



## Gareth Edwards (Star Wars Director) acknowledges: The force is strong in the Angelman Alliance.

It is often said that parents will do anything for their children. A rare disease called Angelman Syndrome is proving testimony to this fact. Driven by an unstoppable love for their children parent organisations from 15 countries have formed an alliance to work together to progress research that may help their children to speak, run, and live life to their full potential. As Gareth Edwards, patron of the UK Charity that hosted this years' conference in Liverpool, England, said during his speech at the conference: "Angels go further and beyond."

With the support of ISIS pharmaceuticals, recent findings by professor Art Beaudet (USA) are expected to progress to clinical trials. Results from other researchers, in collaboration with pharmaceutical companies also have promising results to improve the quality of life for children & adults with Angelman Syndrome.

Initially having to overcome language barriers, cultural differences and different legal systems the parent organisations created an international Alliance on Angelman Syndrome (ASA) to drive research forward, pooling resources and funds. In the first two years over half a million euro's (550.000,-) was raised, with more parent organisations worldwide continuing to join. The parent organisations met this year in Liverpool during the 50<sup>th</sup> anniversary of Angelman Syndrome. At this conference representatives came from: England, Ireland, Belgium, Netherlands, Germany, Austria, France, Italy, Portugal, Japan, Israel, Hungary, Poland, Finland and Switzerland.

As professor Ype Elgersma (NL) said: "These are very exciting times, because we might actually have the possibility to reverse a severe genetic disease." Therefore the need to get things going is stronger than ever within the Alliance and the need for more funding is evident. Because in the end every parent wants their child to be as happy and healthy as possible.





## You can read more about Angelman Syndrome on :

www.angelman-afsa.org (France)

www.angelmanuk.org (UK)

www.sindromediangelman.org (Italy)

www.angelmansyndroom.nl (Netherland)

www.angel.pt (Portugal)

www.angelmansyndroom.be (Belgium)

www.angelman.de (Germany)

www.angelman.ie (Ireland)

www.ninafoundation.eu