### FEEDING ISSUES

# An experienced parent's perspective, 15 years later

CHI family conference – Segrate, Italy, September 17-18 2013

## 2 minutes to get the picture...

You can imagine a week....

By mouth, Catherine drank liquids and ate purees until 7 years old

## Impacts of HI on feeding – Step by step

#### Post-natal period - investigation of hypoglycemia

Need of glucose IV and/or tube feeding

#### **Impacts**

Breast or bottle feeding

#### Infancy and childhood

• Need of continuous or bolus tube feeding

#### **Impacts:**

- > Sensory skills
- Parent/child relationship
- Care load
- Socialization

## Theories explaining feeding issues associated with HI

- Derived from treatment (medication, invasive feeding)
- 2) Physiological
- 3) A combination of both

If it is not only explained by 1) there is an urgent need to investigate, answer and treat 2)!

## What helped us through it

- 1) Getting support from special education (sensory and motor skills)
- 2) Getting support from specialized feeding issue psychologist
  - > seeing feeding issue as part of the disease not as something my child intently did
- 3) Medication (Megastrol acetate)

Not all feeding issues are as long lasting and as difficult but if you struggle with feeding issues, Get support and know you are not alone!

