NEARLY HALF OF CHILDREN WITH AUTISM WANDER OR “BOLT” FROM SAFE PLACES

Study by Kennedy Krieger’s Interactive Autism Network finds children with autism are four times more likely to wander than their unaffected siblings

October 8, 2012 (Baltimore, MD) – A new study published today in the journal Pediatrics (Epub ahead of print) found that nearly half of children with autism spectrum disorders (ASD) are reported to wander or “bolt,” and more than half of these children go missing. Led by researchers from the Interactive Autism Network (IAN), the nation’s largest online autism research initiative and a project of the Kennedy Krieger Institute, this study provides the most comprehensive estimate of elopement occurrence in a United States community-based sample of more than 1,200 children with ASD.

“Since the launch of IAN, we have heard from families of children with autism that their children often place themselves in danger by wandering or eloping,” says Dr. Paul Law, senior author and director of the IAN Project at the Kennedy Krieger Institute. “These are the first published findings in the U.S. that provide an estimate of the number of children with ASD who not only wander or elope, but go missing long enough to cause real concern.”

Participants in the study included families of 1,218 children with ASD and 1,076 of their siblings without ASD recruited through an online questionnaire. The primary outcome measured by researchers was elopement status beginning at age 4, when elopement and wandering are increasingly atypical behaviors. “Missing” status was a secondary outcome; a child who eloped and had gone missing long enough to cause concern was coded as missing, whereas those who had not were coded as non-missing. The study’s findings on elopement prevalence, characteristics correlated with elopement and qualitative measures of family stress are presented below.

Eloped Prevalence
- **49 percent** of children with ASD attempted to elope at least once after age 4.
- Of those who attempted to elope, **53 percent** of children with ASD went missing long enough to cause concern.
- From age 4 to 7, **46 percent** of children with ASD eloped, which is **four times the rate** of unaffected siblings.
- From age 8 to 11, 27 percent of affected children eloped compared with 1 percent of unaffected siblings.

Eloped Behavior
- When eloping, **74 percent** of affected children eloped from their own home or someone else’s home. Children also eloped from stores (40 percent) and classroom or schools (29 percent).
- Close calls with traffic injury were reported for **65 percent of the missing children**.
- Close calls with drowning were reported for **24 percent of the missing children**.
• Elopement attempts peaked at age 5.4 years. Of parents reporting on the “worst year ever,” 29 percent said that their child attempted to elope multiple times a day; an additional 35 percent reported that attempts occurred at least once per week.
• While eloping, children with Asperger disorder were more frequently described by their parents as anxious; children with ASD were more frequently described as happy, playful or exhilarated. In either case, elopement was goal oriented, with the intent to go somewhere or do something.

Characteristics of Eloping
• Children who have eloped are older, more likely to have an ASD, present more severe autism symptoms and have lower intellectual and communication scores than non-elopers.
• Children who were reported as missing were older, more likely to have experienced skill loss and less likely to respond to their name. They were also more likely to have lower intellectual and communication scores than non-missing children.
• On average, children were missing for 41.5 minutes.

Impact of Elopement on Family
• 56 percent of parents reported elopement as one of the most stressful behaviors they had to cope with as caregivers of a child with ASD.
• 50 percent of parents reported receiving no guidance from anyone on preventing or addressing their child’s elopement behavior.
• After children went missing, parents most frequently contacted neighbors (57 percent). Parents also called police (35 percent), school (30 percent) and store personnel (26 percent).

“We hope that the results of this study will inform families, physicians, educators and first responders of the real consequences of elopement,” says Dr. Law. “Parents often fear being viewed as neglectful when their children leave from safe places. This study demonstrates that we urgently need interventions to address elopement and provide support to affected families.”

Future research is needed to determine whether there are different types of elopement, requiring different prevention strategies. With a greater understanding of elopement, researchers will have the ability to develop more targeted interventions to assist parents in coping with this extremely stressful behavior.

This research was funded by the Autism Research Institute, Autism Science Foundation, Autism Speaks, Global Autism Collaboration, and National Autism Association.

About the Interactive Autism Network (IAN)
Launched in 2007, the IAN Project connects individuals on the autism spectrum and their families with researchers nationwide to accelerate the pace of autism research and aid advocacy efforts for improved services and resources. Housed at the Kennedy Krieger Institute in Baltimore, MD, this innovative online initiative has nearly 43,000 participants who contribute information to create the largest pool of autism data in the world. For more information or to join the search for answers, visit www.ianproject.org. Learn how the IAN Project has impacted autism research and advocacy nationwide in this online discussion with Dr. Paul Law that marked the project’s five-year anniversary in April 2012.

About the Kennedy Krieger Institute
Internationally recognized for improving the lives of children and adolescents with disorders and injuries of the brain and spinal cord, the Kennedy Krieger Institute in Baltimore, MD serves more than 18,000
individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how disorders develop while pioneering new interventions and earlier diagnosis. For more information on the Kennedy Krieger Institute, visit www.kennedykrieger.org.