



Royal Irish Academy Grants Report

Title:	Dr
First Name:	Aisling
Surname:	De Paor
Discipline:	Humanities and Social Sciences
Year of Award:	2018
Project Title	Gene editing, disability and the UN Convention on the Rights of Persons with Disabilities – emerging law and policy perspectives

I. Research background:

My area of research is genetics law and policy. I have published widely in this field particularly on topics such as genetic discrimination and genetic privacy (and the regulation of these issues), and related areas of health law and policy. My research has been published in journals such as the European Journal of Health Law, the Industrial Law Journal, the International Journal of Law and Psychiatry and the Journal of Community Genetics. My research also focuses on genetics and disability law and policy. I authored a monograph: 'Genetics, Disability and the Law' (Cambridge University Press, 2017). I am also co- editor of a book entitled 'Genetic Discrimination – Transatlantic Perspectives on the Case for a European Level Legal Response' (Routledge 2014).

The research carried out through the Charlemont Grant has built upon my research background and my publications in this field.

2. Please outline the findings of your research and/or milestones achieved (did you achieve the primary objectives - if not, what did you learn from the process)?

The trip to Syracuse University and the research carried out while I was there was very productive. I achieved the primary objectives (as outlined above).

I successfully carried out research on the current state of the art of gene editing (and its likely future orientation). I identified the key ethical, legal and public policy concerns arising as the technology advances. I refined the research around the connection between genetics and disability, and particularly refined the implications for disability rights in this area. I also examined the application of the United Nations Convention on the Rights of Persons with Disabilities in this area, and developed policy guidance on this topic.