



Subject: Wandering Deaths In Children With Autism

To Whom It May Concern:

Similar to wandering behaviors in seniors with dementia or Alzheimer's, children with an Autism Spectrum Disorder (ASD) are prone to wandering away/elopeing from a safe environment. Unfortunately, many cases end in tragedy.

According to a 2011 study by the Interactive Autism Network (IAN) through the Kennedy Krieger Institute (KKI)¹, 49% of children with an ASD wander/elope from safe supervision. This is at a rate nearly four times higher than their unaffected siblings, indicating it is not an issue of bad parenting. It is, however, a growing crisis in need of awareness, understanding and hyper vigilance.

From 2009 to 2011, accidental drowning accounted for 91% of total U.S. deaths reported in children with an ASD ages 14 and younger subsequent to wandering/elopement.² Many children and teenagers with ASD have little understanding of danger and are unable to respond to their name when called. Dangers associated with wandering/elopement include drowning, getting struck by a vehicle, falling from a high place, and hypothermia.

Children with ASD often leave a safe environment to get to something of interest, or away from something, such as loud noises or bright lights. In 2008, Danish researchers found that the mortality rate among the autism population is twice as high as the general population.³ In 2001, a California research team found that elevated death rates were attributed in large part to drowning.⁴ Wandering in ASD has become so common, it was assigned a medical diagnostic code [V40.31], which went into effect in October of 2011.⁵

Because children with ASD are challenged in areas of language and cognitive function, it can be difficult to teach them about dangers and ways to stay safe. As such, our organization respectfully requests your help in allowing, or providing, resources and safeguards that could potentially save a child's life. This may include offering swimming lessons to special-needs children, allowing fencing to go around an at-risk child's home, tightening security around nearby water and pools, informing parents of any wandering incidents on school grounds or other non-home settings, and providing close and constant adult supervision.

We are grateful for your commitment to child safety. Should you have questions, you may reach us at 877.622.2884 or naa@nationalautism.org.

Sincerely,

A handwritten signature in black ink that reads 'Lori McIlwain'.

Lori McIlwain
Executive Director
National Autism Association

1. Interactive Autism Network Research Report ASD Elopement, 2011 2. McIlwain, L. National Autism Association – Lethal Outcomes In ASD Wandering. January 2012. 3. Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. Department of Child and Adolescent Psychiatry, Bispebjerg University Hospital, Copenhagen, Denmark. July 2008 4. Shavelle RM, Strauss DJ, Pickett J. - Life Expectancy Project, San Francisco, California, USA. December 2001 5. ICD-9 Code for Wandering, Centers for Disease Control. October 2011 cdc.gov.