



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA AND HYDROCEPHALUS



**UNFOLD  
THEIR  
POTENTIAL  
*(Y)OUR*  
RETURN ON  
INVESTMENT**



# 5

## BACKGROUND

To mark the first World Spina Bifida and Hydrocephalus Day, on 25 October 2012, the International Federation for Spina Bifida and Hydrocephalus (IF) has organised an international photo exhibition with the patronage of Mrs. Diane Dodds, non-attached Member of the European Parliament, and the participation of people with Spina Bifida and/or Hydrocephalus and their representative organisations. The title of the exhibition is "Unfold Their Potential: (Y)Our Return on Investment".

IF launched a photo competition among its member associations and other associations of people with Spina Bifida and Hydrocephalus around the world. It received over 181 pictures from 21 associations representing 20 different countries from five continents. A jury evaluated and selected a final group of pictures according to creativity, photographic quality,

*‘Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine’.*

# 7

and relevance to the theme of the exhibition. The selected entries are reproduced in this catalogue and displayed at the European Parliament in Strasbourg between 22 and 25 October 2012.

## *International Federation for Spina Bifida and Hydrocephalus (IF)*

IF is the worldwide umbrella organisation for Spina Bifida and Hydrocephalus organisations. It was created in 1979 by national organisations of people with these conditions and their parents. The mission of IF is to improve the quality of life for people with Spina Bifida and/or Hydrocephalus across the world, and to decrease the incidence of Spina Bifida through primary prevention. Today, more than 45 regional and national umbrella organisations of people with Spina Bifida and/or Hydrocephalus are members of IF. IF is an International NGO with consultative status special category with the Eco-

## 8

conomic and Social Council of the United Nations and participatory status at the Council of Europe.

### **World Spina Bifida and Hydrocephalus Day**

The World Spina Bifida and Hydrocephalus Day takes place on 25 October every year. IF and its member organisations will use this day to raise awareness and increase understanding about Spina Bifida and Hydrocephalus, and the ways in which these disabilities can be reduced through primary prevention.

The 2012 Day highlights unmet needs across the globe. While medical and healthcare advances have greatly improved the lives of some people with these disabilities, significant challenges and issues still need to be tackled. The theme of the 2012 World Spina Bifida and Hydrocephalus Day is “Unfold Their Potential: (Y)Our Return on Investment”. This theme revolves around three major messages.



# 9

## Three key messages for the 2012 Day

The 2012 Day aims to deliver powerful worldwide messages:

**1. The rights of children with Spina Bifida and/or Hydrocephalus to proper care and treatments should be respected.** Newborns with Spina Bifida and/or Hydrocephalus will grow into children who have the same aspirations for their lives as other children. A child who develops Hydrocephalus needs proper treatment to preserve his or her chances for 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, even in some parts of the European Union. Children with Spina Bifida and/or Hydroceph-

# 10

alus have the right to proper healthcare and to be treated in line with the best knowledge and expertise available.

## **2. Adults with Spina Bifida and/or Hydrocephalus should be provided with specialised and comprehensive healthcare.**

The vast knowledge and experience of professionals working with children with Spina Bifida and/or Hydrocephalus need to be developed into coordinated and holistic health services for adults. Adults with Spina Bifida and/or Hydrocephalus 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 Spina Bifida and/or Hydrocephalus the multidisciplinary care necessary for the maintenance of health.

*‘The major components of economic cost are the loss of productivity from insufficient investment in educating disabled children, and exits from work or reduced work related to the onset of disability, and the loss of taxes related to the loss of productivity. Non-economic costs include social isolation and stress and are difficult to quantify’.*

# 12

**3. Workplaces need to be disability-friendly to facilitate participation in the labour force and independent living.** Many people with Spina Bifida and/or Hydrocephalus fear that potential employers struggle to see beyond their disability, putting them at a disadvantage when applying for work. They face difficulties 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 Spina Bifida and/or Hydrocephalus have the right to perform a job that caters to their specific needs, to live independently and make autonomous decisions concerning their lives.

# 13

## *Spina Bifida*

Spina Bifida (literally meaning 'split spine') is one of the most common birth defects; the most serious one compatible with life. It 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. Spina Bifida can be surgically closed after birth, but this does not restore normal function to the affected part of the spinal cord. Most babies with Spina Bifida also develop Hydrocephalus. The estimated incidence of Spina Bifida is 1 in 1,000 people worldwide, with certain populations having a significantly greater risk.

## *Primary Prevention and Preconception Care*

Although we do not know the exact causes of Spina Bifida, which is probably connected with both ge-

*‘States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible to persons with disabilities’.*

Article 27 of the United Nations Convention  
on the Rights of Persons with Disabilities

# 15

netic and environmental factors, we do know that folic acid (vitamin B9) helps to protect unborn babies from developing severe birth defects like Spina Bifida. The incidence of Spina Bifida can be decreased by up to 70% if women take daily folic acid supplements at the right time. According to the World Health Organisation, women should take 0.4 mg of folic acid per day two months before conception and during the first three months of their pregnancy. Preconception care can determine the health of newborns and ensure that health inequalities do not start before birth. However, since not all pregnancies are planned, we must actively pursue other ways of ensuring women's folate levels are kept sufficiently high.

## *Hydrocephalus*

The primary characteristic of Hydrocephalus is excessive accumulation of fluid in the brain. Although Hydrocephalus was once known as 'water on the

# 16

brain', the 'water' is actually cerebrospinal fluid (CSF) - a clear fluid surrounding the brain and spinal cord. The excessive accumulation of this fluid results in an abnormal dilation of the ventricles (spaces) in the brain, causing potentially harmful pressure on the tissues of the brain.

Hydrocephalus is treated surgically either by the insertion of a shunt or by an endoscopic third ventriculostomy (ETV) which creates a natural bypass for the cerebrospinal fluid. However, inserting a shunting device, which is the normal treatment, does not 'cure' the Hydrocephalus. The injury to the brain tissue remains but the shunt controls the pressure by draining excess CSF, so preventing the condition from becoming worse. Symptoms caused by raised pressure usually improve, but other problems of brain injury will remain. The estimated incidence of Hydrocephalus is 1 in 500 newborns.



# 17

## THE EXHIBITION

USA

TURKEY

CROATIA

UK - NORTHERN IRELAND

UNITED-KINGDOM

UK - WALES

ESTONIA

UGANDA

KENYA

IRELAND

AUSTRALIA

ITALY

SWITZERLAND

COSTA RICA

BULGARIA

SLOVAKIA

ARGENTINA

AUSTRIA

BELGIUM





***Freedom*** A pre-school attendee enjoying a moment of freedom while relaxing at the Spina Bifida Association's 2011 Conference's Kids!Camp.



***NYPD Blue.*** *Fort Apache, The Bronx* is the title of a movie starring Paul Newman. It is also the very same South Bronx precinct that NYPD Officers Wil Carradero and Komiko Candalario patrol together. They have served the public of New York City for 18 and six years respectively.

***Awarded for her dedication*** Known as “The Cathedral of Baseball,” the new Yankee Stadium was completed three years ago. Theresa has worked as a customer service representative for four years in both the current and former Yankee stadiums. Recently she received an award on the field in front of 55,000 fans in recognition of her dedication to the Yankee organisation. It was presented by the team’s World Series Champion manager, Joe Girardi.



***Community is vital*** Since she was 15, Theresa has exercised at Burke Rehabilitation Center in Westchester, NY. She works out with weights, has fun playing table tennis and wheeling around the track. A lively community of athletes is involved in the centre ranging from the disabled to the Olympic, and have fully integrated Theresa into a network of support and friendly competition.







USA

# 24

*(previous pages)* **A dedicated employee** The Department of Environmental Protection safeguards New York City's water supply and is the City agency responsible for the environment by regulating air quality, hazardous waste, and critical quality of life issues, including noise. Among the Department's six thousand employees, New Yorkers of every background are represented, including individuals with all types of disability. Theresa has worked there for five years.

Between the economic environment and lack of opportunity, many of Theresa's friends with disabilities remain unemployed. Theresa brings a smile and a positive attitude to work and life, hoping that more doors will open while attitudes and outlooks change one person and employer at a time, thus unlocking the potential of so many ready to fully participate in society.





***“Life is to be enjoyed and joy is to be shared”***  
Gathering of children and their families in activities  
organised by the Turkish Spina Bifida association





*A basic necessity* “I need this for walking.”

*Sense of achievement* Denia: “Look at me, I am standing!”



*Pride* "My walking giraffes - aren't they cute?"





***A special school; a special smile*** As part of the ongoing Shine campaign, “Go Folic!”, Shine team visited Mitchell House, a school in Belfast, Northern Ireland, to make a film about Michael. While there they were privileged to meet Katie. This portrait shows Katie at the school where she benefits from specialised education services that enable her to progress in spite of her disability.





***Friends forever*** Katie (left) and Poppy (right) are good friends and this image captures the lovely character of both girls as they spend some time in the playground at Mitchell House, Belfast during their lunch-break.

***Determined to be independent*** Michael lives with his family in Belfast, Northern Ireland. This image was captured during a visit to Michael's school, Mitchell House, which specialises in education for disabled children. Michael is full of life and is successfully learning to use his walking sticks to increase his level of independence.







*A story with a happy ending* Eva was born with Spina Bifida and Hydrocephalus in 2011. This photo of Eva and her father was taken at the Shine Head Office whilst the family spoke with Shine staff about her recent birth and subsequent operations. Eva underwent pioneering surgery in Germany and has since moved to the United States.

# 36

***Ready to compete*** Natalie is a para-equestrian rider with the Great Britain Potential Squad. This image shows Natalie and her horse Fizz as they prepare for a competition at Hickstead, UK.

***Performance through partnership*** Here we see Natalie and Fizz competing in the para-dressage competition at Hickstead. Natalie has overcome many challenges, from her Spina Bifida to the expense of equestrian sport, in order to realise her ambitions.







***A desire to improve*** Gobi is one of the world's top para-badminton players. He has overcome many challenges, including life-threatening surgery, to achieve his ambitions. This photo was taken while Gobi was training ahead of several international competitions during 2012. He trains three times a week as well as working full-time for Shine's 9,500 members with Spina Bifida and/or Hydrocephalus.

***“Bon appétit!”*** Gobi is a very sociable person and is well-known amongst the fans at his beloved football club, Queens Park Rangers. This image shows Gobi out with friends at his favourite eatery before a QPR home match.

***“SHOOT!”*** It would be difficult to count how many QPR games Gobi has attended. For years he has watched his team through many ups and downs. Here we see Gobi engrossed in the match from his pitch-side seat, a place he has occupied for many years as a devoted QPR fan.









*“There’s always a solution”* Gobi is a fan of cars and has customised many vehicles over the years. This image shows Gobi performing a task which is familiar to many disabled drivers; lifting a wheelchair into the car after settling into the driving position.



***“Thanks Coach!”*** In the Õismäe swimming pool in Tallinn, Estonia, trainer Jane and young swimmer Erik work hard to overcome disability. Four times a week, children and young adults with Spina Bifida enthusiastically take part in swimming lessons that are specially organised for people with disabilities. It’s a breeding ground for future Paralympic champions.



***“Together, we can do it better”*** Regina, who has Spina Bifida, lives in Tallinn, Estonia. She goes to mainstream school and likes music, reading and sports. Her dream is to become a schoolteacher. Regina’s legs are weak and she has just started to use orthopaedic boots. She exercises and is learning how to walk. Regina’s 12-year-old sister is a good coach.

***Newly mobile*** After a successful operation, rehabilitation and training, Brenda is able to walk and play like all the other children. Soon, she will be attending school.





***Ready for action*** Ambrose, Spina Bifida coordinator for Western Uganda, tanks up his motorbike and prepares to make his home visits.



*In safe hands* Ambrose checks on the progress of Justice, a nine-month old girl with Spina Bifida who was abandoned by her mother.









***Hope for Hope*** Ambrose with Hope, a baby girl who is doing well thanks to her dedicated parents.





## 53

***A blessing for Blessing*** Blessing waits to see the doctors during a mobile clinic, co-organised monthly by the surgical hospital in Eastern Uganda and the rehabilitation centre in Western Uganda.

***Waiting for follow-up*** A father and daughter in the waiting room during the Bethany Kids mobile clinic in Kitale. This mobile clinic gives everybody the possibility to come for regular follow-up in their own region.





***Abandoned, but not neglected*** Nine-year-old Esther suffers from Hydrocephalus and a club foot. Here she is in the ward at Bethany Kids hospital in Kijabe with her mother Rose. The father left them when the first symptoms were seen in 2002.

***Triumph over adversity*** John Njoroge was born in 1981 with closed Spina Bifida. After his mother abandoned him in the streets of Nairobi, a policeman found John and brought him to a children's home. There he grew up normally, but there was one big problem: his nerves were affected and he couldn't control his bladder. In 1998, after surgery of nearly eight hours at Kijabe Hospital he



woke up for the first time on clean bed sheets without a single drop of urine. Now John is a fantastic nurse and a real support for children and their parents.

***A word of comfort*** John explains the necessary treatment for Wilson, a little boy of two months with Spina Bifida and Hydrocephalus, to his loving mother Janet Kiara.

**Action heroes!** Various images of youngsters with Spina Bifida and Hydrocephalus enjoying themselves at a sports day in Ireland.









***On the up, down-under!*** Shanaya is an indigenous Australian. She is 5 years old and has just started school. She enjoys life and loves playing with her friends. Shanaya can walk with orthotics but uses a wheelchair most of the time. Here she leans on a beach ball imprinted with the Australian flag, symbolising the theme “Life is a Ball in Australia with our sunny climate and beautiful beaches.”

*(next pages)* **Nothing is impossible** Ilaria: “Over the years I have had the opportunity to try different sports such as tennis, fencing and archery. For several years I practised swimming. When I had the possibility to try skiing I was immediately fascinated. When I first sat on the mono-ski I felt completely unstable and was so scared of falling that I couldn’t even move a muscle; I was so tense! But my ski instructors put me at ease and allowed me to relax. After my first fall, totally unharmed, I finally made my first descent on my own - but under the careful supervision of a ski instructor - and I felt free and happy. No sport has ever given me such a beautiful feeling and I hope to practice it more and more in the future and learn, improve and enjoy it with friends.”







***Success through sport*** Lukas from Switzerland: “I need to move and I need sport. I love to go to the limit and to meet with success. Through sport I feel fit and healthy.”



**Holidays** A wheelchair or a bike, we have fun anyway!  
Greece I love water, I feel light and free. I can leave my  
wheelchair for a while.







# 66

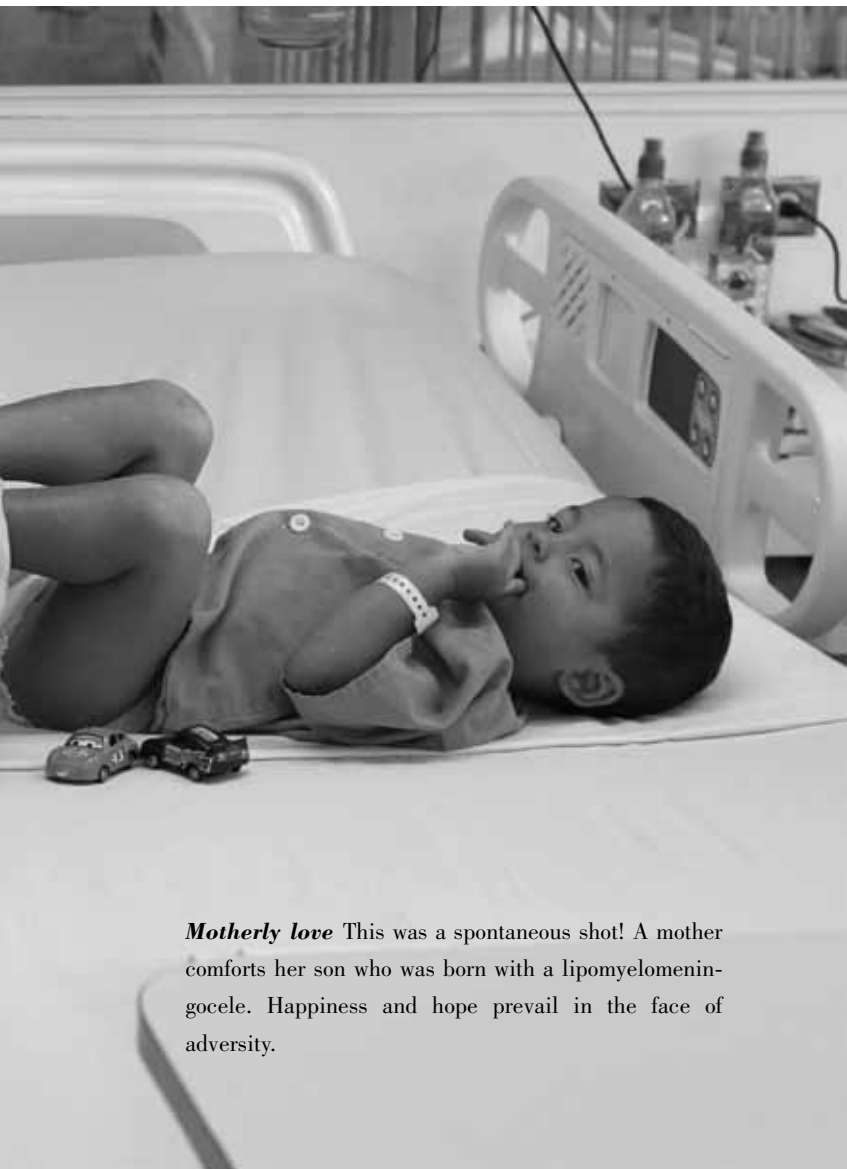
***Inner strength*** Larissa from Switzerland, in a picture which so clearly symbolises her inner strength: “Sometimes I need help, but I can also give something to others”.






***Through the eyes of a child*** A child with Spina Bifida and shunted Hydrocephalus comes into the clinic, his smile reflecting our everyday efforts to improve the care for these children.





***Motherly love*** This was a spontaneous shot! A mother comforts her son who was born with a lipomyelomeningocele. Happiness and hope prevail in the face of adversity.





***Intensive care*** A newborn with Spina Bifida, just a couple of hours after birth and already under general anaesthesia, being prepared to face the first of many surgeries to come. The neurosurgeon's hands are visible, reflecting the intention to make a difference to the quality of life of this child.

БЪЛГАРСКА  
ЛИГА  
2010

BULGARIA



WWW





# 73

***A key member of the team*** Tsvetomir is an eight-year old boy living with his parents in Sofia, Bulgaria. He was born with Spina Bifida and Hydrocephalus. He has a lovable heart and a strong spirit. His nickname is Tsetsi. Tsetsi wrote a letter to Santa Claus by himself asking for a new basketball kit. A couple of weeks later, Tsetsi was so happy to become the youngest player and also the talisman of Sofia's wheelchair basketball team. His Christmas wish came true.

***Total determination*** People who know Tsetsi can often see a determined look on his face. It is the most noticeable feature of his character, whether it is a refusal to do his homework, clean his room or to eat that green salad his Mom insists should be eaten. Of course all parents are happier if their kids do as they are told, but Tsetsi's dogged determination has very positive as well as negative consequences. It is seen most vividly when he is playing basketball. His mother is so proud to see her son

# 74

so fixed on success; to see the fire in his eyes – the same determination directed in a different way. While the ‘fire in his eyes’ is there, Tsetsi will be able to reach every objective he sets for himself in his life - whether that is to avoid eating a healthy salad or to win a basketball game!





***When my daughter kisses me*** “When my daughter kisses me the whole world just stops turning, time stops running, my eyes stop seeing. It is a joyful and peaceful moment for me. I feel as though I am the only mother in this world. I am the only one who is blessed with that.”

***Look, I can do it!*** Timshel is a three-year-old girl from Bulgaria, born with Spina Bifida and Hydrocephalus. She is so proud that she can lock and unlock the door by herself. It may sound a simple task, but it’s not as easy as it looks. For Timshel it took months of hard work:



# 76

learning to straighten up and change her position from the walker to the wall; learning which way to turn the key; learning to stop being scared of falling; and to wait several months before she had grown sufficiently to reach the handle (because she is not able to stand on her toes).

***And now anything is possible!*** Timshel knows very well how much effort she has invested and that is why she is so proud to show her small triumphs.



# 77

The name Timshel is not a traditional Bulgarian name. In fact it became a real name when Timshel was born. The word originally comes from Hebrew and it is one of the most important symbols in Steinbeck's novel, *East of Eden*. *“But the Hebrew word, the word timshel — ‘Thou mayest’ — that gives a choice. It might be the most important word in the world. That says the way is open. That throws it right back on a man. For if ‘Thou mayest’ — it is also true that ‘Thou mayest not.’”*

*“Whether we believe in a higher power or not, it’s interesting to think that we have the power to change our lives for better or worse.” -John Steinbeck, East of Eden*

Timshel's parents believed that by giving her that name they will give her the power to choose which way, and how far to go in her life, and also the power of will. Because the way is always open.



***Barriers are there to be overcome*** She cannot do everything! But who can? We are lucky that Barborka can do everything with us her own way. Everybody has a freedom of mind, a freedom of movement, a freedom of feeling. Children have to learn it, society has to learn it. Disabled children have the power to show that the barriers which they have to overcome are not as big as the barriers society puts in their way.



***“It is always good when we are together”*** Gathering of children and youths in activities organised by the Spina Bifida and Hydrocephalus association Slovakia.



***Smiling through adversity*** Tiziana Costa is a spirited and loving girl who circumvents the difficulties that life imposes.

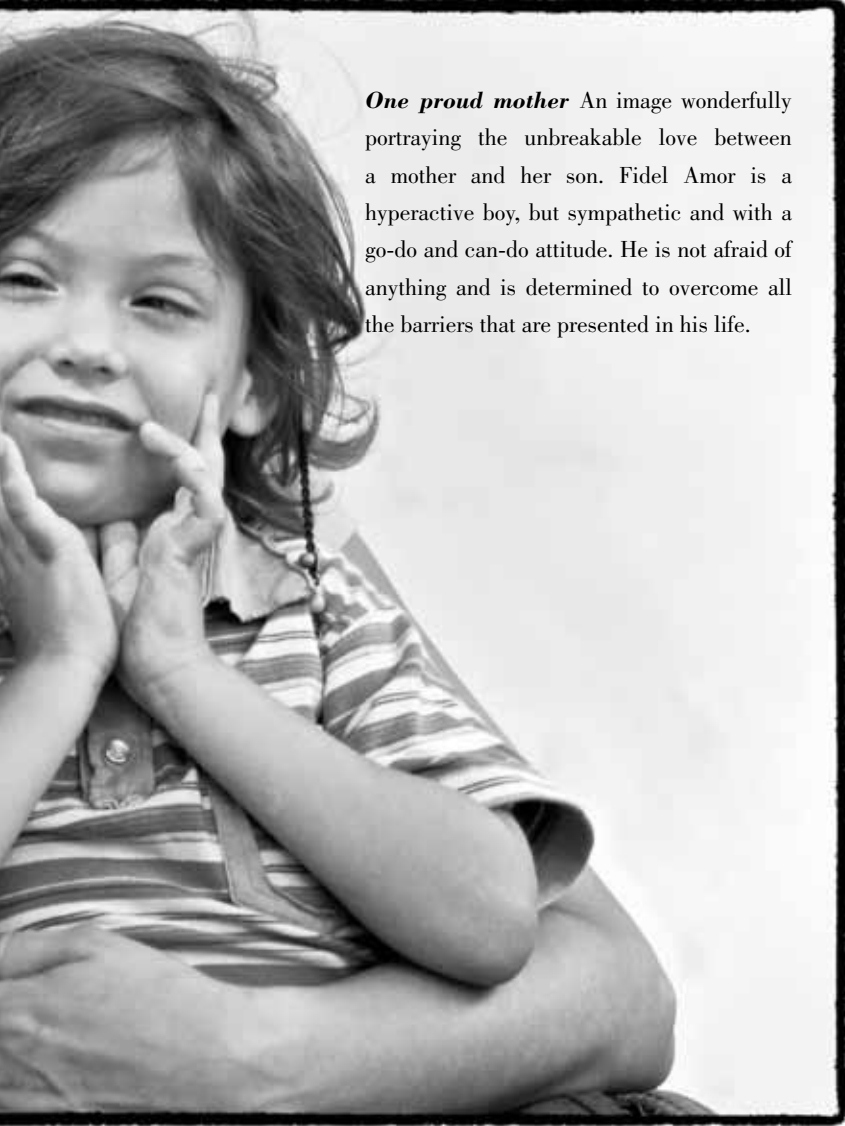




***The determination to succeed*** She might be called “Life Challenging”, but Tiziana Forlano is full of perseverance to achieve her objectives. Her crossed arms symbolise the spirit that is deep within her.

ARGENTINA





***One proud mother*** An image wonderfully portraying the unbreakable love between a mother and her son. Fidel Amor is a hyperactive boy, but sympathetic and with a go-do and can-do attitude. He is not afraid of anything and is determined to overcome all the barriers that are presented in his life.



*Together we will find the answers* They could be called the Moon and the Sun. She (Luna) is a young, independent and thoughtful young girl. He (Julian) is a young, adventurous and optimistic boy, with a great capacity to be self-reliant. Together they represent the changing universe of adolescence.



***With love, anything is possible*** She (Aylen) has a strong character. He (Ivan) is a skilled athlete. They are in love with each other. Together they represent the hope and future of every young person.



***A lover and a dreamer*** Edgardo is a sympathetic, friendly and elegant man, who is always falling in love with every pretty girl who passes through his life.






## 89

***Strength through partnership*** Hanna and Leo from Austria are both 18 years old and proudly proclaim: “You are not handcuffed! You are not deprived if you have to live with a handicap!” They are convinced that dancing is a wonderful way to bring this message to people around the world.

***“You make me feel like dancing”*** “We both love dancing and taught ourselves how to dance. We have been dancing for ten years and love to dance in front of anyone, and everywhere we can.”





***His name means “He will laugh”. And he does.***

***A lot!*** This three-year old boy is Isaak. His name was chosen because the parents were asked to sacrifice their boy in pregnancy to create “a perfect world” (just like Abraham in the Old Testament was asked to sacrifice his son Isaak). They refused. The result is this charming kid, full of joy of life, determined to achieve as much as he can. He continually surprises everyone because he has already reached further goals than they ever imagined. He goes to a regular school, where everybody adores him; he plays wheelchair basketball; he rides a horse; and he undergoes every hospital examination with a smile. In short, Isaak teaches everybody the true values in life.















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Asociación para Espina Bifida e Hidrocefalia (APEBI), Argentina.

*[www.apebi.org.ar](http://www.apebi.org.ar)*

Spina Bifida Service - The Children's Hospital at Westmead,

Australia. *[www.chw.edu.au/rehab/spina\\_bifida](http://www.chw.edu.au/rehab/spina_bifida)*

Vereniging voor Spina Bifida en Hydrocephalus vzw, Belgium.

*[www.spinabifida.be](http://www.spinabifida.be)*

Spina Bifida and Hydrocephalus – Bulgaria, Bulgaria. *[www.sbh.org](http://www.sbh.org)*

Spina China (Hongwei Sun), China. *[www.spinachina.org](http://www.spinachina.org)*

National Children's Hospital of Costa Rica (Spina Bifida Clinic),

Costa Rica. *[www.chcrf.org](http://www.chcrf.org)*

Udruga osoba i roditelja djece sa spinom bifidom "Aurora",

Croatia. *[www.spinabifida.hr](http://www.spinabifida.hr)*

MTÜ Eesti Seljaajusonga ja Vesipeahaigete Selts, Estonia.

[www.kelluke.ee](http://www.kelluke.ee)

ASBH Bereich Hamburg e.V., Germany (Hamburg).

[www.asbh-hamburg.de](http://www.asbh-hamburg.de)

Entfesselt im Rollstuhl, Austria. [www.entfesselt-im-rollstuhl.com](http://www.entfesselt-im-rollstuhl.com)

Spina Bifida Hydrocephalus Ireland (SBHI), Ireland. [www.sbhi.ie](http://www.sbhi.ie)

Associazione Spina Bifida Italia onlus (ASBI), Italy. [www.asbi.info](http://www.asbi.info)

Parent group SHAK: Spina Bifida & Hydrocephalus Association, Kenya.

Bethany Kids Hospital, Kenya. [www.bethanykids.org](http://www.bethanykids.org)

Scottish Spina Bifida Association, Scotland. [www.ssba.org.uk](http://www.ssba.org.uk)

Slovenská spoločnosť pre spina bifida a hydrocefalus, o.z.,

Slovakia. [www.sbah.sk](http://www.sbah.sk)

SBHV - Schweizerische Vereinigung zugunsten von Personen mit Spina bifida und Hydrocephalus, Switzerland. [www.spina-hydro.ch](http://www.spina-hydro.ch)

Spina Bifida Derneği, Turkey. [www.spinabifida.org.tr](http://www.spinabifida.org.tr)

OURS - Rehabilitation centre, Uganda.

[www.ruharomissionhospital.org/ours.home.html](http://www.ruharomissionhospital.org/ours.home.html)

Shine, United Kingdom. [www.shinecharity.org.uk](http://www.shinecharity.org.uk)

Spina Bifida Association, USA. [www.sbaa.org](http://www.sbaa.org)

Spina Bifida Resource Network, New York, USA. [www.thesbrn.org](http://www.thesbrn.org)

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