



Children's Health Ireland
at Crumlin

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ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE

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Dr Susan Byrne

Consultant Paediatric Neurologist / Senior Lecturer
Children's Health Ireland at Crumlin
Cooley Rd, Crumlin, D12 N512

2nd September 2021

REC Reference: **GEN/739/19**

Interrogation of the functional basis of neurogenetic disorders in children and young people, and understand the impact on management and outcome

Principal Investigator: Dr Susan Byrne

Co-Investigators: Dr Gary Brennan, Prof David Henshall, Prof Gianpiero Cavalleri

Dear Dr Byrne,

Following your correspondence to the CHI Research Ethics Office dated 22nd April 2021, I can confirm that you have successfully address all of the comments raised by the CHI at Crumlin Research Ethics Committee at the meeting which occurred on the 13th April 2021.

Your subsequent email correspondence on the 2nd September 2021 confirmed that the necessary material transfer agreement (MTA) have been put in place between CHI, UCD and RCSI.

Thereby, this study is fully **APPROVED** and data collection may commence immediately once the final DPO approval letter is submitted to the CHI Research Ethics Office.

I wish you every success with this study and should you require any assistance in the future please do not hesitate to contact me.

Yours sincerely,

Dr Eugene Dempsey

CHI Research Ethics Officer