The International Federation for Spina Bifida and Hydrocephalus: Priorities in developing countries

L Bauwens, MA, MBA

Secretory General, International Federation for Spina Bifida and Hydrocephalus, Brussels, Belgium

Corresponding author: L Bauwens (lieven.bauwens@ifglobal.org)

The International Federation for Spina Bifida and Hydrocephalus (IF) is the global umbrella organisation for national and regional spina bifida and hydrocephalus associations. Currently, IF has 50 members, representing people with spina bifida and hydrocephalus from 46 countries. IF’s mission is to increase the quality of life of persons living with disabilities associated with these conditions and to decrease the incidence of these impairments by primary prevention. IF members share this mission and work locally to achieve these goals.


Why primary prevention?

In 2005, the members of the International Federation for Spina Bifida and Hydrocephalus (IF) agreed on a resolution that flour fortification with folic acid is the most effective way to reduce the incidence of spina bifida. This easy and cheap method slightly increases the folate status in a population, but has a direct impact on the incidence of spina bifida and erases folate-deficiency anaemia. Countries that mandate obligatory flour fortification with folic acid report an average reduction of 46% in the incidence of neural tube defects and a 1:12 - 48 favourable cost-benefit ratio.[1] Other strategies, e.g. social communication supporting folate supplementation, do not have the same public health impact. Although it is widely known that women of childbearing age should take a daily supplement of 400 µg folic acid, starting about 8 weeks before conception, compliance is low, especially among women of lower socio-economic status.

Warf[7] also successfully pioneered a new treatment technique, i.e. endoscopic third ventriculostomy/choroid plexus cauterisation (CPC), in order to remove another barrier, i.e. dependency on shunts and tendency of shunts to fail. This treatment has proved to be successful in children <1 year compared with ETV alone.

Access to initial treatment: Affordable shunts and endoscopic third ventriculostomy/choroid plexus cauterisation

In most developing countries, treatment for complex disabilities does not exist and capacity is insufficient. However, in many cases attitude is responsible for the non-availability of healthcare.

Warf[7] showed that the usage of a low-cost shunt system (US$35) had the same outcome as a more expensive shunt (US$600) over a year. The barrier to healthcare access was lowered to 5% of the initial cost, allowing IF to donate over 3 300 shunts annually to its partners.

Warf[7] also successfully pioneered a new treatment technique, i.e. endoscopic third ventriculostomy (ETV) combined with choroid plexus cauterisation (CPC), in order to remove another barrier, i.e. dependence on shunts and tendency of shunts to fail. This treatment has proved to be successful in children <1 year compared with ETV alone.

Access to lifelong follow-up: Spina Bifida and Hydrocephalus Interdisciplinary Program

A person born with spina bifida and initial or acquired hydrocephalus is not cured after the first treatment and lifelong follow-up is
required. This involves the co-operation of different stakeholders, who all have a different view on the person’s treatment and care. IF developed the Spina Bifida and Hydrocephalus Interdisciplinary Program (SHIP) with the purpose of helping the different partners in a country to communicate better, understanding each other’s role in the entire process and developing an individualised healthcare programme that meets the needs of the patient. The SHIP framework is further supported by tools such as protocols and a SHIP passport, the latter being a method to personalise the treatment process. IF is still investigating the possibilities of data collection through lifelong follow-up.

Access to healthcare: Continenence management
One of the successful interventions during IF’s 20 years of working experience in developing countries has been the low-cost method for clean intermittent catheterisation. With renal failure being one of the main causes of (premature) death, correct continence management is of the utmost importance. Correct continence care is cited by many patients as being the most important aspect towards their social inclusion in and compliance with their care programme. Verpoorten and Buyse have published a paper on the abovementioned method and are involved in the IF continence programme.

Parents’ and children’s roles in the process
The overarching objective is to help children with spina bifida and hydrocephalus to become independent and healthy adults. Studies have shown the importance of involvement in the different healthcare services, which will advance compliance with therapy and mutual understanding, thereby improving quality of life. It is the aim of IF to involve parents and children/youth directly in its programme, considering them to be experts with regard to their care. They are allowed to shape programmes at every stage as well as implementing and evaluating them.

References

Further reading
• Flour Fortification Initiative (flour fortification information, including country profiles for many individual countries). http://www.ffinetwork.org [accessed 19 March 2014].