**International Angelman Day** 

Letter-to-the-Editor Template

Submitted by [Insert Name] to the [Insert Name of Media Outlet]

## We can do better: 50% rate of misdiagnosis is unacceptable

Nearly 50 percent of individuals with Angelman syndrome, a genetic disorder, were incorrectly diagnosed with another disorder before receiving a proper diagnosis. Of those individuals, more than 70 percent waited one year or longer before receiving a proper diagnosis of Angelman syndrome, according to the Angelman Syndrome Foundation. During this time, these individuals lost opportunities to get early treatment and therapy.

As the parent, I can tell you first hand the heartache that misdiagnosis creates. My [son/daughter], [Insert individual's name], is a happy person and [he / she] is always smiling. Smiling is one of the traits of Angelman syndrome, and so are life-threatening seizures (if not properly treated), major developmental delays, and lack of speech (or cooing or babbling as an infant). We did not stop visiting doctor after doctor until finally one was aware of Angelman syndrome and recognized these traits, leading to the proper diagnosis. We were thankful to finally have a diagnosis, but this process took too long and treatment opportunities were missed because of this delayed diagnosis. Too many other families face these same problems.

By educating parents of children with a "general developmental delay" (as some doctors diagnose) we can hopefully reduce these statistics. We also need to educate medical professionals who are unaware of this disorder. It will ensure that our loved ones with Angelman syndrome get the critical treatments they need, as early as possible.

February 15 is International Angelman Syndrome Awareness Day. Please help educate families and medical professionals about Angelman syndrome by directing them to www.Angelman.org/Diagnosis.

It may help save a life.