



# MIKE COLLE, MPP

## Eglinton-Lawrence

### Angelman Syndrome Day Act, 2015

#### **What is Angelman Syndrome?**

Angelman Syndrome is a severe neurological disorder that occurs in approximately one in every 15,000 births – although it is commonly misdiagnosed and actual numbers may be higher.

Angelman Syndrome is characterized by developmental delays, lack of speech, seizures and balance problems. The developmental delay of Angelman Syndrome generally becomes noticeable by the age of 6 to 12 months in infants. Children with Angelman Syndrome typically have a happy demeanor with frequent smiling, laughter, and hand-flapping movements.

Individuals with Angelman Syndrome require life-long care. Angelman Syndrome is often misdiagnosed as cerebral palsy or autism due to lack of awareness.

#### **Causes of Angelman Syndrome:**

Angelman Syndrome is most often caused by problems with a gene located on chromosome 15, the ubiquitin protein ligase E3A (UBE3A) gene.

Typically, Angelman Syndrome occurs when part of the maternal copy of the UBE3A gene is missing or damaged. In few cases, Angelman Syndrome is caused when two paternal copies of the gene are inherited; instead of one from each parent.

#### **Na'ama Uzan & The Angelman Syndrome Lemonade Stand Initiative:**

Na'ama Uzan, the 5-year old Founder of the Angelman Syndrome Lemonade Stand Initiative, initially set up her lemonade stand to raise research funds for Angelman Syndrome, in support of her big brother Nadav. Through her lemonade stand Na'ama ended up raising \$50,000 –far surpassing her \$100 goal. Na'ama's stand raises funding for the Foundation for Angelman Syndrome Therapeutics (FAST).

The Angelman Syndrome Lemonade Stand Initiative was born from Na'ama's inspiring efforts. This Lemonade Stand Initiative gathers together children between the ages of 7-11 that are interested in running a stand, and rewards their young fundraisers when they achieve their fundraising benchmarks. The Lemonade Stand Initiative has inspired many others, both near and far, to raise money to find a cure for this disability. Na'ama's widely garnered support has enabled FAST to create a research grant in her name, titled the Na'ama Uzan FAST-TRAC Grant.

#### **Angelman Syndrome Day Act:**

If passed, this Bill would proclaim February 15th Angelman Syndrome Day, and would help to bring awareness to this very rare and serious disorder.

#### **For more information please contact:**

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