Some common characteristics of AS:

- Usually very sociable, happy; can become over excitable.
- At times the smiles and laughter can also express anxiety, fear, even pain
- Delays in development and learning
- A severe speech impairment - most have no words at all.
- Abnormal sleep patterns (require very little sleep); sleep can improve with age
- Epilepsy occurs in approx. 80%, onset usually around 2 yrs of age
- Delays in sitting and walking, fine motor skills development, and toilet training
- Many have feeding complications when young. GI issues/reflux can continue into adulthood.
- Frequent drooling, excessive chewing and mouthing behaviour/tongue thrusting
- Constipation
- Hyperactive with a very short attention span when young; appears to decrease with age.
- A strong attraction for water, music, lights and reflections can be common early on. Water poses a potential accident risk.
- A movement/balance disorder (ataxia). A wide-based gait and jerky movements. Up-lifted, flexed position of arms on walking.
- Increased sensitivity to heat
- Scoliosis

WE SUPPORT

GLOBAL ANGELMAN SYNDROME REGISTRY

angelmanregistry.info

CONTACT US

E: angelmannetwork@gmail.com

Ph: 021-1382878

c/o The Angelman Network

21 Wilson Road, RD 1, Warkworth, 0981, Auckland

FIND US ON FACEBOOK

THE ANGELMAN NETWORK

DONATE NOW AND SUPPORT OUR CAUSE:

Charities Commission Register number - CC46746

Bank Account: ANZ Bank 06-0817-0352270-00

Donate via our website or our Givealittle page

www.angelman.org.nz

THE ANGELMAN NETWORK

Connecting and supporting those affected by Angelman Syndrome (AS)

"While persons with Angelman syndrome have a wide range of abilities and different areas of interest, they all share the capacity for making our world a better place."

The Angelman Network encourages a person-centered approach based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), for all people who have Angelman syndrome.

Welcome to The Angelman Network

The Angelman Network is a family/whānau driven charitable trust, 100% volunteer-run, and based in New Zealand. We aim to connect and support those affected by Angelman syndrome (AS).

The website is our primary resource for sharing the latest global up-to-date information about Angelman syndrome. We also distribute information via our social media sites, info packs and newsletters. We aim to keep families connected by encouraging and assisting with regional gatherings and fundraising activities across the country.

Though every family's story is unique, our families all share a similar journey. For more information on The Angelman Network and Angelman syndrome, please contact us or see our website at:

www.angelman.org.nz

Our Vision / O motor kitenga

That people with Angelman syndrome are / Te tangata mau i te mate AS ka:

- accepted and acknowledged as unique individuals / whakaaetia, manakotia hoki kia u ki to rátou mana ake
- given access to a full language system (AAC) so that their voices can be heard / kia whiwhi ai ki nga ara reo kia rongohia ai o ratou reo e te katoa ma roto i te àpititanga me etahi atu whakamòhiotanga
- valued as contributing members of their community / kia whai hua rátou hei tángata tákoha nó tó rátou hápori

INTERNATIONAL ANGELMAN DAY FEB 15

On the 15th February each year we celebrate International Angelman Day (IAD) to help raise funds for research and spread awareness of the condition.

What is Angelman syndrome?

Angelman syndrome (AS) is a rare neuro-genetic condition caused by a reduction of expression of the UBE3A gene located on chromosome 15. AS occurs through 4 different genetic mechanisms, all involving chromosome 15. In about 80% of cases clinical diagnosis can be confirmed by laboratory testing. Most cases are sporadic but some genetic mechanisms can have implications for other family members.

AS is not a degenerative disease nor caused by anything parents may have done before or during pregnancy. With good health management and appropriate supports - especially AAC for communication - most people born with Angelman syndrome will have a normal life expectancy. With a prevalence of 1:15,000 it affects males and females of all racial/ethnic groups equally.

Communication Support

People with AS have severe to profound communication impairments. Receptive language is typically more advanced than expressive language. Verbal speech is extremely limited, so all children with AS are excellent candidates for Augmentative and Alternative Communication (AAC).