



Live and Learn

CALLS

HFM Follow-Up
Study

Summer 2012

What happens to the information gathered in this study?

In the first phase of this follow-up study, we used 10 different questionnaires and tests to collect information from parents, children and teachers. In the current phase of follow-up, we are using twice as many tests and surveys. You may be wondering ‘what happens to all of this information?’ Here, in a nutshell, is what happens: Answers are coded, scored, entered into a database, checked for errors, and corrected if necessary. A team of psychologists, epidemiologists, and statisticians conduct statistical analyses to address a specific research question. For example, do parents of children with hemifacial microsomia rate their child’s quality of life the same as parents of unaffected children do? A manuscript is then written, which includes why the particular re-

search question is worth studying, who participated in the study, what the study results are, and what the findings mean. The manuscript is then submitted to a journal for peer-review, where other researchers together with the journal editor decide if the results are valid and important enough to be published. If the decision is yes, then the manuscript becomes a journal article that will be published, making it available to the general scientific community and public. With a study like ours that collects lots of information, many different articles will be published over many years. To date, we have published 11 articles, 2 are under-going peer review, and 3 are in preparation. And we anticipate many more. We couldn’t do this without your help – we appreciate it!

Measuring quality of life

When the children in our study were 5 to 12 years old, we asked parents and children to fill out a survey about the health-related quality of life of the child. The survey asks 23 questions about problems children may experience during physical activities like sports, managing their feelings, getting along with other kids, and going to school. We wanted to know if answers would be different between kids with hemifacial microsomia (HFM) and kids of about the same age without HFM.

Children’s answers were about the same, on average, for kids with and without HFM. The only difference we found was that kids with HFM more often said they were absent from school for doctor visits than the children without HFM said.

Parents of children with HFM also answered that their child missed more school and also said that their child had more difficulty with physical activities, relating to others, and feeling sad or blue than the parents of children without HFM. However, it is important to note that parents in both groups reported their child’s quality of life to be good, and there

were few reported problems in either group. For example, 12.6% of parents in the HFM group reported that their child had problems with sports activities or exercise, compared to 4.9% in the unaffected group. Although this difference gives us important clues about what we might watch as children age, the numbers also show that most parents did not see any problems in this area. The biggest difference between the two groups of parents was about their child being teased by other kids. Here, 28.1% of parents in the HFM group reported that their child was teased by others, compared to 12.4% in the group without HFM.

Overall, these findings suggest to us that children and parents in our study have few problems related to quality of life. However, parents’ views suggest to us some areas that deserve special attention for children with HFM. Missing school due to doctor’s appointments may not be avoidable, but we can make health care providers aware. In CALLS, we are still asking parents and children about quality of life to learn what life is like at older ages.



Meet our CALLS Testers

CALLS FACTS & STATS

As of July 2012, we have tested 162 children in 21 states and Canadian provinces.

Here are the states we've visited so far:

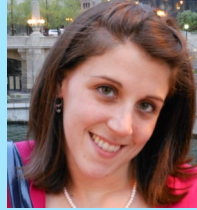
- Alaska
- Arizona
- California
- Connecticut
- Georgia
- Illinois
- Indiana
- Kentucky
- Louisiana
- Massachusetts
- Michigan
- Missouri
- New Hampshire
- New Jersey
- Ohio
- Ontario (Canada)
- Oregon
- Rhode Island
- Texas
- Virginia
- Washington

We have 348 more children to test; we'll be returning to many of these states and visiting others for the first time.

EMILY

What do you enjoy doing in your free time?

Outdoor activities such as skiing, camping, hiking, reading, traveling, hanging out with friends.



Most cherished childhood experience?

Camping with parents in the summer.

If you could choose to have any superpower, what would it be and why?

Flying- so I could get to places faster and have the ability to see the world as a bird sees it.

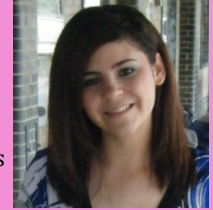
A favorite memory of a testing experience:

Once during one of my testing sessions it started to snow. As a break we went outside and played in the snow for a few minutes.

CHRISTINE

What do you enjoy doing in your free time?

I love to travel and explore new places, which is part of what drew me towards this job. I lived in England and really grew to love it.



If you could choose to have any superpower, what would it be and why?

Flying- so I could save time and it would be so much cheaper than plane tickets!

A favorite memory of a testing experience?

It is always great to see the kids do their best, even the really difficult tests. You can really feel the kids' sense of accomplishment when they're finished.

CASSANDRA

Most cherished childhood experience?

Spending time at the beach, swimming and surfing.



What do you enjoy doing in your free time?

I love running, biking, swimming, and triathlons, where I get to do all three.

A favorite memory of a testing experience?

I always enjoy meeting families and describing the testing experience. It's great when kids become interested in the testing and get excited about new things they might learn about themselves from the testing. Also, traveling to different places to do testing is always fun and exciting.

MYLIEN

What do you enjoy doing in your free time?

I love to hike, so whenever I have a few hours before or after a study visit, I find local trails.



If you could choose to have any superpower, what would it be and why?

Being able to transport myself in the blink of an eye from one place to another- Star Trek style.

A favorite memory of a testing experience?

When I see kids working through the tough parts. It's always inspiring to watch how they overcome any worries they might have and do their best.

Please don't hesitate to contact us for any reason:

If you live east of the Mississippi River, contact our Boston site **617-734-6006, ext. 450** or by email **calls@bu.edu**

If you live west of the Mississippi River, contact our Seattle site **206-884-7492** or by email **Tristen.Nash@seattlechildrens.org**

We're on the web — look us up at:

www.bu.edu/slone/calls

Boston staff: Martha Werler, Principal Investigator; Lisa Crowell, Study Coordinator; Emily Comella and Christine Goodwin, Psychometrists; Michael Bairos, Database Analyst; Helen Lee and Stan Fonseca, Office Assistants; Mary Khetani, Consultant

Seattle staff: Matt Speltz, Co-Principal Investigator; Brent Collett, Co-Investigator; Tristen Nash, Study Coordinator; Kristen Daniels, Data Coordinator; Cassandra Cerros, Mylien Duong, and Kate Silver-Heilman, Psychometrists.