Hello!

Welcome to the very first edition of the CARE Study Newsletter. My name is Rochelle D’Souza, a fourth year intern working on the CARE study. I will be sending you monthly updates on the progress of the study, as well as communicating any changes, set backs or successes we might have. If you would like to add anything to the newsletter, you can always reach me at mpsrc@mcmaster.ca.

An Introduction
This study is a prospective, repeated measures cohort pilot study, focused on assessing the quality of life of caregivers of patients referred for a surgical feeding tube within the first year after insertion. The caregiver’s demographic information will be collected and they will be given 3 surveys to measure their quality of life. Pre-insertion data will be collected at 2 points prior to the procedure and follow-up will take place at 2 weeks, 3, 6, 9, and 12 months following their surgery.

Enrollment Update
The CARE study, which started on November first, is in full swing. So far we have enrolled 3 patients into our study. We’d like to thank Dr. Flageole for her help in enrolling our first patient! It really got the ball rolling. We’d also like to thank all the doctors, nurses and residents for their help in scanning and recruiting eligible patients.

Our goal for this pilot study is approximately 56 patients to be recruited over a period of 12 months.

Screening for Patients
Since this is a pilot study we have been keeping track of the number of patients that we have been able to enroll (3) as well as those that may be eligible but we have not had time to recruit them (7). We’ve noticed that most patients that come through the clinic have been asked to participate, however we’ve missed a significant number of in-patients. This might be due to the fact that their surgeries are not scheduled ahead of time, so we are not able to assess if they are eligible before their child undergoes surgery. So even if you operate, or see a patient who does not have time to be recruited before their surgery, or if you approach a family and they say no-please let Julia know as that information is VERY important to our pilot study!

Current Progress
We are currently in the process of setting up a database to input and code all the information gathered from the three surveys that we are administrating: the SF-36, the PECI and the CSI, and following our enrolled participants. With your continued help, we hope to see our recruitment numbers increase over the next little while.

We Need YOU
We’d like to remind you that any time you see a patient who fits the inclusion criteria of the CARE study please contact our Research Coordinator, Julia (Pager 7058), immediately so that she can try to enroll them.

The INCLUSION criteria for the study is:
1. Child of the primary caregiver is under the age of 18 and is referred to the McMaster Pediatric General Surgery service for surgical insertion of a feeding tube
2. Primary caregiver of the child is present at most meal times
3. Primary caregiver is responsible for feeding the child greater than 50% of the time
4. Primary caregiver is able to read, write and understand English
5. Primary caregiver is able to provide informed consent

The EXCLUSION criteria for this study is:
1. The child of the primary caregiver has previously had a surgically inserted feeding tube
2. The primary caregiver is responsible for feeding the child LESS than 50% of the time prior to the referral for a feeding tube
3. The child of the caregiver is 18 years or older
4. Caregiver does not provide informed consent
5. Caregiver does not understand written and spoken English

Keep an eye out for our colorful posters to be found around the 2Q clinic!

We also have handy pocket cards-contact Julia if you would like one!

Thank you for your support and we wish you happy holidays!

The CARE Study Team