



#### Lindsey Rigby

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## The Manchester experience

- Services commissioned by the government in 2006 both at Manchester and GOSH, London
- Binary centre, between Liverpool (Alder Hey Children's Hospital) and Manchester – 40 miles

#### The nuclear team

- 6 Endocrinologists
- 2 Nurses
- 1 clinical/research fellow
- 2 dieticians
- 1 SALT
- 1 psychologist
- 1 administrator/secretary

- New hospital in 2009 on the Manchester site
- New development planned for Liverpool in 2015
- Beds on both sites
- PICU and HDU on both sites
- PET scanning on Manchester site since 2011

#### Collaborations

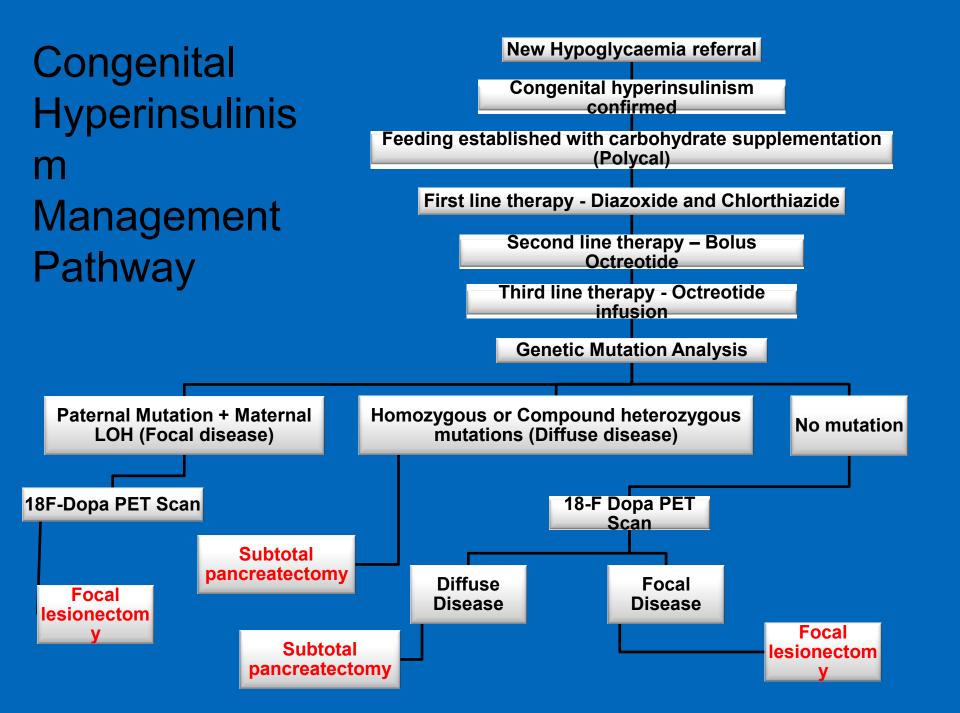
- University of Manchester
- Great Ormond Street Hospital
- Exeter for Genetic studies

# The Patient Experience

- Initial management at a local hospital with telephone management from CHI centre
  - Less complex/treatment responsive stay there for management until discharged home with our education package
  - Out-patient follow up at CHI centre

# More complex/treatment unresponsive

- Transferred to CHI centre
- Management maximised
- +/- PET scan
- +/- Surgery
- Discharged home with education package
- Out-patient follow up at CHI centre





- Community services mobilised prior to discharge
- On going telephone support by CHI CNS, altering treatment/feeds in response to blood glucose levels and general condition

### Parents support group

- Telephone numbers shared with permission
- Informal support
- Annual Parents day
- Fund raising
- Days out





# Thank-you

