

# DEVELOPING THE FIRST CHILDREN'S RARE DISEASE CENTRE AND SERVICE



**Birmingham Women's and Children's NHS Foundation Trust**

*Kerecuk L, McKerracher G, Tuberville-Greenley J, Adamson T, Broad M, Kokocinska M, Parkes S, Kainth J, Ash P, Bull C, McCathie L, Smith M, Boazman M.*

## BACKGROUND

- Birmingham Children's Hospital (BCH): major Specialist Children's Hospital with 35 specialties & Emergency Dept, Intensive Care
- Approximately 9000 patients with over 500 different rare diseases (RDs) from UK
- 11 highly specialised services with funding for multidisciplinary care: small proportion total patients with RDs.
- Most patients with RDs: multiple specialists, seen on separate days without coordination.



## AIMS

- To develop a dedicated RD facility
- To enable the best care with coordinated multidisciplinary & multispecialty RD clinics with peer support and access to research, information and treatments.
- To redefine best care from a one-size-fits-all to a patient-centred approach.

## METHODS

- Consultation with children & families to design the RD Centre with architects
- Events held to gather views of children, young people & families affected by RDs
- Activities such as "graffiti wall" to tell us what the children wanted in the centre, washing line with "tops and pants" for children to express what is good and bad about their experiences, respectively.



- Parents & carers forum groups including families who had lost their child
- Consultations were also held with Patient Support Groups



## METHODS

- To develop a **Fundraising Campaign** with Birmingham Children's Hospital Charity: named the **Star Appeal: Lighting the way for children with Rare Diseases**; launched in October 2015



- To provide support to families affected by RDs applied for funding for specialist nurses from **Roald Dahl's Marvellous Children's Charity**



## RESULTS

The RD Centre located on the ground floor of the new clinical building & includes:

- Family area as a waiting room & Patient Support Organisations can attend
- Play areas within the waiting room
- Kitchen for parents & storing special feeds
- Sensory room for patients with multiple sensory deficits & learning difficulties
- "Chill out room" for teenagers/children with autistic spectrum
- Disabled toilets & adult changing
- Wheelchair access
- Braille & Induction Loop Hearing
- Quiet room for difficult conversations
- 8 consulting rooms
- Physio & Occupational Therapy Room
- Research room
- Seminar Room for multidisciplinary meetings between professionals



*MDT clinic for Tuberous Sclerosis: families seen by all specialists in one visit*

## RESULTS

- The **Fundraising Star Appeal** reached target of £3.65 million by involving patients in the campaign and raised awareness of rare diseases

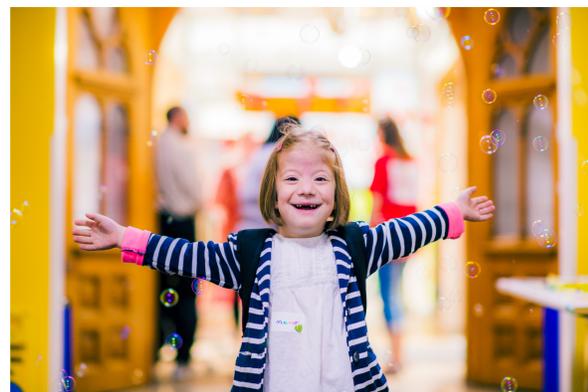


- **Roald Dahl's Marvellous Children's Charity** funding for
- Two Roald Dahl Specialist RD Nurses &
- One Roald Dahl RD Transition Sister who provide families with extra support help in accessing services available to improve their quality of life.



## CONCLUSION

- We are very proud to have the first Rare Disease Centre for children in the world designed by children, young people, families and Patient Support Organisations
- Collaborative working has helped the support for the patients and their families so this is a new concept in patient-centred care and much more than just a new building: it is a rare disease service
- Next Steps is to continue collaborations for research into all aspects of Rare Diseases including delivery of healthcare.



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**By your side**

