# Yourtobe Newsletter

#### Study update—200 Families recruited!

As a reminder, the Your Tube study started in February 2019 and involves two linked studies. The first was a qualitative study involving interviews with families and healthcare professionals to understand more about the impacts (which we call outcomes) of gastrostomy feeding. The second is what we call a cohort study. This will assess the safety, benefits and risks of gastrostomy feeding, comparing children who have formula feeds with children who have blended food in their diet. We hope to include 300 children in this part of the study.

Over the last year, research in the NHS has been dominated by a focus on urgent public health studies and studies involving COVID-19. More recently, many of the local research teams, across the 28 NHS Trusts supporting the study, have finally started to shift their focus away from urgent public health research, back to other areas of important research. A renewed effort to approach eligible families about taking part in the Your Tube Study has meant we have now recruited 200 families to the study! **We would just like to say a huge thank you to all the clinicians and research personnel across the NHS and the four Children's Hospices supporting the study, who have made reaching this milestone possible.** We hope this momentum will continue as we approach the October deadline for recruitment.

## The Martin House RESEARCH CENTRE

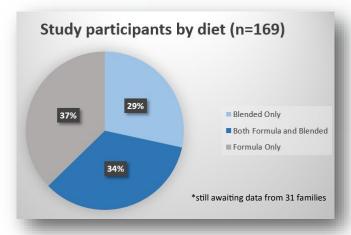
#### Martin House Research Centre

The Your Tube Study is just one of many research projects being carried about by the Martin House Research Centre.

The Martin House Research Centre is a multi-disciplinary centre for research on the care and support of children and young people with life limiting conditions or medical complexity, their families and the workforce that care for them.

The Centre recently held it's 2nd biennial conference, virtually. The full conference is available to watch using the links on the conference page, available here:

https://www.york.ac.uk/healthsciences/ research/public-health/projects/ martinhouse/mhrcconf2021/



## Get to know the team

#### Karen Horridge—Co-investigator

Karen is a paediatrician with over 30 years of NHS experience of providing healthcare for disabled children and young people. She now works in South Tyneside.



Karen is committed to improving the

evidence to support child and family-centred decision making about choices for eating, drinking and improving nutrition for disabled children and young people.

#### What are the diets of the children taking part in the study?

We have so far been able to recruit 106 families feeding their child on any amount of home-blended food through a gastrostomy (48 on blended food only and 58 on a mix of blended and formula). We currently have 63 families who are feeding their child on prescribed formula feeds-only. This is close to a 2:1 ratio. Overall we are aiming for a 1:1 ratio between these two groups, that is any amount of home-blended food versus milk-based formula only.

We would therefore like to ask our research partners in the NHS and across the four children's hospices to focus on approaching families whose child is on a **prescribed formula-only diet**. This will allow us to collect sufficient information on these two different groups in order to make meaningful comparisons, and to achieve the overall goals of the study. We are still happy to recruit more families whose child is on a home-blended diet, as more participants means we are able to collect more data, and be more confident in our findings at the end of the study.

"It is great to be part of the co-production journey with children, young people, their families and other experts in this research journey to better understand what works best for improving quality of life for children and young people who are tube-fed."

## Contact the study team

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#### Study website

https://www.york.ac.uk/healthsciences/ research/public-health/projects/yourtube/

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