



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS

Consultative status special category with Economic and Social Council of the United Nations
Participatory status, Council of Europe

RESOLUTION ON ACTIVE TERMINATION OF LIFE OF NEWBORN CHILDREN WITH SPINA BIFIDA AND/OR HYDROCEPHALUS AND THE RIGHT TO LIVE

**Adopted by the IF Annual General Meeting
on 30 June 2006 in Helsinki**

1. Introduction

In its 2000 resolution *Prenatal Diagnosis and The Right to be Different* IF already sharply condemned active termination of life on the grounds of disability. This selection and termination of life on the grounds of disability is now extended to newborn children with impairments as shown by the Dutch 'Groningen Protocol' (published in *New England Journal of Medicine* 2005; 352:959-962). The Groningen Protocol advocates legislation on the active termination of life of newborn children with severe impairments. The proposed legislation is to widen the euthanasia legislation to newborns.

The paediatricians from Groningen that developed the Protocol documented 22 cases, all concerning children with neural tube defects whose lives were actively ended with the approval of the Public Prosecutor. They argue that these newborn children were 'in agony' or 'suffering unbearably and hopelessly'. These arguments for having ended the lives of the 22 babies are now being contested by other paediatricians in the Netherlands who claim that spina bifida is no reason for unbearable suffering and that in those cases where a newborn child is suffering many means to alleviate the pain are available.

Proposing parents to actively end the life of their newborn child with Spina Bifida and/or Hydrocephalus puts considerable psychological pressure on them. Arguments of the negative quality of life of people with Spina Bifida and/or Hydrocephalus are put forward and their extra social and medical costs are emphasised, which violate the internationally accepted human rights principles. Instead, parents of a newborn child with Spina Bifida and/or Hydrocephalus should be provided with concrete experiences on disability.

This IF resolution underlines the right to live of all newborn children with Spina Bifida and/or Hydrocephalus and the right to access all treatments which can improve their quality of life and prevent them from further impairment.

2. Combining the medical and the social approach

The conditions for a good quality of life depend on many factors which are equal for all children irrespective of their physical and intellectual condition. One's future quality of life cannot be predicted. The vision that newborn children with Spina Bifida and/or Hydrocephalus will have a bad quality of life only takes the medical approach into account, which locates the phenomenon of disability exclusively within the individual. However, since its 2001 publication *International Classification of Functioning and Disability (ICIDH-2)*, the World Health Organization considers disability an umbrella term combining the existing medical and social definitions. The latter clarifies that the impairment of a capacity does not count in itself as a disability, but becomes a disability if treated by society in a manner that disadvantages the person with impairment. The argument of a bad quality of life as implied in the Groningen Protocol contradicts this universally accepted vision. The fight of the right to life includes a needed commitment of the society on the path of the quality of life of people with Spina Bifida and/or Hydrocephalus.

3. International instruments promoting human rights

Several internationally adopted instruments promote the right to live of newborn children with impairments including the *UN Universal Declaration of Human Rights (1948)* and the *UN Convention on the Rights of the Child (1989)*. The Groningen Protocol as such breaches article 1 and 3 of the former and article 6 and 24(1) of the latter. The *Convention for the Protection of Human Rights and Fundamental Freedoms (1950)* of the Council of Europe too, unequivocally provides in its article 2 that "everyone's right to life shall be protected by law." This principle is also reflected in article II-62 of the current draft of the *Constitution for Europe*. The Constitution's articles II-61 and II-63 respectively refer to the Human Dignity and to the Right to the Integrity of the Person.

4. Proposal

The IF members at their Annual General Assembly, held the 30th of June 2006 in Helsinki, have agreed the following resolution and decided to transmit it to all relevant stakeholders at the national and international level:

1. All newborn children with Spina Bifida and/or Hydrocephalus have the right to live and to all treatments which can improve their quality of life or prevent further impairment. Active termination of life of newborn children with Spina Bifida and/or Hydrocephalus should not be permitted on the basis of their expected quality of life;
2. Spina Bifida and/or Hydrocephalus should never be an argument not to provide available life-saving and life-improving treatment;
3. Pain and suffering of the newborn child should not promote the solution of active termination of life, but rather the alleviation of that pain and suffering;

4. It should be acknowledged that differences enrich society and that all people can contribute to society as soon as these differences are accepted and means are provided in favour of inclusion. The level of a society's civilization can be measured by the attitude towards those people who find themselves on the other side of the spectrum of what is regarded as the norm;
5. Erroneous societal assumptions about the quality of life of people with Spina Bifida and/or Hydrocephalus or social provision cost factors should not justify active termination of life on the grounds of disability. These violate the internationally accepted human rights principles;
6. Organisations of Spina Bifida and Hydrocephalus must be full partners in debates on the moral and ethical dilemmas raised by decision making for newborn children with Spina Bifida and/or Hydrocephalus;
7. Counselling for parents should be supportive, focusing on all aspects of life for a child with Spina Bifida and/or Hydrocephalus. Parents should be informed about all recent scientific advances that have improved considerably the quality of life of people with Spina Bifida and/or Hydrocephalus, and about legislative initiatives, including non-discrimination and human rights legislation, which offer more legal protection to disabled people and their families. Parents should be given time to adapt to their new situation and should feel free to make fully informed decisions;
8. Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with Spina Bifida and/or Hydrocephalus is a form of discrimination and is in breach of human rights principles and may be open to legal challenge;
9. Any form of discrimination against people with Spina Bifida and/or Hydrocephalus should be outlawed including in any legislation on active termination of life of newborn children with impairments;
10. The wording euthanasia is misleading when it concerns a newborn child with Spina Bifida and/or Hydrocephalus that is not dying and should in that case not be used interchangeably with active termination of life.