Executive Summary

Newcastle Foundation Trust and UCB pharma Ltd: Adult testing for rare epilepsies

Collaborative Working Project Executive Summary

The Newcastle Foundation Trust, and UCB Pharma Ltd, are embarking on a collaborative working project to find adult patients with undiagnosed, or unidentified, rare genetic epilepsies. The parties have agreed that the project should be undertaken in accordance with the principles and guidance relating to collaborative working between the NHS and the pharmaceutical industry.

An estimated 1:15,000 people have Dravet syndrome, if this figure is correct, then current figures suggest that there are less than a quarter of the people with Dravet identified in the North of England.

The current NHS England epilepsy genetics panel has over 400 genes on it, but the most common positive answer is SCN1A (80% of patients have a genetic mutation of this variant), the cause of Dravet syndrome. It is expected that with an increase in genetic testing potentially half of all results will result in a clinical change of treatment.

The primary objective of the project is to consent and test historical, and future, adult patients within a profiled cohort across multiple sites in the North of England for rare genetic epilepsies. For people with Dravet this may include stopping certain medications (such as sodium channel drugs) or unlocking the ability to prescribe new medications only licensed for Dravet. There is a benefit for both patients and carers and additionally an understanding of genetic cause helps with diagnosis, prognosis and provides the fullest possible explanation of why someone has a complex epilepsy.

In addition, the NHS Trusts in the collaborative working project will also test for additional rare genetic epilepsies and these can also be reviewed and treated accordingly in line with more recent therapies and updated treatment algorithms.

The resource commitments from the parties were similar.

The project commences in August 2023 and is an 18 -month commitment.

Intended benefit:

For the patient	• Quicker access to more recent therapies • Aligned treatment decisions with NICE guidelines for historical patients. • Accurate diagnosis • Care closer to home • Fewer hospital admissions • Better information about conditions and treatment options • Better experience of the healthcare system
For the NHS	• Provision of resources for genetics • To support accurate diagnosis • Support improvement in future diagnosis and reductions in long term healthcare costs. • Higher quality care • Services configured around patient needs • Better health outcomes • Better use of resources in line with Value Based Healthcare • Lower hospital admissions
For UCB	• Accurate diagnosis of rare epilepsies may include the opportunity to use UCB therapies.

	• Better understanding of patient profiles for adult patients for future indications and to further inform future UCB products and service developments. • Deeper relationships / partnership working with NHS. • Potential expansion of the relevant and eligible patient population because of the activity • Increase in the appropriate use of medicines aligned to local or national guidance • Better understanding of the challenges faced by the NHS in delivering high-quality patient services and care • Faster implementation of NHS policy which may be relevant to an organisations business.

It is anticipated that a report on the outcomes from this collaborative working project will be published April 2024

For further information please contact:

Elaine McNaught. Rare Epilepsy Launch Lead, UCB Pharma Ltd.

Email: elaine.mcnaught@ucb.com

Consultant Neurologist Dr. Rhys Thomas

Newcastle Foundation Trust

Email: rhys.thomas9@nhs.net