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# Act against Europe's most common birth defects: one year on *Defining Neural Tube Defect prevention strategies in Europe*

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Spina Bifida and Hydrocephalus**

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# About the International Federation for Spina Bifida and Hydrocephalus (IF)



## About us:

- Worldwide umbrella organisation for Spina Bifida and Hydrocephalus organisations
- Created in 1979 by national organisations of people with these impairments and their parents
- Today IF's membership consists of 41 regional and national umbrella organisations

## Our mission:

- Improve the quality of life of people with Spina Bifida and Hydrocephalus in the world and decrease prevalence by primary prevention

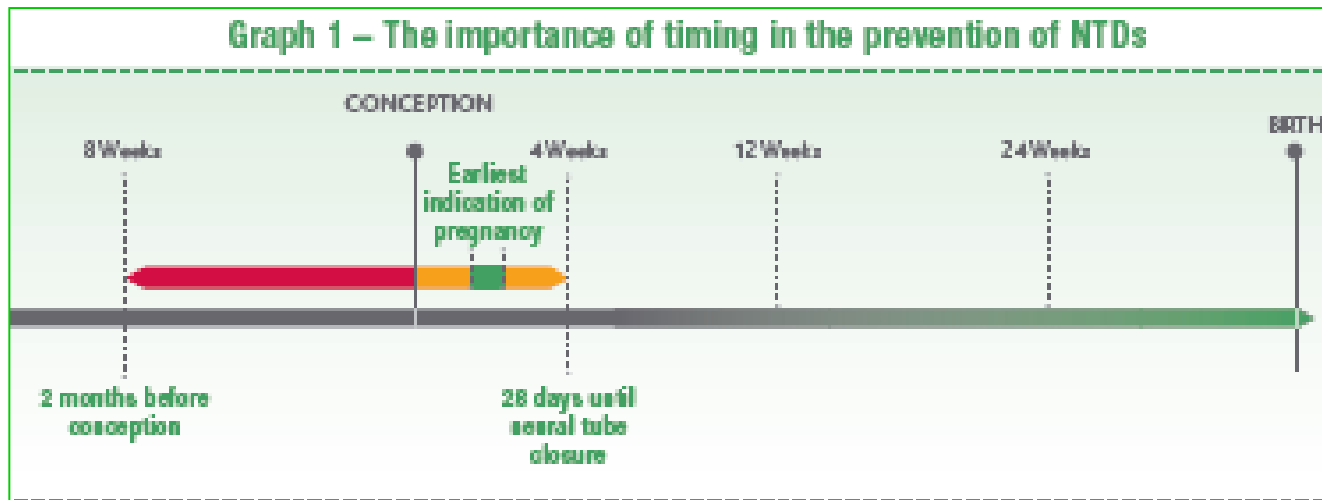


# What are Neural Tube Defects (NTDs)?

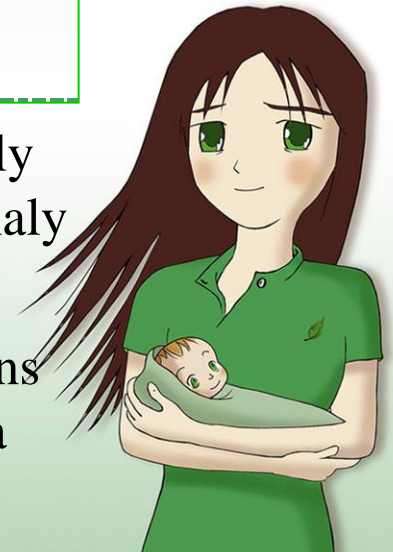


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- Birth defects which occur when the neural tube fails to close **within the first 28 days of pregnancy** and which result in severe malformations



- There are three types of NTDs: Encephalocele, Anencephaly and Spina Bifida. Infants with Encephalocele or Anencephaly are often not compatible with life
- Spina Bifida cannot be cured. Through surgical interventions and lifelong care most people with Spina Bifida now live a meaningful life.



# A few facts and figures on NTDs



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- Up to **70% of NTDs are preventable** with appropriate folate levels in women of childbearing age prior to conception
- **2** is the minimum number of months for women to start taking **0.4 mg of folic acid daily before conception** to reduce the risk of a NTD affected pregnancy
- More than **4,500** annual cases in Europe of which an estimated 72% are terminated after prenatal diagnoses



# Why is NTD prevalence so high?



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## Women of childbearing age are not receiving the right advice about NTD prevention at the right time, i.e. prior to conception

1. In many countries, up to 50% of pregnancies are estimated to be unplanned, and women are therefore not able to ensure they have the necessary folate levels in advance of conception
2. Little awareness among women of childbearing age about preventive measures of NTDs before conception and in early pregnancy
3. Most women are not following the recommendations on folic acid use to prevent NTDs
4. Limited access to proper and systematic preconception care



# About the 2<sup>nd</sup> report on NTDs – 2011 update



## 1. Partners

Led the drafting and sponsored (MC and Bayer)



Endorsed



Supported with data



Endorsed two factsheets



**THANK YOU TO ALL  
FOR YOUR TIME &  
DEDICATION!**



## 1. Concept:

- Follow-up on the 2010 report on NTDs which benchmarked 7 EU countries only
- Focus on policy impacting NTD prevention from a horizontal perspective in 24 Member States\* + Norway

*\*EU27 excluding Cyprus, Luxembourg and Malta*

## 1. Key Messages

- Little has happened in the last 20 years and no progress in reducing NTDs since the first report
- More can be done in the area of prevention



# Methodology & Sources

- EUROCAT 2009 report
- EUROCAT revised data, Feb 2011
- Online questionnaire sent to national representatives of IF and Bayer at national level – 25 countries represented incl. Norway
- Qualitative input from the partners
- Other scientific papers: MRC, Ray, etc



# Key Findings of the 2<sup>nd</sup> report on NTDs – 2011 update



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- Despite existing knowledge about preventive measures, **prevalence is still too high.**
- Termination of pregnancies are often misperceived as preventive measure in some European countries.
- **Younger women** and **women from disadvantaged backgrounds are at a greater risk** of a NTD affected pregnancy
- **NTD related policy** still **not** including **preventive measures** to raise women's folate levels



# Key Findings of the 2<sup>nd</sup> report on NTDs – 2011 update

- Voluntary fortification with folic acid and healthy diet are **insufficient** to raise women's folate levels
- Recommendations on daily intake of folic acid are often **not fully in line** with WHO Standard (especially timing) **and scarcely implemented**
- Health **education campaigns too scarce** and often limited in scope, duration and effectiveness (e.g. no reference in sexual education curricula)



# Our call to action



 <b>Pierre Mertens</b> International Federation for Spina Bifida and Hydrocephalus, President	 <b>Lars Jonsson</b> Bayer HealthCare Pharmaceuticals, Head Global Advocacy	 <b>Denhard de Smit</b> MedCura, Director projects and research
 <b>Yann Le Cam</b> EURORDIS, Chief Executive Officer	 <b>Silke Poles</b> European Foundation for the Care of Newborn Infants, Chairwoman of the Executive Board	

## Call to Action

1. Ensure national recommendations on folic acid intake to prevent NTDs are updated, in line with the WHO's standard on NTD prevention, and that their implementation by healthcare professionals is monitored.
2. Raise awareness about NTDs and NTD prevention among women of childbearing age and the healthcare community through education campaigns, and by including NTD prevention in the curriculum for sexual and reproductive health education in schools throughout Europe.
3. Ensure that NTD prevention by raising women's folate levels is promoted in health-related policy, e.g. on rare diseases, maternal health, preconception care, etc.
4. Investigate further the costs and benefits of food fortification or other supplementation strategies.
5. Improve NTD surveillance systems and the collection of comparable data across the EU, including compliance with folic acid intake recommendations.
6. Explore new methods to raise women's folate levels prior to conception, regardless of whether their pregnancy is planned or not and in view of addressing health inequalities.



# What can the EU do?



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- Ensure NTD prevention is included in related EU policy (e.g. Rare Disease Road Map, Health Inequalities)
- Continue funding European registries and push for more and better collection of comparable data
- Coordinate action and ensure exchange of best practices at national level
- Explore new methods to raise folate levels of women of childbearing age including food fortification and supplementation strategies



# What can national governments do?



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- Explore new ways to reach out to all women of childbearing age
- Include importance of preconception care and folate levels before conception in schools' health and sexual education curricula
- Adopt and align recommendations of folic acid intake with WHO Standard and monitor implementation by healthcare professionals



# What can the civil society do?

- Liaise with national stakeholders (incl. policy makers) to demand more ambitious national prevention strategies
- Push national governments to implement actions to increase folate levels of all women of childbearing age
  - Inclusion in health and sexual education curricula at school
  - Health and promotion campaigns (e.g. Pharmacy campaign, use of mass media, etc)





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**Thank you for your attention!**



**Any questions?**