NEWSLETTER

ISSUE 1
WINTER 2019

# HOUSTON I-ACQUIRE

## Welcome to I-ACQUIRE!

This newsletter is brought to you by the Parent Council for the I-ACQUIRE trial. We – and this newsletter – will be active throughout the trial; with the aim of supporting and engaging everyone involved.

All of us on the Parent Council are proud parents ourselves to a child who survived a stroke. Some of us have taken part in clinical trials previously; some of us haven't – but we are all truly excited that the future for pediatric stroke rehabilitation is going to be in the spotlight with this study.

You are now part of this incredible $13.5million funded 5-year program, and we hope you're as keen as we are to see what it brings. This huge monetary figure mostly covers the usual costs associated with the therapists' time.

The Fralin Biomedical Research Institute, a university-level research institute of Virginia Tech, will oversee the trial, which includes funding for the program's work in Roanoke as well as sub-awards to a clinical coordinating center at the University of Cincinnati, an assessment core at The Ohio State University, a data management center at the Medical University of South Carolina, and a neuroimaging center at Stanford University.

**Did you know?**
**This trial is the first and ONLY phase III pediatric clinical trial - we're already making history!**

A team of I-ACQUIRE master therapists in Roanoke trained 30 therapists from across the 12 sites earlier this year and are now embarking on the first of approximately 240 infants (8m-24m) partaking in the trial.

The primary outcome of the trial will be focused on the upper limb function, with secondary and tertiary outcomes respectively being how well the limb is then incorporated into everyday (bimanual) life; and assessment of gains in other areas such as speech, cognitive function, and socio-emotional development.

Another aspect of the study worth emphasizing at this point is that any trial must be a true, unbiased, test. Remember not to let your assessors know which treatment group you are assigned to. Personal opinions or hearsay cannot influence judgement – which could invalidate any results. Those results in black and white are what will provide information on the efficacy of this treatment – it's going to be a long but worthwhile wait for the answers!

### ENROLLMENT

| | |
|---|---|
| Ann Arbor | 1 |
| Baltimore | 0 |
| Birmingham (pending) | 0 |
| Boston | 6 |
| Chicago | 0 |
| Cincinnati | 3 |
| Columbus | 0 |
| Houston | 0 |
| New Haven | 1 |
| Philadelphia | 0 |
| Roanoke | 4 |
| San Diego | 0 |
| **TOTAL** | **15** |

As of 2/6/2020

### PARENT RESOURCES:

**pediatricstrokewarriors.org**
Nonprofit support site: request a "Warrior Bag"; full of useful advice for newly diagnosed families.

**chasa.org**
Children's Hemiplegia and Stroke Association. We also advocate their Facebook group. facebook.com/groups/chasahemiplegia

**nihstrokenet.org/i-acquire**
Here you can satiate your knowledge for the trial and its' backers - download the full trial protocol document, manual of procedures, and more.

**visithoustontexas.com**
Go-to website for visitors to Houston. Featuring a full events calendar and lots of ideas for things to do outside of therapy.

**CIMT.** I-ACQUIRE is a form of pediatric Constraint-Induced Movement Therapy (CIMT). You may have reservations or misconceptions about CIMT: will my child be OK with the constraint? What if they can't handle the length of therapy they're assigned? What if they're drawn into the delayed treatment group? These questions are all ones that we, as the parents, have asked ourselves. From experience we know that children tolerate the cast incredibly well. What we genuinely don't know yet is the optimum dosage of therapy nor the best age for intervention. In smaller trials, significant benefits were seen – across the treatment groups. If this larger trial is a success; then the I-ACQUIRE approach could well become "business as usual". It's intensive: either 3 or 6 hrs a day; 5 days a week for 4 weeks. The therapy techniques involve movement, reinforcement, repetition, and refinement – or "shaping" – and are provided in a home or natural environment. The total child is always considered – it's not *just* about the hand.

## MEET THE THERAPIST: KELSEY BURKE

**Kelsey Burke** is a senior occupational therapist in the Fralin Biomedical Research Institute Neuromotor Research Clinic, in Roanoke. Kelsey received a Bachelor's degree in Exercise Science and a Master's degree in Occupational Therapy from the University of Alabama in Birmingham. She recognises that intensive therapies help people gain independence and confidence: "I'm passionate about empowering and equipping kiddos with the skills to play to the highest extent possible".

Kelsey herself both works and plays hard: "I am always planning another international trip. I enjoy meeting others and listening to what most excites them... I chase mountain top views, food, and long drives down the Blue Ridge Parkway."

## IN THE NEWS ...

In this segment, we'll try to bring you some interesting news and views from the world of pediatic stroke; for example a published paper that will bend your mind for half an hour. To start with, we're recommending you google this one:

**"Neurophysiological mechanisms and functional impact of mirror movements in children with unilateral spastic cerebral palsy"**