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Ongoing ACC Research Efforts

For 17 years, the ACC Network has shared information about callosal conditions with individuals, families, and professionals. Today, numerous ACC research projects exist both in the United States and around the world. Perhaps some of you have participated in these studies or have plans to do so. We are grateful for your help in the growth of new knowledge about callosal conditions.

In this issue of *The Callosal Connection,* we will share information about recent research here at the ACC Network. We will also share research news and information sent to us by other ACC researchers who have been in contact with us.

ACC Network, University of Maine, Orono, Maine

We are pleased to announce the publication this spring of our report "Health-related issues in individuals with agenesis of the corpus callosum" in *Child: Care, Health, and Development*. In this report, we compared information collected from family surveys about individuals with ACC and their siblings who have a corpus callosum. We identified some health issues that are more common in these individuals with ACC. Our data support the stories you have told us about eating, elimination, and sleep problems and unusual responses to painful situations. You can read an early version of this report on the ACC Network website (www.umaine.edu/edhd/research/accnetwork.htm) by clicking on the "Research" link. We'd like to thank all the families who supported us in this effort by filling out surveys or by sending donations to cover the research costs.

In May, Gary Schilmoeller presented our health-related research findings at Grand Rounds, an event sponsored by Eastern Maine Medical Center, in Bangor, Maine. This lecture to community healthcare providers focused on information that would be important for them to know when providing healthcare to persons with ACC. We hope to continue utilizing opportunities such as this to educate communities about issues related to ACC.

Boston Children's Hospital, Boston, Massachusetts

By Omar Khwaja, M.D., Ph.D.

At Boston Children's Hospital, two programs serve families with children who are diagnosed with ACC. Neurologists Omar Khwaja, M.D., Ph.D. and Adre du Plessis, M.D., and geneticist Christopher Walsh, M.D. collaborate in these research and clinical programs.

The Advanced Fetal Care Center accepts referrals of families given a prenatal diagnosis of an abnormality of the corpus callosum. Families can receive access to state-of-the-art diagnostic imaging and meet with neurologists and other specialists, such as geneticists and neurosurgeons. During a coordinated visit, the Advanced Fetal Care Center team aims to provide the best available advice about diagnosis, management, treatment, and outcome.

When appropriate, families are offered the opportunity to be involved in research on ACC. For example, Children's Hospital neurologists currently are using advanced MRI techniques to examine the normal and abnormal development of the corpus callosum in the unborn baby's brain.

Research at Boston Children's Hospital is focused particularly on identifying different patterns of corpus callosum abnormality and what these imply for a baby's future neurological and psychological development.

The second program available at Boston Children's Hospital serves families who have an infant or young child diagnosed with ACC. The Children's Hospital Fetal-Neonatal Neurology Program provides comprehensive neurological care from birth into childhood by a team of neurologists, neurology nurses, therapists, and psychologists. Families with babies and young children with ACC can receive assessment and management of their child through this program and may be able to participate in further research on corpus callosum development.

If you are interested in learning more about the services and research at Boston Children's Hospital Fetal-Neonatal Neurology Research Program, please contact the program administrator, Kristin Feltz, at 617-355-8994. Referrals to the Advanced Fetal Care Center can be made by contacting 617-355-3896 or 1-866-FETALCARE. You can learn more about these programs or Boston Children's Hospital by visiting their website at <www.childrenshospital.org>.

California Institute of Technology and Travis Research Institute, Fuller Seminary,
Pasadena, California

By Lynn Paul, Ph.D.

ACC researchers in the fields of neurology, neuropsychology, neuroscience, neuroradiology, genetics, and evolutionary biology met at California Institute of Technology in Pasadena, California, in January 2006. The new research collaborative includes teams led by Elliott Sherr, M.D., Ph.D. from University of California, San Francisco, Warren Brown, Ph.D., from the Travis Research Institute, Fuller Seminary, and Lynn Paul, Ph.D. from California Institute of Technology. The goal of this collaborative effort is to accelerate ACC research and to facilitate translating research into clinical practices that may be useful to families affected by ACC.

Currently, the Travis Research Institute and California Institute of Technology are seeking volunteers with ACC for their cognitive and social research projects. The testing may include standard neuropsychological measures, MRI, EEG, and eye-tracking assessments, depending on the age of the participant. Testing takes place in Pasadena, California, and qualified participants may receive some assistance with travel expenses.

To participate in this study, individuals must:

- Be 7 years of age or older
- Have complete or partial ACC
- Have a full scale IQ score of 80 or greater.

For more information about this research project, or if you are interested in participating, please contact Lynn Paul, PhD., using the contact information below.

e-mail: lkpaul@hss.caltech.edu
Phone: (626) 395-4077

University of California,
San Francisco, California

By Mari Wakahiro, M.S.W.

Dr. Elliott Sherr and his colleagues at University of California, San Francisco, continue their research into the causes of callosal conditions and the impact of ACC (see their report in *The Callosal Connection*, Spring 2005 issue). They are excited to announce the recent publication of two articles stemming from their research. One has been published in the journal *Neurology* and describes their use of comparative genomic hybridization (CGH) arrays to find regions on chromosomes that are deleted or duplicated in individuals with ACC. The second manuscript, which will be published in the *American Journal of Roentgenology* this spring, describes the brain features seen in MRI scans from over 100 individuals with ACC. This is the largest collection of scans analyzed to date. It also forms the foundation of their ongoing study to understand whether radiographic features can help predict outcomes for children newly diagnosed with ACC.

For more information about participating in this study, visit their website <www.ucsf.edu/brain/callosum/callosum.htm> or contact their study coordinator, Mari Wakahiro, using the contact information below.

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University of London, United Kingdom

By Rhonda Booth

Researchers at the University of London, United Kingdom, currently are conducting a study of social adaptation in people with partial or complete absence of the corpus callosum. This study is being led by Francesca Happé, Ph.D., in London, in collaboration with Lynn Paul, Ph.D., at California Institute of Technology and Warren Brown, Ph.D. of the Travis Institute, Fuller Seminary. They are investigating how ACC may impact individuals in their understanding of emotions and of social situations. Participants of this study are asked to complete tasks assessing social understanding and emotional processing in stories, video clips, and computer-based games.

To participate in this study project, individuals must:

- Be 6 to 60 years of age
- Have complete or partial ACC
- Have no additional medical conditions, such as a genetic syndromes
- Not have a severe visual impairment
- Not be severely developmentally delayed.

Dr. Happé plans to test participants in Great Britain and in the United States during future research visits.

If you are interested in participating or would like to know more about this study, please contact:

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Closing

Additional research projects are taking place in the United States and around the world. We will keep you updated as we learn more about these projects and the information they generate.

The Callosal Connection is a newsletter produced by the:

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