

THE ULTRA RARE DISEASE, DISORDER AND  
DISABILITIES FOUNDATION

DIRECTOR'S REPORT

2017 TO 2018

Founder/Directors: Terence Hoey  
Maureen Hoey



**2017-2018**

## **DIRECTOR'S REPORT**

### **Introduction**

The Ultra Rare Disease, Disorders and Disabilities Foundation (URDDAD Foundation) is a charity set up by two Directors, Terence Hoey and Maureen Hoey.

The Background of the charity is they are the grandparents of Cavan Tommy Hoey. Their grandson Cavan was a five year old child who took ill, his parents thought he had a childhood illness, the Doctor's thought he had glandular fever. He was not getting better after six weeks and his weight plummeted, his Doctor and his parents admitted him to the Cornwall Hospital. He remained there for a further six weeks and they carried out tests on Cavan, but the tests came back blank. The family became very worried and demanded that further tests be done. His bloods were sent to all major hospitals within England.

His parents did not have to wait long until his results started coming back with various diseases. It was Bristol Children's Hospital who came back with definite diagnosis of HLH and Cavan had to be rushed to Bristol. The Doctors told his parents it was urgent, he got there following a four-hour journey by ambulance. When he arrived Cavan took a major seizure and Doctors gave him 48-hours to live. They carried out further tests and they found Cavan had another disease called XLP, they were told that this was a very rare disease and that there were only 100 children in the world with it.

Cavan got through the 48 hours and managed to fight back, he remained in hospital for one year as Doctors tried to fight the HLH and XLP. In that time his grandparents set up the Cavan Tommy Hoey Trust, and Terence Hoey spent his time researching into XLP and HLH. At that time he went on the web but could not find much information and he decided to set up a website for Cavan. He blogged day and night telling the story about his grandson and his work went viral.

He started getting results from all over the world. He realised very quickly that HLH was a rare disease that seemed to affect people in America. He found that XLP was ultra-rare. He started to blog about rare diseases and with the help of Google Rare Disease, it went viral. Every drug manufacturing companies started to set up sites for rare diseases. They, for the first time, started to take notice of Terence Hoey blog sites and the media started taking notice. Terry and Maureen started holding Rare Disease days and they put about raising awareness of ultra-rare disease. They followed the same plan as rare disorders and they found that drug manufacturers called ultra-rare disease as orphan diseases, so they started out to change the name "orphan" to "ultra" as it was a name that would cause a bigger impact on the web. They set out to blog day and night about ultra-rare disease, it set a fire on the web that drug companies and Doctors started to take notice. This was when Terry and Maureen set up the Foundation, they also found how having a child with a rare and an ultra-rare disease affects the family circle.

The Foundation is moving from strength to strength. It had to go through a very lean time due to fundraising, the Foundation has found it very hard to raise funds due to being a small charity and because of the bigger charities starting their TV ad campaigns, although the Foundation is holding its own and it's fundraising is now showing an increase.

The Foundation is happy to report that due to it bringing on two new volunteers it has greatly improved the work the charity can do, and it frees up time for the Directors to do other work. They



are involved in setting up a client base of good fund raisers and also setting up road shows to raise awareness. The Foundation is also raising awareness of the web.

We are glad to report that the Foundation is building up its client base on the web and is now making inroads on building a bigger and stronger base with other groups all over the globe, from America, South Africa, Australia, India, Pakistan, Ireland and United Kingdom. This work is vital to the Foundation. In Northern Ireland it is running road shows and is trying to break through the hold that much bigger charities has on Northern Ireland. We have been building on our client base and working to increase this client base in Northern Ireland. The Foundation is also building a client base in Europe, this is vital to be prepared for Brexit. The Foundation is building this base in readiness of a "No Deal" Brexit, we take this work as vital to the Foundation and the European plan on Rare Disease.

### **Funding**

We are adding to our client base daily, we depend on raising our funds through collection boxes. The Foundation is setting its sights on raising funds in Northern Ireland and it is increasing its numbers of clients within the area and is at present increasing its supply of charity boxes throughout the Province. Its main area is Belfast, we are seeking to expand on this.

### **Directors**

Mr Terence Hoey had a kidney transplant in June 2017. He had a lot of infections to get over but we are glad to report he is getting back to fitness again.

Report ends.

Signed by Directors:

Founder/Director:

Terence Hoey

Founder/Director:

Maurice Hoey

Date:

28th May 2019