International Alternating Hemiplegia of Childhood (AHC) Day
18th January 2022

PRESS RELEASE

Ten Year Anniversary
Today marks the 10th anniversary of the ground-breaking genetic discovery for Alternating Hemiplegia of Childhood (AHC).

On this day in 2012, following a large international collaboration between families and researchers, the ATP1A3 gene was discovered as the cause of AHC in approximately 80% of cases. This was a momentous event and has directed research into this ultra-rare neurological disease for the last ten years. Further ATP1A3 diseases have also since been discovered.

What is AHC?
AHC is an ultra-rare neuro-developmental life-long disease. It has a prevalence of 1 in a million. Symptoms typically present in infancy, before the age of 18 months. It is a very unpredictable and variable condition.

Although paralysis is a key feature of the condition, it can present with a wide-ranging constellation of neurological symptoms. It can also affect many other areas including cardiac, respiratory, gastrointestinal, and psychiatric. Symptoms vary between individuals, and across their lifetime.

Living with AHC and the future
Today, we highlight the impact of living with AHC for individuals and families in our international social media campaign #AHCawareness #1inamillion.

We celebrate the genetic breakthrough 10 years ago and the research over the last decade which has improved our understanding of this condition.

However, we also recognise the need for more research and knowledge of this complex rare disease. There is still no effective treatment for AHC. Families live with uncertainty and unpredictability daily. We hope that the next 10 years sees a breakthrough for individuals living with this condition; improving their quality of life, and ultimately a treatment and cure.

Signed by all the International AHC organisations listed here:
Asociación Española del Síndrome de la Hemiplejia Alternante (AHC Spain), AHC Association of Iceland, AHC Bulgaria, AHC Denmark, AHC Federation of Europe, AHC Foundation, Association Française de l'Hémiplégie Alternante (AHC France), AHC Ireland, Associazione Italiana per la Sindrome di Emiplegia Alternantevice (AHC Italy), AHC Poland, AHC UK, AHC Vereniging Nederland (AHC Netherlands), AHC 18+, Cure AHC Chile, Cure AHC, Hope for Annabel

References/more information:

- Heinzen EL et al. *De novo mutations in ATP1A3 cause alternating hemiplegia of childhood.* Nat Genet. 2012 Sep;44(9):1030-4. doi: 10.1038/ng.2358
- Information on AHC: https://epi-care.eu/wp-content/uploads/2021/12/AHC-Leaflet.pdf
- Award winning documentary on AHC 'Human Timebombs': https://www.youtube.com/watch?v=NPHiKxCqAUg
- 'Overview of Alternating Hemiplegia of Childhood': https://www.youtube.com/watch?v=Ndt7oFo_QtI&t=14s