"Ethical discussion on prenatal selection in EU countries involving spina bifida/hydrocephalus user groups network"
Final Report PS/2004/035

Figure 1: left typical medical imaging – right another way of portraying the same children with the same disability.

Executive Summary
The partners in the project on Ethics were the Belgian, Dutch, Estonian, Maltese, Polish and Slovak associations for Spina Bifida and Hydrocephalus and IF-Europe, the European division of the International Federation for Spina Bifida and Hydrocephalus. They discussed their living conditions and their perception of the quality of life with spina bifida in their countries. They explored ethical issues concerning the impairment, which is on verge of that ethical discussion especially concerning prenatal diagnosis and the termination of pregnancies.

Methodology
The perception of ‘Quality of life of persons with spina bifida’ influences ethical attitudes. That is the reason why in 2000 IF-EUROPE combined the perception of quality of life with the ethical discussion on termination of pregnancy when the unborn child has spina bifida. This resulted in a
resolution ‘the right to be different’ (attached). The same approach was used in the new European states.

Starting from this point, IF - Europe examined the impact of the perception on the quality of life on the ethical debate including termination of pregnancies as well as active euthanasia. The steps in the project were:

- Translation of the book Liesje (personal impression of a parent on selection criteria and health policy at the birth of his child with spina bifida)

- Design of a questionnaire
  - where do we stand as a society in taking care of our persons with this disability?
  - What is level and availability of care in the new member states
  - What are the needs and problems of persons with spina bifida and hydrocephalus
  - Etc..

- IF-Europe held several workshops, both locally as internationally, including users, parents and caregivers. Topics included:
  - What are legal issues?
  - How do professional caretakers react to the diagnosis of spina bifida and/or hydrocephalus?
  - What are barriers encountered both socially as physically?
  - Ethical reflection on the termination of pregnancy.

- Given the actuality¹, IF - Europe played and active role in the public debate via press actions and lobbying.

- IF-Europe studied primary prevention as an alternative for termination of pregnancy.

### Background on termination of pregnancy and euthanasia on babies

The ethical discussion on pre and postnatal selection on babies with spina bifida started years ago with the decision of doctors to treat only selectively good cases of newborns with the impairment. This decision was based on a study by doctor Lorber in the late 60’s. Care has dramatically improved since, as did the quality of life of newborns and adults equally. However, decision-making procedures have not changed (as much) in accordance with the evolutions in medicine and care, they are still often based on out-of-date information. Consider the pictures on the first page of this report: left the “medical cases”, right examples of a life worth living. Dr. Carla Verpoorten, medical consultant to IF, concludes a literature study on the topic as follows:

> The prognosis for children with spina bifida anno 2000 is much better than indicated by Lorber. Professionals should change their pessimistic view on long-term prognosis and need to counsel parents about the full spectrum of impairment in addition to the effects of modern forms of treatment on the outcome of unborn infants with spina bifida. The pessimistic public opinion has to be changed before we can assure prospective parents that they and their future child will be welcomed whether or not the child has a disability.

¹ Groningen-protocol doctors reported on 22 children with spina bifida killed at birth due the expected poor life quality. More information later in the report.
Doctors and gynaecologists also face huge litigation risks related to the birth and treatment of babies with spina bifida. This evolution was quickened by some court cases in France where doctors were convicted because a severely impaired boy did not have the right NOT to be born.

Due to these juridical claims gynaecologists are motivated to detect the impairment in the earliest stages of the pregnancy. The ethical questions remain: what happens if the foetus has a disability? Who decides whether a life is worth living? What are the rights of the unborn child? Who can judge if a life is worth living? In 2000, on the international conference of IF, 270 people with spina bifida stated the following:

Most adults with spina bifida underline that their quality of life is not automatically - and should not be given as - a reason for abortion.

Can these 270 people not be considered the best consultants on the quality of life of people with spina bifida and hydrocephalus? Doctors are focussing too much on the medical deficit and not on the opportunities of people with disabilities.

This is a societal evolution related to the increased availability of diagnostic tools. Information given to future parents is often biased, leading to a termination of the pregnancy.

From a legal point of view, a foetus does not have a status: it is not a person. This creates a lower threshold for abortion. Sophie Blanchquaert concluded in her paper that ethical education of all levels is lacking and that it should start at school, where it is not a part of the curricula for the moment.

This evolution reached dramatic heights in the Netherlands, where 22 “cases” of active euthanasia on terminally ill babies were recorded (all “cases” were babies with spina bifida) and not prosecuted albeit the strict illegal character of the intervention. The spina bifida (and hydrocephalus) community reacted promptly and unanimously negative on the decision of the Dutch doctors to work towards and with tools as the Groningen-protocol so not to treat or actively commit euthanasia on babies. Spina Bifida is not a sufficient reason to defend euthanasia. Again, we can quote dr. Carla Verpoorten:

If the child with a disability is not a problem for the world, and the world is not a problem for the child, perhaps we can diminish our desire for prenatal testing and selective abortion and can comfortably welcome and support children of all characteristics.

Towards a better care
The IF policy statement - developed in the course of 2000 and following years - had 13 agreed statements:

1. That people with spina bifida and hydrocephalus can live a full life with equal value to that of any other citizen and they should not be seen as a medical condition. Their views should
be sought and heard by governments and health professionals, who should acknowledge the right of people with spina bifida and hydrocephalus to speak for themselves.

2. That people with disabilities have the right to aim for lives as rewarding as those of their peers who have what is regarded as a normal life. Supportive systems must be in place when they are needed.

3. That experience over the past 30 years has improved considerably the medical outcome and the quality of life of people with spina bifida and hydrocephalus.

4. Most adults with spina bifida underline that their quality of life is not automatically - and should not be given as - a reason for abortion.

5. That prenatal counselling for parents should be carried out by skilled professionals. The counselling should provide access to the full range of issues relating to spina bifida and hydrocephalus. Counselling by its very nature should be non-judgmental. Parents deserve time to adapt to this new situation before being confronted with a proposal to terminate the pregnancy. Parents must feel free to make a choice.

6. After diagnosis, professionals should work with parent organisations to ensure that information is up-to-date, correct, and understandable by parents.

7. Terminology such as therapeutic abortion and secondary prevention can be misleading.

8. The International Federation is keen to ensure that terminology used is not misleading.

9. Primary prevention should be the focus for the prevention of disability.

10. More research is needed to ascertain all the causes of Neural Tube Defects and in particular the role folate plays.

11. Primary prevention campaigns must not be seen as carrying hidden messages. All campaigns must safeguard the dignity of disabled people.

12. Discrimination such as issues relating to insurance should not impact upon the decisions of the parents.

13. Prevention and prenatal diagnosis is a complex moral and ethical matter. It needs a great deal of deliberation and it will be an ongoing debate. Organisations of and for people with spina bifida and hydrocephalus should be full partners in this debate.

The spina bifida and hydrocephalus community stresses the role primary prevention (i.e. knowledge on folic acid) and the knowledge on the quality of life play rather than a focus on termination of pregnancy (i.e. abortion) and euthanasia.

Care has evolved enormously over the last 30 years, with as an excellent example the integrated system of the Belgian and Dutch governments. Due to the lobbying of IF-Europe, the Belgian government has developed a framework for integrated care of patients with spina bifida in multi-disciplinary teams. IF’s medical consultant dr. Carla Verpoorten, MD, is the spina bifida and hydrocephalus specialist in Belgium, treating about 300 patients. Her expertise lead to the conclusion that people with spina bifida and hydrocephalus should be treated by multi-disciplinary teams, which she has initiated and the corresponding convention with the Belgian government. This team has to be coordinated by a doctor, and the patient has to be able to get integrated care in a straightforward manner. An example is the one-day visit to a certain hospital instead of separated visits to individual practitioners.

This is also a common approach in the Netherlands. IF will initiate projects, implementing the multidisciplinary approach in other European countries, as the need for such a solution is high.
Resulting directly from the project is the question of Dr. Frantisek Horn, PhD to help setting up such a multidisciplinary team in Slovakia - an exchange of good practise and expertise. Having doctors from all countries participating in the project (except from Malta) has an enormous impact on health care.

Towards another perception
Perception of spina bifida and hydrocephalus is negative in general and the information given to parents is often too negative reducing the information on all medical deficits and not on the positive potentials. In Europe more that 90% of the parents follow the advice of doctors to terminate pregnancy.

The spina bifida and hydrocephalus community has poor PR. Better balanced information on the outcome of children with spina bifida in Australia where that parents feel totally free to take a decision whether or not to terminate a pregnancy the majority of the parent opt not to terminate the pregnancy, albeit knowledge of possible obstacles. This proves that the quality of information and counselling determines the majority of the parent’s decisions.
Conclusions of the project

The conclusions of the participants were:

- Working with the questionnaire was a good tool for starting the ethical discussion, although it was not possible to compare the results towards general conclusions: every answer is subjective and depending on the level of care available in that specific country. We could see a big difference in the situation of Malta and the former communist states. However, the perception of the situation in the different countries indicates clearly where actions should be undertaken;
- European standards of care for persons with spina bifida are not reached in the newly accessed EU-states. Quality of life is also depending on the availability of good care;
- Handicap-specific organisations for spina bifida are considered crucial to defend the rights of the target group and to ensure better services. Every organisation had similar problem related to organisation building and working with volunteers: they had divers life cycles in the organisation, funding was a difficult issue, reaching the target group is a challenge, finding motivated volunteers is always difficult;
- The participants underwrite the IF policy statement (attached to this document). The life of a person with spina bifida and/or hydrocephalus is worthwhile to be lived, the existence of spina bifida and hydrocephalus in the foetus is not sufficient reason for the termination, the (free) choice needs to be based on clear and conscious information;
- Religion, rather than living conditions and quality of care, often has a bigger impact in the ethical debate than in the rest of Europe. This is mentioned explicitly in the case of Malta, more indirectly in the case of the Eastern European countries;
- Concerning the fall of the Iron Curtain, the quality of care and accessibility of treatment has dropped in recent years. Expensive private systems, inaccessible to many, develop parallel with deteriorating public systems. This private care system risks implementing an overactive and fragmentated high tech care, because if is often based on individual and economical motives;
- The countries provide a good legal framework, but they often lack resources or progress in implementation. Wealthier countries often import expensive techniques (prenatal surgery, among others) which do not necessarily improve living conditions for people with a disability.

The project resulted in:

- Underwriting of the IF resolution 'The right to be different' by the participating countries.
- A written statement to the Economic and Social Council of the United Nations on Prenatal diagnosis and Accurate Information on the Quality of Life, unanimously accepted at the last General Meeting, June 2005 in Minneapolis, USA.
- An IF policy paper on Mandatory Food Fortification as the alternative in prevention of spina bifida.