

Neural Tube Defects – A Case Study

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Neural Tube Defects

- Failure of closure of neural tube
- 4-6 weeks of pregnancy
- Any part of neural tube may be involved



Types of neural tube defects

- Anencephaly
- Encephalocele
- Meningocele
- Myelomeningocele
- Spina bifida occulta

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- Encephalocoele
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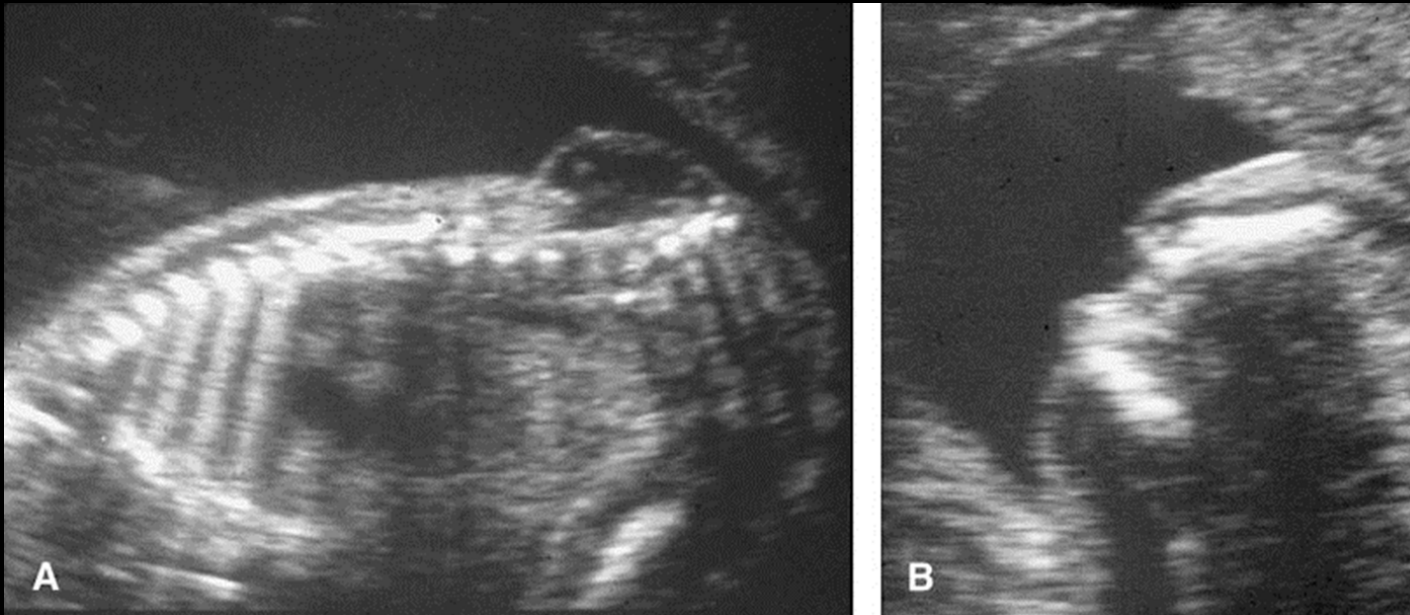
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Prenatal Diagnosis

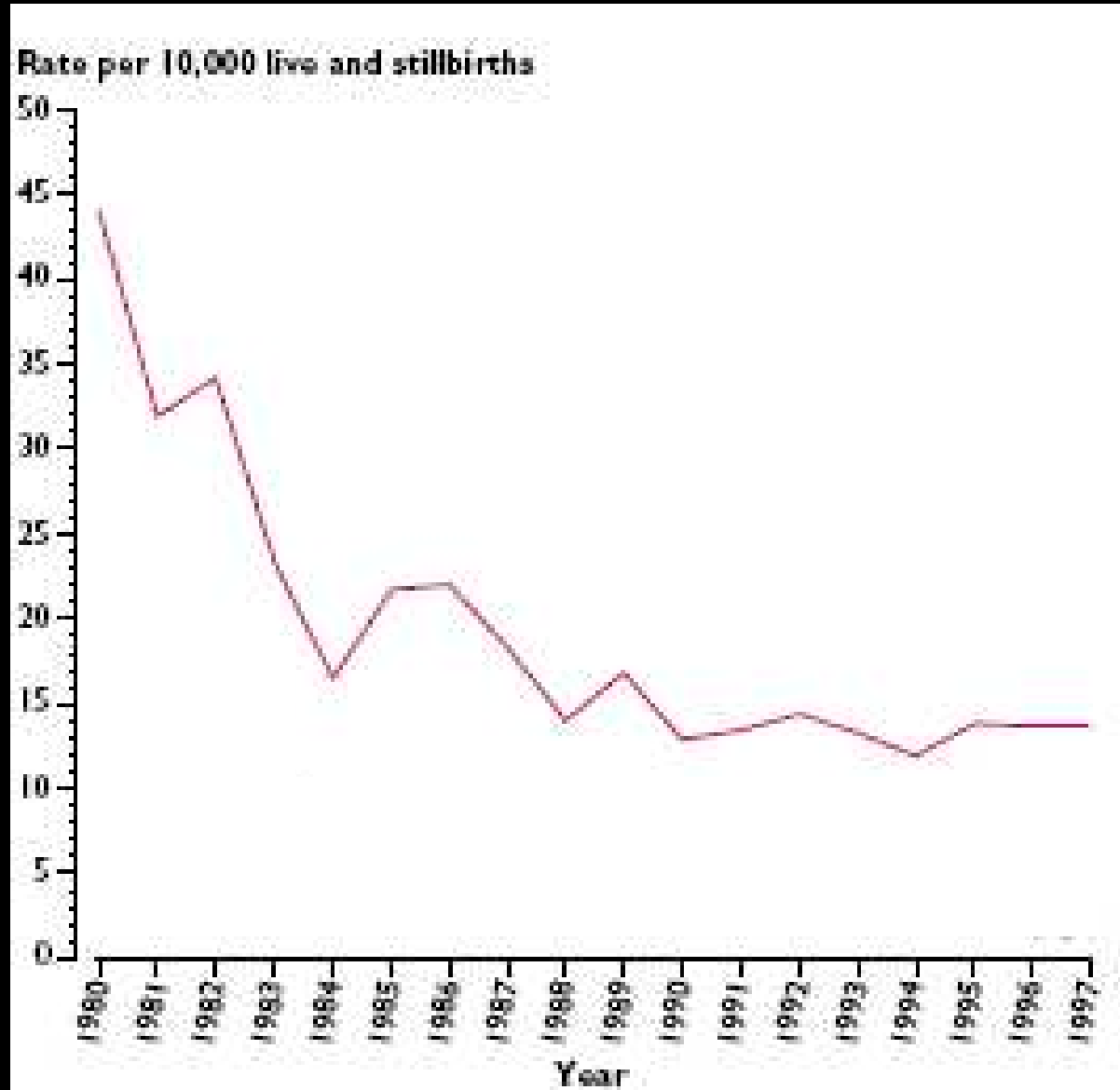
- Raised serum alpha fetoprotein - 15-16 weeks
- Ultrasound scanning – 18-20 weeks



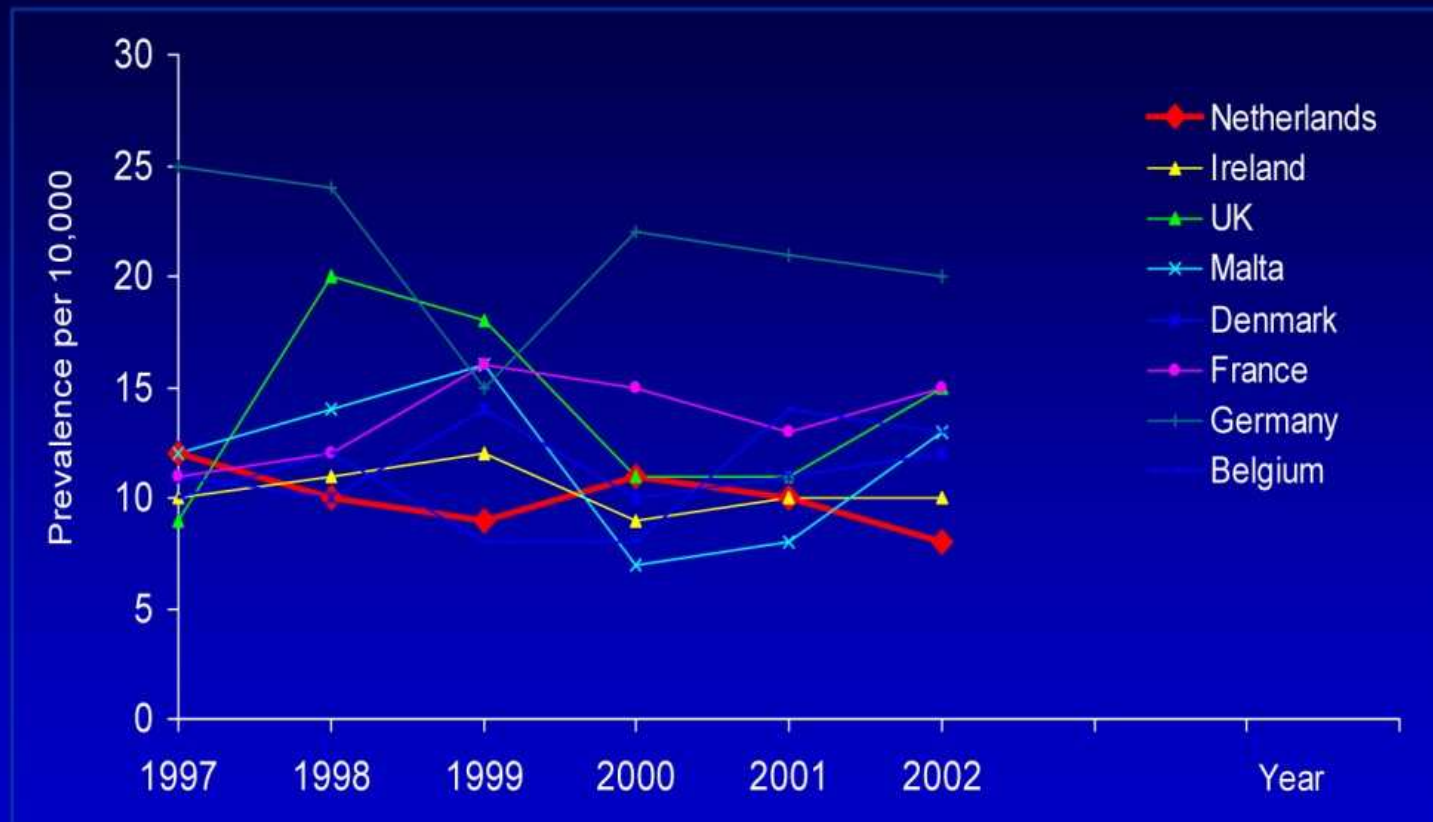
Incidence

- 1:1000 pregnancies
- Natural decline in incidence
- Almost 75% pregnancies are terminated
- Geographic variation
- Higher in areas of social deprivation

NTD Rates (England & Wales)

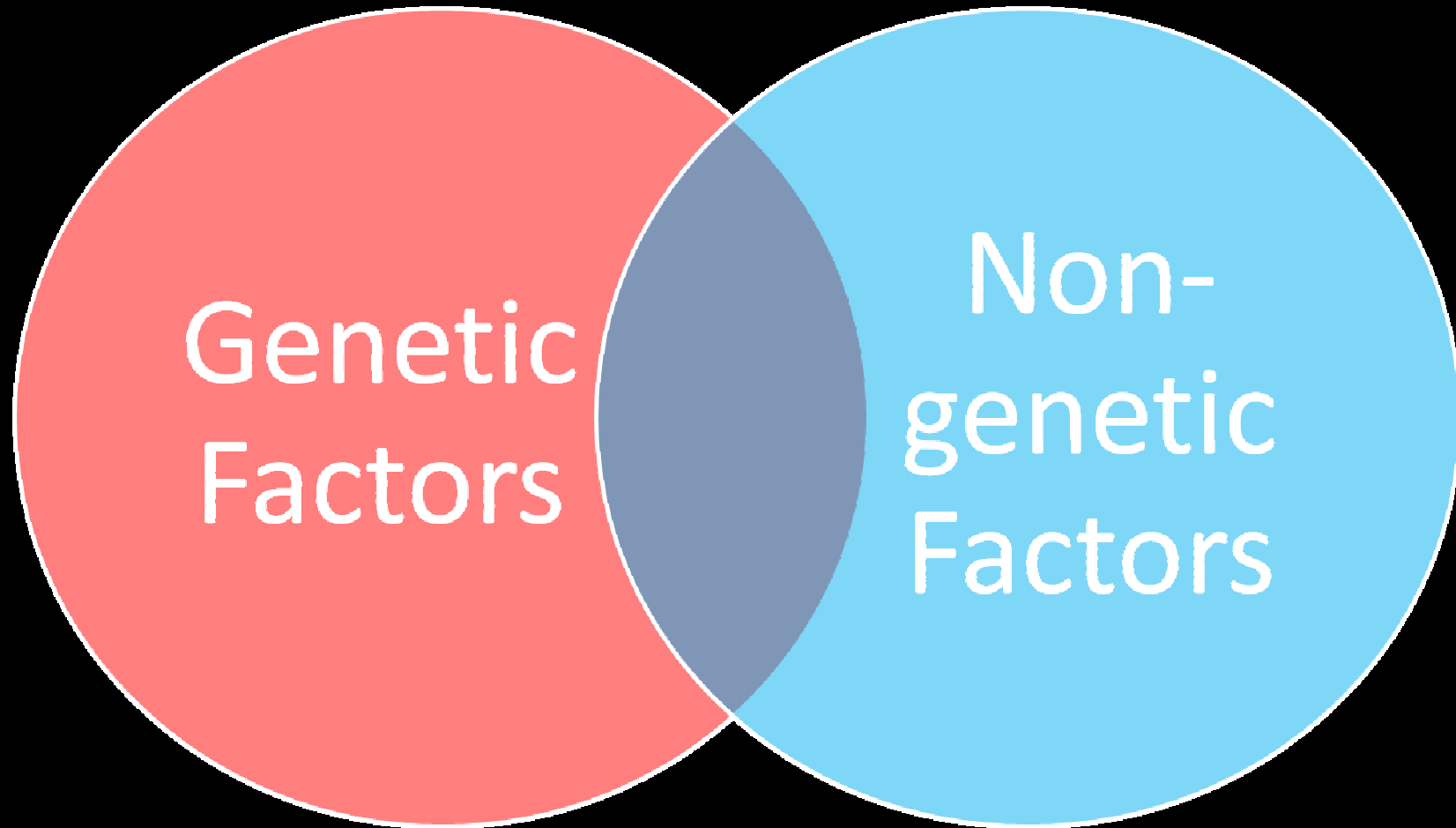


Prevalence of NTDs in Europe 1997-2002



Data from the Eurocat report (2005)

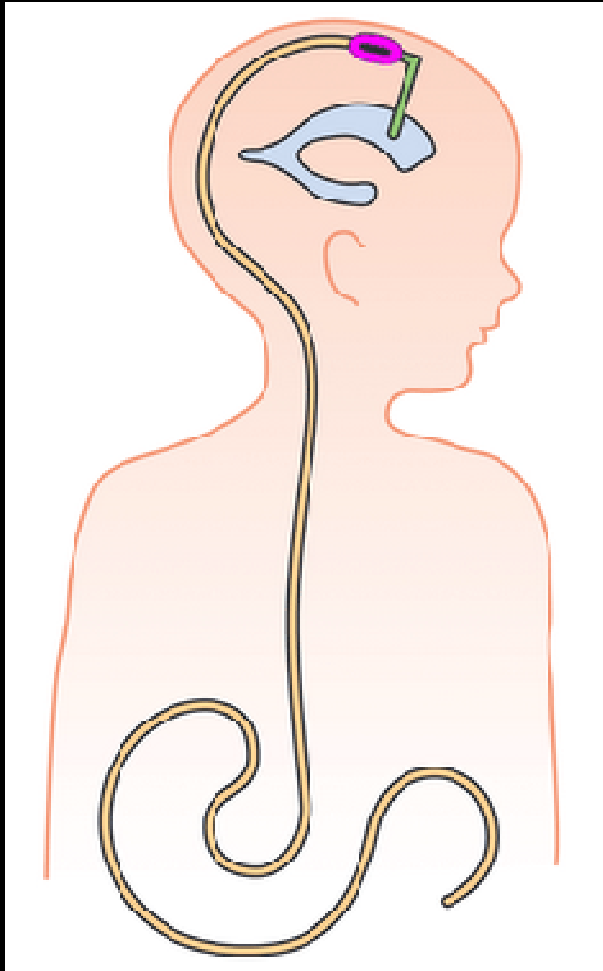
Aetiology



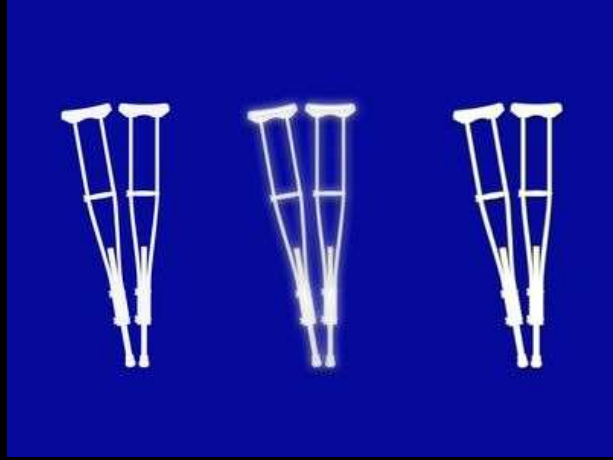
Myelomeningocele – Spina Bifida

- Hydrocephalus (80 – 90%)
- Motor deficits (50% wheelchair users)
- Sensory deficits (pressure sores)
- Sphincter control impairment (75% incontinent, risk of renal failure)
- Scoliosis
- Learning disability
- Arnold-Chiari Malformation Type II
- Tethered cord

Hydrocephalus



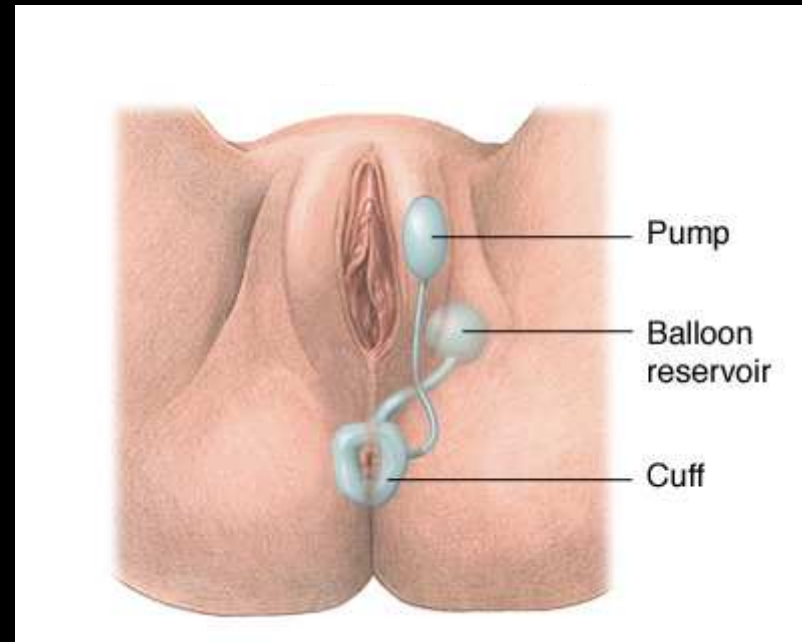
Motor Deficits



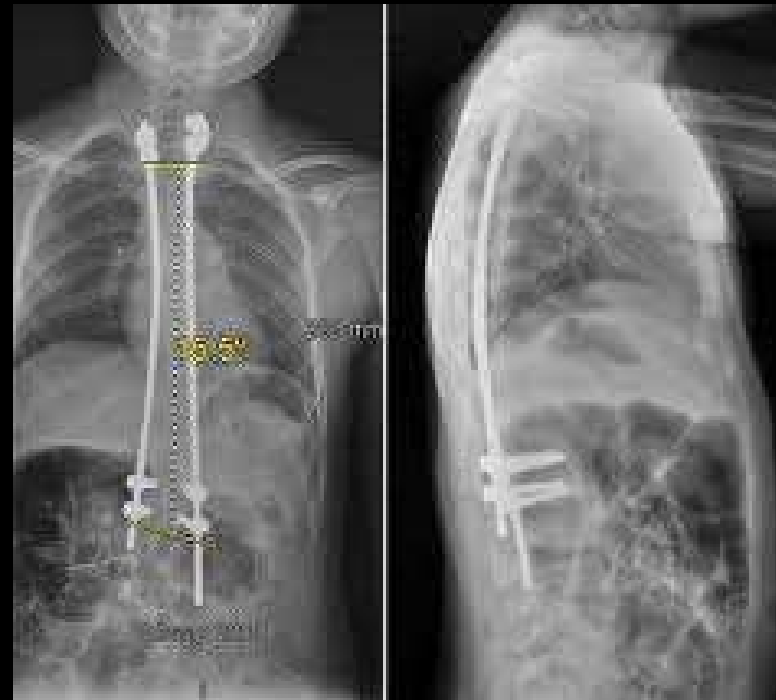
Sensory Deficits



Sphincter Impairment



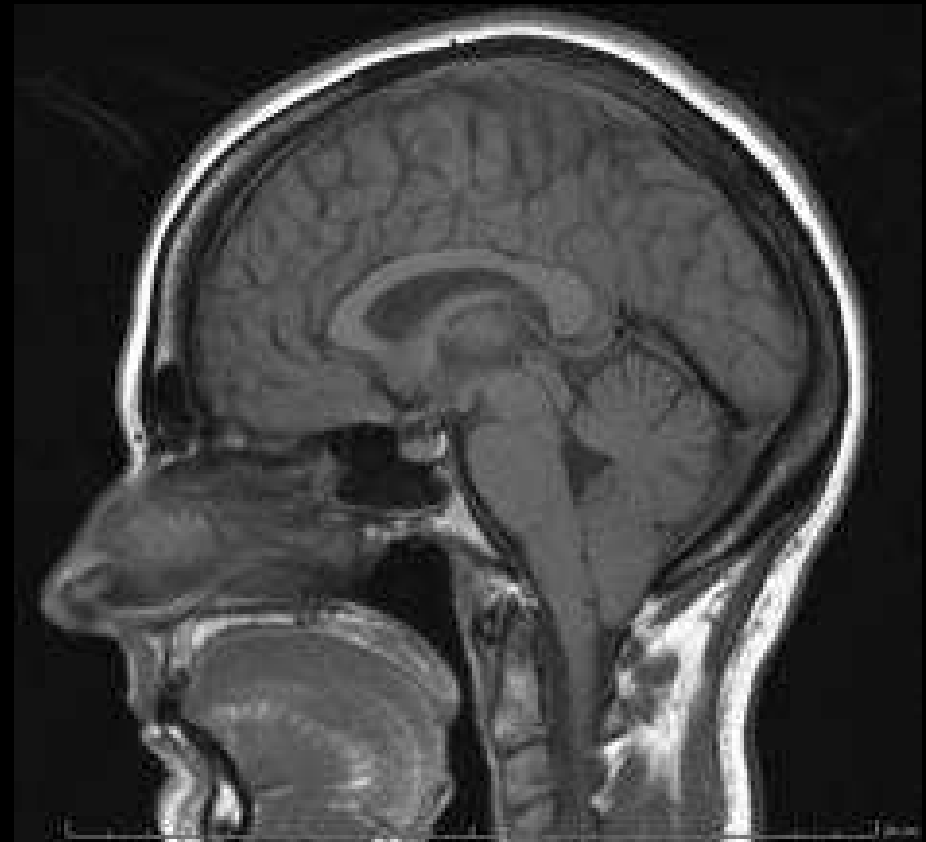
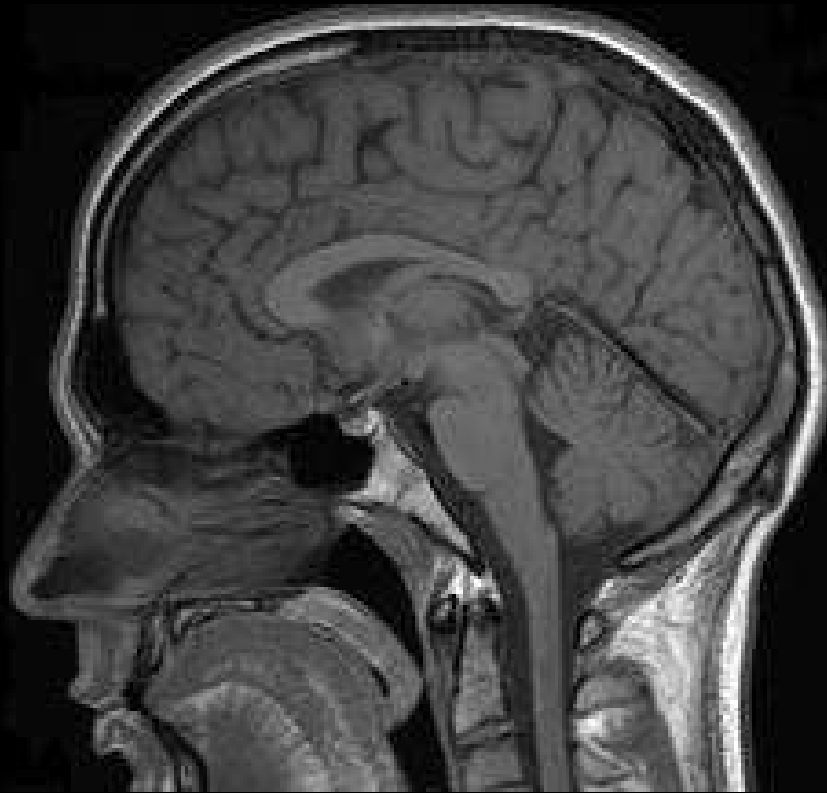
Scoliosis



Learning Disability



Arnold Chiari Malformation



Tethered Cord



Impact on Family Life

- Parental Anxiety
 - Health
 - Education
 - Recurrence
- Siblings
- Financial Burden
- Housing Adaptations
- Mobility

Nicola



December 1983 – Closure of lesion

January 1984 – Insertion of V-P Shunt

April 1984 – Hospital admission Shunt
over draining

September 1984 – Blocked Shunt
Replaced



July 1985 – Ilio-psoas Transfer of Right Hip

August 1985 – Adductor Tenotomy of Right Hip

November 1985 – Replacement of infected shunt



March 1987 – Tendon Release Right Foot

August 1987 – UTI

August 1987 – Shunt malfunction, no surgery required

November 1987 – Admitted for bladder irrigation

November 1987 – Fitted with calipers with a thoracic band



February 1988 – Commenced prophylactic antibiotics for UTIs

February 1988 - Blocked Shunt Replaced

August 1989 – Infected Shunt Replaced



March 1991 – Pressure Sore on Toe

April 1991 – Commenced CIC at school

May 1992 – Blocked Shunt Replaced

July 1992 – Blocked Shunt Replaced

December 1992 – Admitted UTI



January 1993 – Shunt replaced

February 1993 – Shunt replaced x 2



December 1996 – Problems with constipation

April 1997 – Full-time wheelchair user

April 1997 – Costo iliac pressure sore, fitted with spinal jacket



May 1998 – Blocked Shunt Replaced

June 1998 – Admitted with
headaches and nausea – ‘Slit
Ventricles’

February 1999 – Pressure sore in
groin



































































 SCOTTISH
SPINA BIFIDA
ASSOCIATION

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Specialist 4 Wheel Alignment



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TIMEX

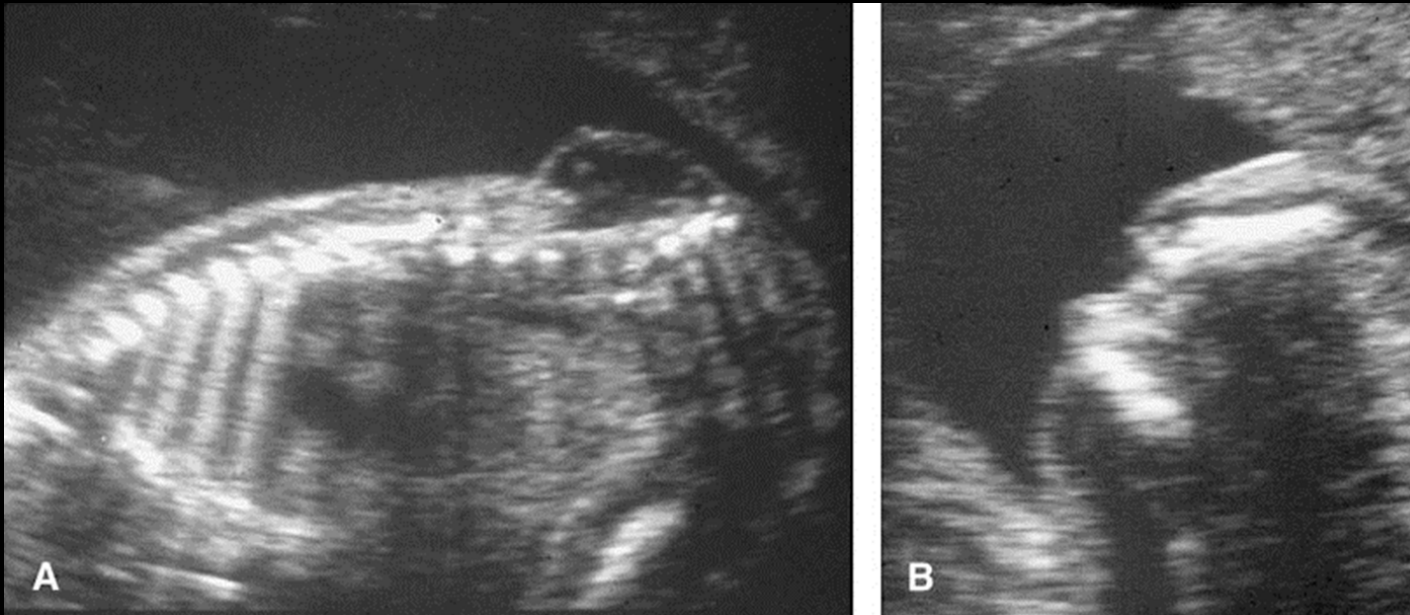
FLORA LONDON MARATHON 2009





Prenatal Diagnosis

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- Ultrasound scanning – 18-20 weeks





International Federation for Spina Bifida and Hydrocephalus





IF's mission is to improve the quality of life of people with Spina Bifida and/or Hydrocephalus throughout the world and to decrease the prevalence of Spina Bifida and Hydrocephalus by primary prevention.



International Solidarity



Human Rights



Network Development

IF is recognised as an NGO with Participatory Status at the Council of Europe

IF is recognised as an NGO with Consultative Status Category II with the Economic and Social Council of the United Nations

IF has signed a Memorandum of Understanding relating collaborative arrangements between the United Nations Department of policy co-ordination and sustainable development (DPCSD), New York

IF collaborates with WHO

IF collaborates with I.S.O.

IF is full member of EDF

IF is in communication with ICOD and IR

Prevention



IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

BAYER Bayer HealthCare

MediClara

Act against Europe's most common birth defects: one year on

Defining Neural Tube Defect prevention strategies in Europe

EDITION 2011

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