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AHC UK Newsletter 5th March 2021

Dear AHC families, researchers and supporters,

Thank you so much for supporting **International Rare Diseases day** with us last Sunday (28th February).

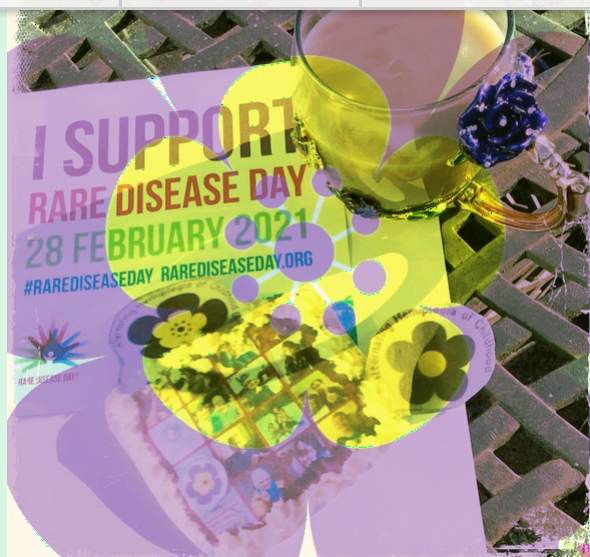
It was also a wonderful start to our fundraising for the **AHC** and **ATP1A3** diseases **Natural History Study** which is underway at London's **Great Ormond Street Hospital** and needs further funds to continue.

Thank you also to everyone who donated to our fundraising "**Rare Treat**" (coffee and cake) to support this important AHC research project continuing. We are delighted that we have raised over **£1300** already from this. Thank you so much for giving up the cost of a coffee and cake to help this AHC research project that is of great value to our AHC community both within the UK and Ireland and internationally.

DONATE TO AHC Research

If you would like more information on this project, please see this previous **Q&A session ([Video Link](#))**.

Funding for this research project runs out in **May 2021**, but the research work is not finished and still needs to

[DONATE](#)

Future Fundraising Events



In the coming week, we will be announcing a big virtual fundraiser. We hope you will join us in this. More information will follow soon so please keep a look out.

Thank you to the many AHC supporters who have helped raised funds or are raising funds for AHC. We were delighted that **Holly Grove Primary School** did an amazing **Mexican Smile** on **AHC Day** in January raising funds for AHC, thank you for sharing your video. We are also touched when we heard that when **Samuel, aged 5**, learnt about AHC and the AHC Champions, he decided he wanted to run a marathon raising funds for AHC research. We will be featuring his story on our blog on the website soon. We would love to hear your stories and recognise all your achievements raising awareness or funds for AHC, so please get in touch if you would like to share them on our blog page of the AHC UK website.

AHC UK Scientific Symposium and Family Day

Last year we sadly had to postpone our event due to Covid-19. This year we are planning a virtual event. Please save this date. The Friday will be the **AHC UK Scientific Symposium Date** and the **Saturday 15th** will be a virtual family day. More details will follow. 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

Vice - Chair & Research Liaison Committee Representative (on behalf of the AHC UK Committee)

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GDPR As you know, at the end of 2020, we succeeded in registering Alternating Hemiplegia of Childhood (AHC) UK as a Charity. This is a great achievement, and we would like to thank everyone on our Committee and our supporters for their help with this. We are now in the process of reviewing all of our policies and procedures. This includes developing our privacy policies in keeping with GDPR. We will continue to keep you updated with this.



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