

## Title

The ART in Family

## About the Artist

I am a photographic artist and PhD researcher at Ulster University in Belfast. My work explores the fault lines where medicine, technology and society meet.

## What is the study about?

Advanced reproductive technologies (ART) present ordinary families living with genetic disease or disability with some of the most challenging decisions gripping society today. I am interested in the complexities of these decisions. To understand them, you must try to walk in someone else's shoes, and think about their lives and their choices. The challenge of this project for me as an artist, is to create a series of photographic portraits that communicate some of these difficult issues to the viewer through the medium of the family photograph.

## Who can take part?

The project will involve finding, photographing and interviewing ten families with rare diseases. The families who participate will all have dealt in some way with the challenging decisions of ART. They will be willing to discuss the decisions they have made publicly and will be comfortable with having a visual representation of their family unit disseminated in the public domain. Some of these families will have actively chosen to use ART and others will, after consideration, have opted not to. The project is about both of those choices and the reasons for them.

The term assisted reproductive technologies or ART refers to in vitro fertilisation techniques such as pre-implantation genetic diagnosis (PGD) and pre-implantation tissue typing (PTT). The project will not exclude families who have used prenatal diagnosis (PND) and chorionic villus sampling (CVS) after choosing not to opt for ART.

## What's involved in taking part?

Participation in this project is entirely voluntary. If you decide you would like to take part, every member of your family will be provided with a

detailed information form and will be asked to sign a photographic and audio release form. It will be the responsibility of one parent/guardian of any children under 18 years of age, or vulnerable adult participants to give consent. If you agree to take part, I will arrange to meet, or speak with you, in advance of the photographic and audio interview session to introduce myself. This will be an opportunity for me to discuss the information sheet and the consent form with you, and to make sure that you understand what participation in the project entails. We will then organise a mutually convenient time for me to visit you at your home. The photographic session and interview will take approximately three hours and the format of the photograph will be a conventional family portrait. I want you to be yourselves, so there will be no need to dress up or tidy up!

There are no costs associated with talking part.

## Are there any risks?

The study involves a photographic shoot and interview session, so the risks in participation are minimal. The photographic shoot will exclude flash photography, reducing the risk to those with photosensitive epilepsy, and families will be asked if there are any additional precautions which need to be considered when photographing their family, based on their individual circumstances. Some participants may find answering questions about their reproductive choices upsetting, and can at any point ask that the interview be stopped.

## Who will benefit?

The artworks that will be produced from these sessions will be used for research and exhibition purposes. The consent form for the images and the audio interviews will therefore cover multiple media platforms. It is hoped that the exhibition will raise a positive discussion in the public domain about ART and their impact on the families living with genetic disease that use them.

## Who is the research funded by?

This research is part of a PhD which is funded by the Department for the Economy (DfE) and is being conducted on behalf of Ulster University. The study has been reviewed by the Ethics Committee at Ulster University in accordance with the University's guidelines.

This research study is not funded or organised by Headlines, and therefore we cannot take responsibility for your involvement in the research.

## How do I find out more?

Please contact Susie Rea, PhD Researcher on [rea-s6@ulster.ac.uk](mailto:rea-s6@ulster.ac.uk)