

# Project Taps Into Sick Kids' Psychosocial Needs

BY MICHELE G. SULLIVAN  
Mid-Atlantic Bureau

When Jennifer Swanberg, Ph.D., gave cameras to a group of sick children, she expected pictures describing their battle against debilitating illness.

What she got were pictures of kids being kids—and that, she said, was even more powerful.

Justin, 16, summed it up pretty succinctly, Dr. Swanberg said.

Justin died last year of cystic fibrosis; his photographs didn't dwell on his medications and limitations but on his activities and love of life instead.

"I wanted him to tell a story about dealing with his medical complications. I even pushed him a little, like, 'What about pictures of your appointments?' He said, 'Hey, I'm a kid first. Nothing else matters.'"

Justin's experience with photoexpression was the genesis for "I'm a Kid, Too," a project Dr. Swanberg launched with the Lexington (Kentucky) Arts and Cultural Council. The project supplied cameras and photojournalism mentoring to 15 children with debilitating illnesses. In addition

to being medically fragile, all the children faced another psychosocial hurdle: They were each adopted.

Dr. Swanberg of the College of Social Work at the University of Kentucky, Lexington, said the youngsters astounded her with their images. "They didn't even really know, consciously, what they were producing, but the results were profound."

Tim, a boy confined to a wheelchair because of spina bifida, drew his inspiration from chalk art on the local playground asphalt. One of his photographs shows a chalk drawing of a bicycle.

Because he shot it looking down from his wheelchair, the picture also includes his feet. "When the kids saw it, they cheered, 'It's the closest Tim will ever get to riding a bike,'" Dr. Swanberg said.

The project's most compelling message, Dr. Swanberg said, is that sick children are, first and foremost, children. "We can't view them as just a diagnosis. They are more than their illness."

The 8-week program culminated with a public showing of the pictures, an event that filled the artists and their parents with pride. Often ostracized because of their illnesses, the children reveled in their accomplishments, Dr. Swanberg said.

So profoundly did the show affect the community that the university has decided to incorporate the project into its health care professions' curricula.

Beginning next year, pediatric and psychology residents, as well as nursing and social work students, will be required to attend a 3-hour seminar about the psychosocial needs of

children with significant medical conditions and about the foster care and adoptive systems they could encounter. The images of "I'm a Kid, Too" will be an important component of the course.

"It's a wonderful opportunity to educate students about the foster care system and the adoption process," she said. "For instance, if a child is in foster care and needs medical attention, who makes that decision? It gets complicated and, when doc-



The "I'm a Kid, Too" project urges children with debilitating illness to express themselves through photography.

tors are unaware of this issue, it can make treatment harder."

In the meantime, Dr. Swanberg said she hopes to secure additional funding to make the program available to larger numbers of children, perhaps by linking it with the local youth-development center. "It gave them such a feeling of self-efficacy and boosted their self-image," she said. "I'd like others to be able to experience that as well." ■

## Using Five-Tiered System Can Double Rate of Autism Diagnosis

BY LINDA LITTLE  
Contributing Writer

GRAPEVINE, TEX. — A tiered diagnostic work-up can double the rate of diagnosis of the syndromes and conditions associated with early-childhood autism, G. Bradley Schaefer, M.D., reported at a meeting sponsored by the American College of Medical Genetics.

The reported incidence of autism has increased fourfold, to 4-5 per 1,000, said Dr. Schaefer, professor of pediatrics at the University of Nebraska, Omaha.

Despite this dramatic increase, only about 20% of patients are now identified with a known syndrome or condition as the underlying cause of the autism, he said.

But that can be increased to 40% of patients if a tiered system of diagnosis is used, he said. His group applied the diagnostic system to all children with autism in University of Nebraska clinics over a 3-year period.

"All patients with autism should see a geneticist," Dr. Schaefer said. "Families need and want to know why the autism occurred and the risk of recurrence. Diagnosing the condition also has implications for outcome and long-term treatment."

What is known is that autism is four times more common in males than females, and the likelihood of recurrence within a family depends on the sex of the autistic child. In a family with an autistic girl, there is a 4% chance of autism in a second child. If the affected child is a boy, there is a 7% chance of recurrence. If two children are affected, the recurrence rate is 25%. "There are different genes associated with autism," he said. "But with some of the newer genetic tests developed in the past 5

years, the diagnosis of the causative syndromes and conditions is increasing."

The initial evaluation to identify autism should include a dysmorphic examination, including a Wood's-lamp evaluation and, if autism is suspected, targeted testing. There should be a standard metabolic screening, sensory screening, EEG, and, if clinical indicators are present, a screening for toxoplasmosis, rubella, Cytomegalovirus, and herpes (TORCH) titers, which detects congenital infections—particularly fetal rubella.

If the underlying condition or syndrome is not detected, then testing for prometaphase chromosomes and fragile X syndrome, as well as a brain MRI, should be done.

The third tier comprises *MECP2* gene testing; 15-interphase fluorescence in situ hybridization (FISH); 15-methylation/FISH for Prader-Willi, Angelman's, and other syndromes; 17q FISH for Smith-Magenis syndrome; serum and urine uric-acid tests; and a subtelomeric FISH panel if the IQ is below 50.

The fourth tier is less clear and includes metabolic tests that are sometimes unavailable, he said, adding that the tests are of unclear utility but can increase the diagnosis rate.

The final tier includes subtelomeric FISH; comparative genomic hybridization; screening for folate-sensitive fragile sites, 7-dehydrocholesterol, and the *UBE3A* gene; and an extended metabolic work-up. If testing is done beyond the initial examination, the rate of identification doubles, he said.

"It's exciting to know that we are better at figuring out the causes of autism," Dr. Schaefer said. "This can have an effect on the long-term outcome of the patient and set the stage for future treatments." ■

## Study Finds No Correlation Between Autism, Macrocephaly

BY DOUG BRUNK  
San Diego Bureau

SAN DIEGO — There appear to be no differences in the mean head circumference between children with and without autism, results from a population-based case-control study show.

The finding differs from other smaller studies that have reported increased rates of macrocephaly in autistic children, Carrie Jones, M.D., said at the annual meeting of the Society for Developmental and Behavioral Pediatrics.

Those studies have proposed that accelerated brain growth in the first years of life is an early biologic marker for a subgroup of children with autism, "but the results are based on very small groups of children, and they may or may not be representative of the general population of kids with autism," said Dr. Jones of the Mind Institute at the University of California, Davis. "Also, they have rarely been correlated with other growth parameters such as weight and height, [and] they rarely have been paired with children from the same population."

For the study, known as Childhood Autism Risks from Genetics and the Environment (CHARGE), Dr. Jones and her associates recruited 175 children with autism aged 2-5 years through six centers that provide developmental disability services to children and adults in

Northern and Southern California. Diagnoses were confirmed with the Autism Diagnostic Interview-Revised and the Autism Diagnostic Observational Schedule.

The investigators used birth records to identify 43 control children from the general population who were matched to the case population for age, gender, and geographic location.

All study participants received a medical exam that included measurement of head circumference, weight, and height. All parameters were plotted by age and gender on National Health and Nutrition Examination Survey III growth charts.

Dr. Jones and her associates found that the mean head circumference of both cases and controls was at the 59th percentile. About 12% of both cases and controls were at or above the 95th percentile, which was higher than expected.

"In linear regression models, the strongest predictor of head circumference was weight," Dr. Jones said. "The heavier kids tended to have bigger heads, but autism vs. general population group membership did not predict head circumference."

The next steps in the study are to examine earlier growth parameters from medical records for trajectories over time in both groups. Dr. Jones said the investigators also planned to measure parent head circumference to assess the correlation with children head circumference. ■