

Project title	Fabry Online Education Programme A collaborative working project between Amicus Therapeutics UK Operations and The Royal Free London NHSFT (The Royal Free)	
Project rationale	Project Rationale: - Fabry disease is often not recognised until adulthood, resulting in organ damage and reduced quality of life. - Awareness among healthcare professionals in the UK is limited due to a lack of formal education, which contributes to delayed diagnosis and treatment. - There is a need to improve education and awareness to enhance early identification, diagnosis, and outcomes for patients with Fabry disease, in line with the UK Rare Disease Framework.	
Project objectives	Project objectives - To support knowledge and understanding of Fabry disease across a wide UK medical audience, through development and launch of a national online accredited Fabry education Programme. - Supporting improved identification and earlier diagnosis of Fabry disease. With an ultimate aim of improving patient experience and outcomes in line with the national strategy for rare disease. Potential patient Benefits - Reduced length of time to diagnosis of Fabry disease through improved knowledge of health care professionals. - Better experience of the journey to diagnosis and improved confidence in HCPs seen throughout their journey. - Improved management of Fabry disease through improved knowledge of HCPs. - Better outcomes as a result of improved clinician management. - Better experience of the overall healthcare system Potential NHS Benefits - Upskilled workforce in an area where education is limited supporting implementation of UK national strategy for Rare Disease. - More efficient use of resource through reducing time to diagnosis of Fabry disease through delivery of HCP education. - Better holistic care for Fabry patients. - Better patient outcomes as a result of improved clinician management. - A positive impact on the broader area of Rare Disease in supporting the diagnostic odyssey. Potential Amicus Benefits - Better holistic care and in turn outcomes for Fabry patients supporting our mission to improve the lives of patients with rare disease - Ensure the appropriate use of medicines for Fabry in line with local or national guidance.	
Project period	Q1 2022 – Q2 2026	
Financial arrangements	The project will be supported by a pooling of skills and resources from both Amicus and The Royal Free with a direct financial contribution provided by Amicus of approx. £108,000	
Plan for publication	No publications planned	
Contact details	Laura Clark General Manager Amicus Therapeutics lrclark@amicusrx.com	Professor Derralynn Hughes Professor Experimental Hematology & Group Director of Research and Innovation, University College London & The Royal Free
Summary of the roles and responsibilities of each party	Roles and responsibilities are agreed and reviewed at monthly steering group meetings	