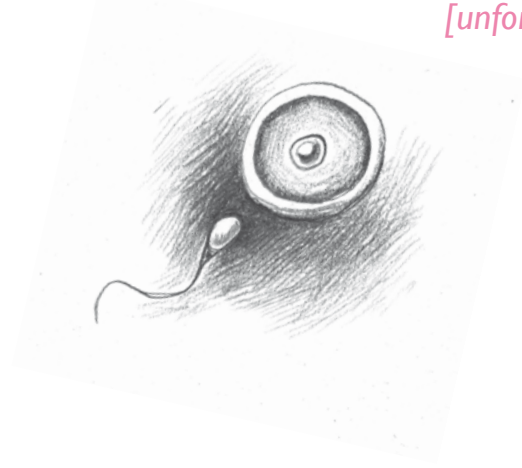


this is a small story
about life and death

[unfortunately, it's not a fairy tale]

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IT ALL BEGINS IN THE WOMB.

It occurs within the first few weeks of pregnancy, **OFTEN BEFORE A WOMAN KNOWS SHE IS PREGNANT.**

It happens when the spine and back bones of the little embryo do not close as they should. When this happens, a sac of fluid comes through an opening in the baby's back. Much of the time, part of the spinal nerves are in this sac and they are damaged.

This malformation is called **SPINA BIFIDA.** A related and often concomitant developmental disorder is **HYDROCEPHALUS** when fluid accumulates in the head.

VERY FREQUENT & LITTLE KNOWN

SPINA BIFIDA & HYDROCEPHALUS are no phantasmagorical dragons in a fairy tale. They are real and huge. They are two of the most common, permanently disabling birth defects in the world.

Worldwide, **ONE IN THOUSAND BABIES** is born with Spina Bifida. Another one in thousand suffers from Hydrocephalus. The two together account for 2 in every 1000 newborns.

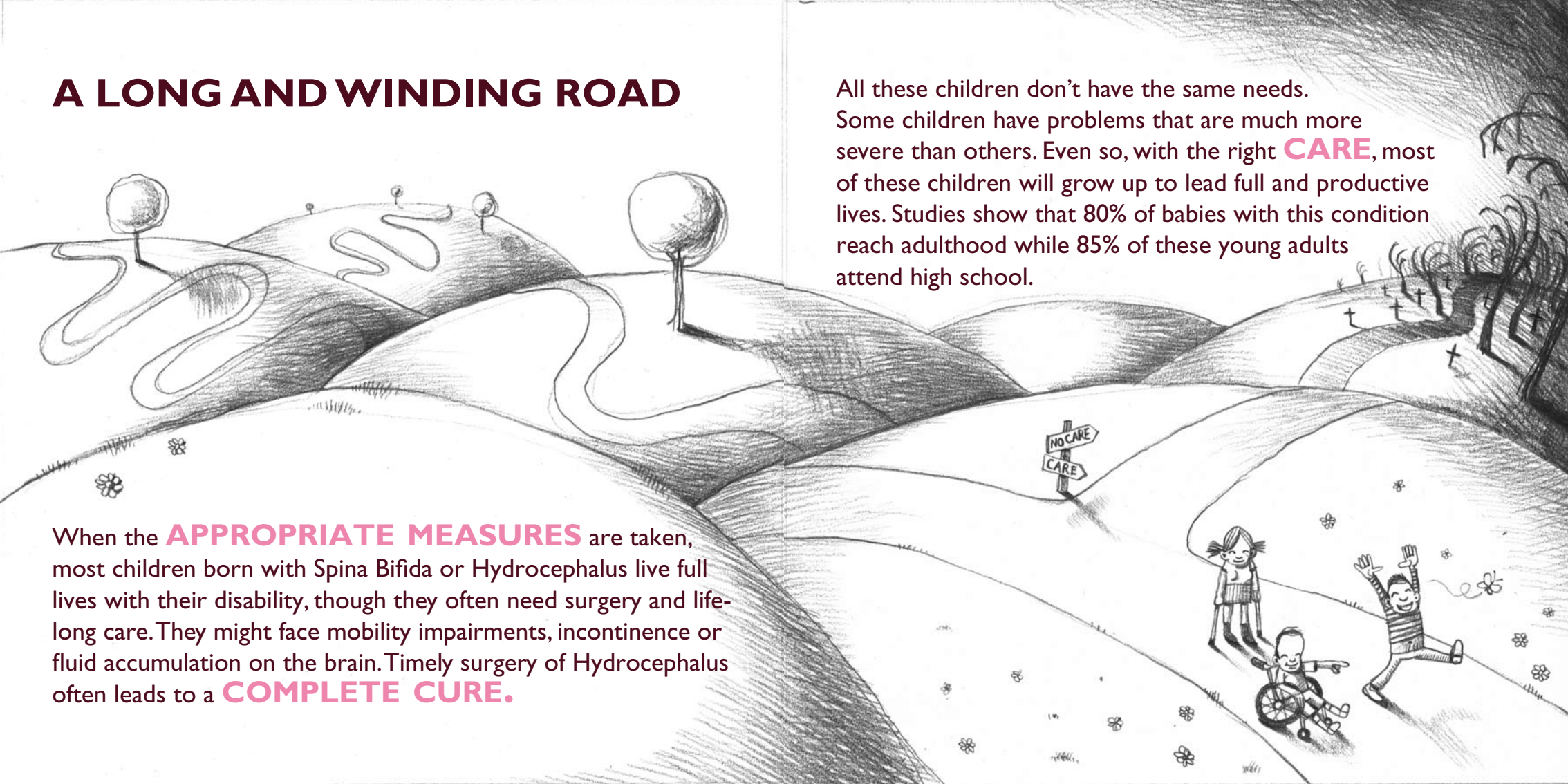
For many reasons this natural phenomenon may disappear from view, unseen because the patients are **HIDDEN IN STIGMA** and often die in pain and solitude.



A LONG AND WINDING ROAD

All these children don't 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 with their disability, though they often need surgery and life-long care. They might face mobility impairments, incontinence or fluid accumulation on the brain. Timely surgery of Hydrocephalus often leads to a **COMPLETE CURE**.





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 did have many worries, not knowing how it would be to raise a child with a handicap. Thanks to the Spina Bifida & Hydrocephalus-network and the excellent facilities provided by the state, she now knows that Spina Bifida cannot be undone, but that **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.



THE TALE TURNS SOUR IN ROMANIA

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 They are faced with outdated and prejudiced knowledge and policies and a lack of facilities, equipment or supplies.

So, it sounds as if the right to treatment of children and adults with a disability - and specifically for Spina Bifida or Hydrocephalus - has never existed.

The signing of international conventions doesn't mean a thing if it ain't got turned into real life commitments. The result is a dour story of neglect, pain en stigma, turning people into outcast patients **IN NEED OF CARE.**



ANDREÏ, ROMANIA

Andreï was born prematurely. He got meningitis which developed into Hydrocephalus. In Romania **NOBODY COULD 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 getting the crucial medical care in Vienna. The Viennese city council covered the costs of the operation and the 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 some 600 children are estimated to be born with Spina Bifida and another 600 with Hydrocephalus who 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 and therefore the problem behind closed doors.



For a detailed story of these children's' lives, see: [website](#).

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 cost little and go 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 & Hydrocephalus may **LIVE HAPPY 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 do so much. The knowledge network of the IF connects all people involved into a global network. A user driven database is only one mouse click away on

WWW.IFGLOBAL.ORG

meer info (sites etc)

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