



# HEALTH

A Mother's Perspective .....

**Medical Students Teaching Programme: Learning Disabilities**

**MONDAY 18<sup>th</sup> FEBRUARY 2012**

Students need to arrive at **The Hickling Suite, Brandon MHU, LGH**  
for 9.15am please : the venue for the day's programme

9.30am -10.15am      Concepts and Causes of Learning Disability  
**Dr R Kiani (Consultant Psychiatrist Learning Disability)**

10.15am-11.00am    **Kylie's ideas**

11.00 am-11.15am    Coffee break

11.15am - 12.15pm    Health related stories' – **Ros (Kylie's Mum)**

12.15pm-1.30pm      Lunch

1.30pm-2.30pm      Autism Spectrum Disorder  
**Dr A Hiremath (Consultant in Learning Disability)**

# Birth – the good and the bad

- Birth –
  - Good – the paediatrician (baby doctor)
    - He was kind and thoughtful and supported me. He fully accepted that she had the right to a chance to live
  - Bad – the paediatric (baby) surgeon .....

## Birth issues

Kylie was born with a duodenal atresia,

You can't live with this,

An operation must be done right away,

The paediatric surgeon came to see me and said .....



Aged two days

“Are you sure you want me to operate?

You do know she has Down’s Syndrome  
and will live if I do?”







Aged 7 – Halloween time



Noddy – aged 6

Before knee problems



Aged 9 – with baby chimp

# The heart doctor

- Asked me to leave the room
- His reason? I would be distressed ....
- What about Kylie?
- I refused to go ....



Aged 10 months

# A GP

- We went for a childhood illness reason
- After dealing with the problem he said to me:
- “She’s a mongol isn’t she? She seems quite bright – have you considered plastic surgery?”



Excited!! First day at school

Aged 4 and three quarters



# Another GP

- Clinical symptoms
- Family history of hyperthyroidism
- Thyroid issues and Down's Syndrome
- “Children with Down's Syndrome don't have overactive thyroids .....



Aged 13

Kylie aged 13 – just before her thyroid went into overdrive



# What happened

- Thyroid count of 288
- Leaky valve in her heart
- Fatty deposits behind eyes which still cause problems
- Thicker neck
- Thyroid burned out
- Thyroxine medication for life



In Africa - Aged 9



# Barriers – TIME ....

- People with learning disabilities need more time than other people
- Kylie and pain reactions – a measurable delay
- Understanding and time
- Waiting in crowded places for a long time



Aged 18 months



# Families matter



# Kylie

