

Report of The Trustees for The Period

Dated 31 August 2017

The Ultra Rare Disease Disorders and Disabilities Foundation

Registered Company Number N1617725 (Northern Ireland

Registered Charity Number NIC 102130

Directors Mr Terence Hoey
 Mrs Maureen Hoey

This is a short statement compiled by the Directors of The Ultra Rare Disease Disorders and Disabilities Foundation Ltd year ending 31 August 2017

We welcome this opportunity to supply our short statement on the Ultra-Rare Disease Disorders and Disabilities Foundation the charity was set up to help families and patients with rare and ultra-rare disease we work to raise awareness of rare and ultra-rare diseases within Northern Ireland and Ireland we do this by our web sites and social media. Our aim is to help families deal with the effects that ultra-rare and rare disease brings with it the foundation works to help with everyday problems like claiming benefits and housing issues and advice.

The Foundation works as a backup to families and patients signposting them to other agencies and also guiding new families to Hospitals within Northern Ireland and Ireland and the United Kingdom who can help with a diagnosis a genetic, rare or an ultra-rare disease the foundation knows only too well how important it is to get the correct diagnosis and it also knows that if a correct diagnosis is not carried out that patients may be treated with the wrong medication plan.

Diagnosis with a rare or an ultra-rare disease is very complex and it needs to be carried out by hospitals designated to diagnosis genetic, rare and ultra-rare disease these Hospitals are known as centres of excellence we have had the experience of patients having blood tests carried out and the bloods having to be sent to hospitals in the United Kingdom such as Liverpool Children's Hospital Bristol Children's university teaching Hospital or Great Ormond Street Hospital to name a few.

The foundation helps to guide and support families who have recently had a child diagnosed with a genetic, rare or ultra-rare disease it helps in many ways like filling out benefit forms or problems with housing, The foundation also helps with day to day problems that arise like debt problems and siblings being bullied at school, We also find that guilt issues also arise caused by the demand of care it takes dealing with a young child who has had a diagnosis of a genetic, rare or ultra-rare disease the pressure it put on the family unit is immense.

The foundation had only four volunteers in 2017 the foundation like other charities has found it hard to bring on volunteers due to people finding full time work the demand for volunteers is huge we at the foundation has witnessed charity shops closing or being temporarily closed due to having no volunteers to run them, The foundation mainly has worked on research of genetic, rare and ultra-rare disease it depends a lot on experience and that is very hard to find due to the nature of the research that the foundation carries out.

We have found that due to the very nature of the work we do it is hard to recruit people who can deal with the pressures it takes to be able to work with families with a child who has a genetic, rare disease, ultra-rare disease, and the problems it brings with it we also have to train our volunteers up on the effects that a diagnosis can cause and the complete devastation it brings to a family due to so many issues that can arise. The foundation knows just how vital training is and just how important it is to meet the standards that we expect of our volunteers.

Due to the shortage of volunteers we at the foundation know just how important it is to bring on people who has experience in fields like book keeping, fundraising, dealing with website design and social media, and sourcing new sites for our charity boxes, and financial standards to deal with HMRC and Funding regulations.

The foundation has had a very tough year caused by lack of funding that it needs to bring in full time staff although the foundation is now bringing on volunteers that have a background of fundraising, and social media, websites, and accounting the foundation has also seen its Director having to take time out to deal with kidney problems in 2017 and 2018 when he had to have a kidney transplant and also deal with infections that rendered him unable to carry out any sort of work for the foundation.

We are very pleased to report that he is now back to his duties and the foundation has learnt that the need for volunteers is vital in the smooth running of the foundation.

The Directors and Trustees

The Ultra Rare Disease Disorders And Disabilities Foundation