AHC UK Research Newsletter

Dear AHC families, researchers and supporters,

It has been an incredibly difficult year due to the covid-19 pandemic. We hope you and your families are all keeping safe and well.

Our AHC researchers continue to work across the world to try and make progress in understanding this complex condition. There are several projects under way, and we will keep you updated on information in the coming months.

The first project we want to highlight is the:

AHC and ATP1A3 Natural History Study Join us on Friday 27th November at 8pm

We are delighted to announce that we will be having a zoom Question and Answer chat with Dr Katerina Vezyroglou on **Friday 27th November at 8pm (GMT)** on her research 'AHC and ATP1A3 Natural History study'.

Many of you will be aware that Dr Katerina Vezyroglou is a senior Paediatric Neurology Registrar and Clinical Research Fellow undertaking her PhD on AHC. She is based at Great Ormond Street Hospital and works closely with Professor Helen Cross, Professor Sanjay Sisodiya and Dr Simona Balestrini undertaking research into AHC and ATP1A3 diseases.



If you are unsure what her study is about; would like to know how it could help your child/family member or patient; or how you can get involved with it, or if you're already enrolled but have new questions to ask her then this Question-and-Answer zoom session will cover the key parts of the study that you need to know about.

We welcome all questions and hope to cover these at the Zoom chat.

If this study is new to you, or you are new to AHC or ATP1A3 diseases then this zoom chat will hopefully provide a helpful overview of some key research being undertaken in the UK.

Dr Katerina Vezyroglou has created a helpful infographic which summaries the study and she is looking forward to having a chat with us all on Friday 27th November. *Please click on this link here.*

To submit any questions in advance, (anonymised if you prefer) then please email us at <u>admin@ahcuk.org</u>. You can also ask questions directly via the Zoom chat on the night.

We look forward to seeing you virtually on Friday 27th November. The Zoom link is below. If you have any further questions don't hesitate to get in touch with us at AHC UK.

With best wishes

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

For the zoom link to join in the meeting please use this link:

Topic: AHC related clinical research in the UK Time: Nov 27, 2020 08:00 PM London

Join Zoom Meeting

https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fucl.zoom.us %2Fj%2F97494790387&:data=04%7C01%7C%7C91338f63f80b4f2ca3cd08d88 a4d6c26%7C1faf88fea9984c5b93c9210a11d9a5c2%7C0%7C0%7C637411412411 724954%7CUnknown%7CTWFpbGZsb3d8eyJWljoiMC4wLjAwMDAiLCJQljoiV2luM zliLCJBTil6lk1haWwiLCJXVCI6Mn0%3D%7C1000&:sdata=vKL3SGX3DrfcX5yy 7K%2FB0nrlu50%2F3Kt4J%2FJN7bjxKas%3D&:reserved=0

Meeting ID: 974 9479 0387 One tap mobile +443300885830,,97494790387# United Kingdom +441314601196,,97494790387# United Kingdom

Dial by your location

+44 330 088 5830 United Kingdom +44 131 460 1196 United Kingdom +44 203 481 5237 United Kingdom +44 203 481 5240 United Kingdom +44 203 901 7895 United Kingdom +44 208 080 6591 United Kingdom +44 208 080 6592 United Kingdom +1 929 205 6099 US (New York) +1 253 215 8782 US (Tacoma) +1 301 715 8592 US (Washington D.C) +1 312 626 6799 US (Chicago) +1 346 248 7799 US (Houston) +1 669 900 6833 US (San Jose) Meeting ID: 974 9479 0387