



Live and Learn

Spring 2011

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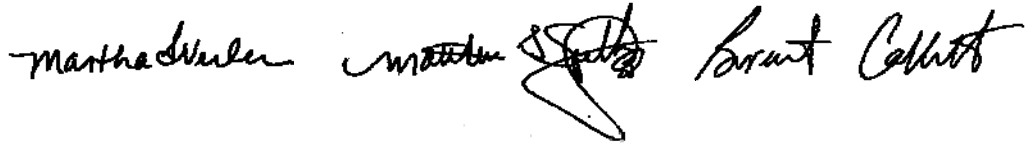
"In 2003, when our study on pregnancy factors and HFM was completed, we knew families also wondered how their affected children would fare as they grew up, and so we decided to expand our research to help answer that question, too."

- Martha Werler



Thank You

We want you to know how much we appreciate you. By taking the time and making the effort to participate in these studies, you are helping us learn about HFM and how it affects children and families. We hope that the information we gather now will help families in the future. While you might never know them, you could have a lasting impact on their lives.



Martha Werler, ScD
Principal Investigator

Matthew Speltz, PhD
Co-Principal Investigator

Brent Collett, PhD
Co-Investigator

HFM Follow-Up Study Outcomes



We wanted to let you all know about the findings from our recent HFM follow-up study. This study looked at the health and development of children with and without HFM between the ages of 5 and 8. This was the first big study of social-emotional, neurodevelopmental, and health-related outcomes in children with and without HFM.

People who work with children with HFM are very interested in the results of our study. We've been writing papers and giving presentations in the hopes of raising awareness about HFM and how it affects children and their families.

To read about some of our study outcomes, turn the page!

Here is a quick breakdown of who participated between 2004 and 2009:

1106 Eligible

Families:

- 839 children without craniofacial problems
- 267 children with craniofacial problems

764 Families

Participated:

- 570 children without craniofacial problems
- 194 children with craniofacial problems



HFM Follow-Up Study Outcomes (Cont.)

Social-Emotional Development

Most children with and without HFM scored in the “age-appropriate” range on measures of social-emotional development. This means that major behavioral or psychological problems were rare. As a group, however, children with HFM tended to be less social or outgoing than children without HFM, according to their parents and teachers. We did not find any differences between the two groups based on the children’s own report. These findings are summarized in a paper to be published by the *Journal of Pediatric Psychology*.

Neurodevelopment and Learning

To find out more about neurodevelopment and learning in children with and without HFM, we had teachers complete screening measures of language and visual-motor skills. We also collected reports from parents and teachers about how kids were doing in school. Again, we found that children generally scored in the “age appropriate” range, but the average scores on these measure were lower for children with HFM. In other words, as a group, children with HFM had more difficulty with language, visual-motor tasks, and academic achievement than children without HFM. These findings were just published in the *Archives of Pediatrics and Adolescent Medicine*.

Sleep Patterns

Good sleeping habits are important for children and adults alike, so we wanted to better understand how well children with and without HFM sleep. Using information collected on 474 children, we found that the average hours of sleep time (10.3 hours) was less than the 11 hours pediatricians recommend for children of this age. Though many different things can influence sleep patterns, we wondered whether children with HFM might be less likely to be ‘good sleepers,’ particularly since some cases can have breathing problems. We found children with HFM were slightly more likely to be sleepy during the day and almost twice as likely to be snorers. Also, 32% of HFM affected children would wake up at least once during the night compared to 25% of children without HFM. These findings were published in *Pediatrics*.

Dental Health

One of our research goals was to better understand the types of dental treatments children with and without HFM receive and their results. We reviewed 503 records and found that dental appointments were of similar length. Children with HFM were: (1) less often reported as having good or excellent oral health as compared to children without HFM (68% vs. 78%); (2) more often reported as having at least one cavity when compared to children without HFM (60% vs. 46%); and (3) more likely to be referred to an orthodontist because their teeth were misaligned. With this in mind, it is important that all children, especially those with HFM, see their dentist every year to prevent significant dental disease.

Breaking News

The National Institute for Dental and Craniofacial Research (NIDCR DE011939) continues to value this work and has recently approved a new five year study so that we can forge ahead and learn more with and from you.

What is the name of this new project?

The Child and Adolescent Learning and Living Study (CALLS)

What is the goal of CALLS?

Based on the findings from our work so far, we hope to learn more about social-emotional, neurodevelopmental, health, and quality of life outcomes in young people with and without HFM. This time, we'll do more detailed assessments. We hope to get a better idea of what kinds of interventions and supports will be most helpful for children with HFM.

Who can be involved in this project, and what will they be asked to do?

We are inviting everyone who has participated in our earlier follow-up study to join this project. We hope to get information for this project from three groups of people: young people, their parents, and their teachers. Here is what we are asking them to do:

Youth: We would like to do more detailed, in-person assessments to better understand how young people with and without HFM see, hear, think, speak, communicate, and process information. We also want to give young people a chance to tell us about how they see their lives going – what's important in their lives right now and how they judge the quality of their lives. Young people who participate will be given \$30.00.

Parents: We will ask parents to complete questionnaires similar to those completed for our earlier project. These questionnaires ask about the family's background, their child's medical history, and their perspectives about their child's development. We plan to be flexible and available to get this information before, during, or after our visit. We also can get some of this information over the internet. We are happy to give participating parents \$80.00.

Teachers: With parent permission, we will invite the child's teacher to complete two surveys by mail about the child's social communication and learning. We will give each teacher \$20.00.

We will be sending a team member from one of our two project sites (Boston or Seattle) to meet with you and your child to gather information.

Here is what that might look like:

1) Here we are



2) We can travel to you



3) We meet with you and your child



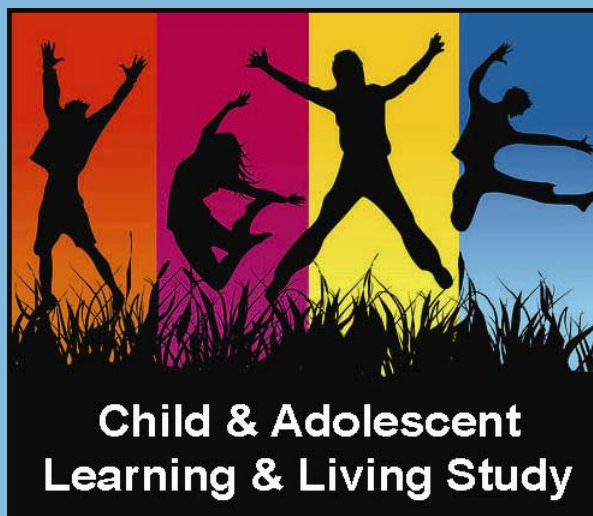
All information we receive is kept strictly confidential. Protecting your privacy is important to us.

Stay in Touch

Please don't hesitate to contact us to learn more about this study or tell us your thoughts.

If you live east of the Mississippi River, we can be reached in Boston at **617-734-6006, ext. 450** or by email at **calls@bu.edu**

If you live west of the Mississippi River, contact our study team in Seattle at **206-884-7584** or by email at **jenna.rudo-stem@seattlechildrens.org**



We're on the Web!
www.bu.edu/slone/calls

Meet Our Team

This project continues to be a strong collaborative effort between researchers and staff at Slone Epidemiology Center at Boston University and Seattle Children's Research Institute. We look forward to traveling out to meet with families like yours in person. Until then, here are some pictures of us so you can see the team behind the work:



From left to right: Matthew Speltz (Co-PI), Jenna Rudo-Stern, Christa McCormick, Diana Prise, Kristen Daniels, Brent Collett (Co-I)



Clockwise from top left: Lisa Crowell, Michael Bairos, Yaina Mercado, Martha Werler (PI), Mary Khetani, Meredith Black