Dear AHC families, researchers and supporters,

Today, **Monday 18th January 2021**, is the **9th International AHC Awareness Day.**

Background

Alternating Hemiplegia of Childhood (AHC) was first described approximately **30 years ago**. However, it was not until this day nine years ago that a breakthrough in understanding AHC was made. International AHC day marks the day of the genetic breakthrough and discovery that the **ATP1A3 gene** was a cause of AHC in approx.70-80% of people with AHC. AHC day is used as an awareness day of AHC for everyone with this condition (both with the **ATP1A3 gene** and those without) in the hope that by raising awareness of AHC we will one day improve the lives of all living with AHC by finding an effective treatment.

Unite today for AHC and make some noise on social media

This year, our awareness will start today on AHC day and last for a week highlighting different aspects of AHC: the facts, the people, the stories, the research and the future.

We ask you all to unite as an AHC community (parents, families, friends, supporters, AHC clinicians and researchers) to raise awareness of AHC in honour of those inspiring AHC champions you know who get up each day not knowing what is going to come.

We are delighted that the **Alliance of AHC** patient organisations and **IAHCRC** will be joining together to raise awareness today and this week with us. Additionally, we are delighted that **EpiCare (European Reference Network for rare and complex epilepsies), ePAG (European Patient Advocacy Group)** and **Rare Revolution** will be highlighting our **International AHC day** on their social media platforms.

How can you get involved?

- **#oneinamillion campaign** please join in with us in the UK and around the world with the international AHC community sharing the hashtags **#oneinamillion, #AHCawareness** and **#raredisease** and sharing a photo of your child/yourself/family members with the hashtags and one finger held to signal **'one in a million'.** This campaign started last year by the **Spanish AHC patient support group (AESHA)** and was adopted by the whole **AHC international** community. We want to build on it this year as a community. We welcome all AHC supporters/researchers/friends to also join in and share their photos on social media (facebook/twitter/Instagram). This will be going on daily throughout the week.
- **Tuesday 19th January #TuesdayTakeover** – we are delighted to say that AHC UK will be taking over the social media accounts of Rare Revolution and sharing AHC facts, videos, posters and more. This organisation has a large following so please join in and engage with the posts and the international rare disease community
- **Wednesday 20th January** – we will be hearing about AHC research that has happened/is happening all around the world. Please join in the discussion on social media.
- **Thursday 21st January – Saturday 22nd January** – we will be highlighting the impact of AHC on families' lives and what it means to them living with AHC by hearing their words, stories and videos, and looking to the future.
- **Sunday 23rd January** – join us in concluding our AHC awareness week with highlights from the week.

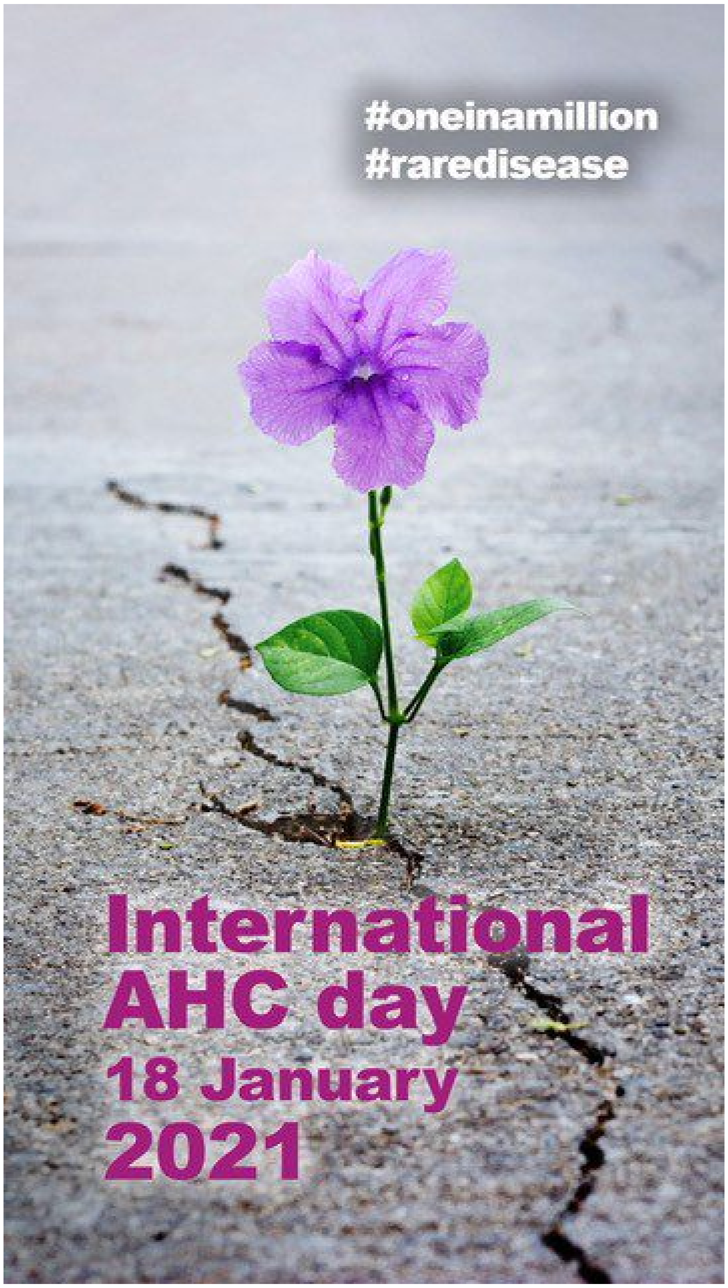
Please comment, like, share and engage with the discussion to raise awareness of AHC on our facebook, twitter and Instagram accounts. We would love to hear and see you this week making some noise for AHC.

If you have any questions, please don't hesitate to get in touch with us via our 'contact us' section on the website www.ahcuk.org or via email support@ahcuk.org

With best wishes

Katherine Behl

Research Liaison Committee Representative (on behalf of the AHC UK Committee)


#oneinamillion
#raredisease
International
AHC day
18 January
2021

Alternating Hemiplegia of Childhood UK | Charity Number: 1192701
75 Charlton Road
Southampton, SO15 5EU
United Kingdom