



Contact: Diana Yee
Director, Media Relations
510-428-3120
dyee@mail.cho.org

Children's Hospital Oakland Scientist First to Characterize Novel Syndrome of Allergy, Apraxia and Malabsorption

New Characterization of Syndrome Offers Hope for Treatment Protocols

July 13, 2009–Oakland, Calif. – A landmark study conducted by Children's Hospital & Research Center Oakland is the first to reveal a new syndrome in children that presents with a combination of allergy, apraxia and malabsorption. Autism spectrum disorders were variably present. Verbal apraxia has until now been understood to be a neurologically based speech disorder, although hints of other neurological soft signs have been described. The new study, led by Children's Hospital & Research Center Oakland scientist and pediatric emergency medicine physician, Claudia Morris, MD, and Marilyn C. Agin, MD, a neurodevelopmental pediatrician in New York, however, suggests that the symptoms of verbal apraxia are, at least for a sub-group of children, part of a larger, multifactorial, neurologic syndrome involving food allergies/gluten-sensitivity and nutritional malabsorption.

“While it is critical to treat verbal apraxia symptoms that often include severe delays in expressive speech production with speech therapy, we need to start asking why these kids are having these problems in the first place so that we can identify mechanisms we can actually target to treat the cause of the symptoms,” says Dr. Morris.

Published in the July/August issue of *Alternative Therapies in Health and Medicine*, the new study takes a major step toward identifying the potential mechanisms that may contribute to apraxia symptoms. In the study, Dr. Morris collected information from nearly 200 families with children who suffered from verbal apraxia in order to better characterize the symptoms and metabolic anomalies of a subset of children. The data clearly demonstrated a common cluster of allergy, apraxia and malabsorption, along with low muscle tone, poor coordination and sensory integration abnormalities. In addition, Dr. Morris was able to gather laboratory analyses in 26 of the children, which revealed low carnitine levels, abnormal celiac panels, gluten sensitivity, and vitamin D deficiency among others. All children genetically screened carried an HLA gene associated with gluten sensitivity and celiac disease. “The sample size is still small and should be interpreted with caution,” says Dr. Morris. “However this is of particular interest given the recent publication by Eaton and colleagues in the July 6 online edition of *Pediatrics* demonstrating a greater than 3-fold risk of autism in children born to mothers diagnosed with celiac disease. This brings some credibility to the anecdotal reports of

gastrointestinal and behavioral improvements in children with autism spectrum disorders and/or verbal apraxia when eliminating gluten from their diets. Although the implications of these observations remain to be determined, this association and the utility of dietary modifications warrant further investigation, particularly if we can identify a genetically vulnerable group”.

Most significantly, the data indicate that the neurologic dysfunction represented in the syndrome overlaps the symptoms of vitamin E deficiency. While low vitamin E bioavailability may occur due to a variety of different causes, neurological consequences are similar, regardless of the initiating trigger. The study suggests that vitamin E could be used as a safe nutritional intervention that may benefit some children. Growing evidence support the benefits of omega 3 fatty acid supplementation in a number of neurodevelopmental disorders. Anecdotally children with verbal apraxia will often demonstrate leaps in their speech production when taking high-quality fish oil. The addition of vitamin E to omega 3 fatty acid supplementation in this cohort of children induced benefits that exceeded those expected from just speech therapy alone, according to parental report.

“While data from a case series is by no means conclusive, the results clearly point to the need for further attention to this poorly understood disorder, and a placebo-controlled study to investigate the potential role of vitamin E and omega 3 supplementation in this group of children,” says Dr. Morris.

She points out that it is equally important for children given an apraxia diagnosis to receive a more comprehensive metabolic evaluation than what is current practice. Many of the nutritional deficiencies like low carnitine, zinc and vitamin D are easily treated. By not addressing the nutritional deficiencies, the child will continue to suffer from significant medical consequences of those deficiencies. The first step is to identify and treat the deficiencies. The next step is to try to figure out why they have these deficiencies and a fat malabsorption syndrome in the first place. However, Dr. Morris does advise families to work closely with a physician rather than trying promising but unproven interventions on their own.

In the mean time, however, Dr. Morris’s study provides the essential foundation for identifying the children who may need these treatments.

“By identifying these early red flags of the syndrome, we’ve provided a way to get these kids treatment at the earliest possible moment. While 75 percent of the time kids identified as late bloomers really are just that, 25 percent of the time there is a true pathologic condition. To miss it is to miss critically valuable time for early intervention. If a child has all these symptoms, chances are they are going to fall into the 25 percent who have a condition that needs further evaluation and treatment.”

###

About Children's Hospital & Research Center Oakland

Children's Hospital & Research Center Oakland is Northern California's only freestanding and independent children's hospital. Children's is the leader in many pediatric specialties including neonatology, cardiology, neurosurgery and intensive care. The hospital is a designated Level 1 pediatric trauma center and has the largest pediatric critical care facility in the region. Children's Hospital has 190 licensed beds, 201 hospital-based physicians in 30 specialties, more than 2,611 employees and an operating budget of \$312 million. Children's research arm, Children's Hospital Oakland Research Institute, is internationally renowned in bridging state of the art basic science and clinical research for the treatment and prevention of human disease. With about 300 staff members and an annual budget of approximately \$50 million, CHORI is ranked among the top ten research institutes in National Institutes of Health funding to children's hospitals. CHORI is a leader in translational research, providing cures for diseases, developing new vaccines for infectious diseases and discovering new treatment protocols for previously fatal or debilitating conditions such as cancer, sickle cell disease and thalassemia, diabetes, asthma, HIV/AIDS, pediatric obesity, nutritional deficiencies, birth defects, hemophilia and cystic fibrosis.

