



Annual Report 2014-15

VHL UK/Ireland Charity Objectives:

To relieve the charitable needs of persons who have von Hippel-Lindau Syndrome (VHL) and similar genetic conditions such as Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC); and Birt-Hogg-Dubé Syndrome (BHD) and their families and carers in the UK and Ireland for the public benefit in particular but not exclusively by:

- 1) Providing support and advice regarding their genetic conditions,
- 2) Providing funds for research into the genetic conditions and for equipment to assist with such research,
- 3) To advance the education of the public in all matters concerning the genetic conditions.

2014-15 was to be a year of rebirth for the VHL UK/Ireland charity and the year in which the first £5,000 was raised to enable recognition as a registered charity with the UK Charities Commission.

The previous incarnation of the group had folded and a few determined volunteers set out to breathe new life into the organisation and one of our main tasks was to raise awareness of the rare diseases which we support.

A new website was created to provide information and blog postings, social media channels were set up and an online shop selling t-shirts, running vests and pin badges was opened. The t-shirts and vests were generously donated so there was no cost to the Charity. We registered with fund-raising websites such as Give as You Live, whereby people can shop online and the seller makes a donation to the charity at no extra cost to the purchaser.

Vixstar Events organised a Masquerade Ball in September and chose VHL UK/Ireland to be a 50:50 recipient of the proceeds (along with Cancer Research UK); a very successful evening which raised £3,000 for the charity.

Thanks to this and all the other wonderful people who have held fund-raising events, we reached the £5,000 target by the end of November 2014 – a marvellous achievement.

This money was donated to Eammon Maher, Head of the Department of Medical Genetics, Cambridge and was used to purchase a Biorad Zoe fluorescent imager (microscope). The Cambridge research team are one of the first groups in the UK to have this type of state-of-the-art equipment and it is in constant use.

We were delighted to find out in January that Vixstar Events has again chosen VHL UK/Ireland to benefit from the 2015 Glitz and Glamour Ball to be held in July.

All in all it was a very successful first year for the Charity and an excellent stepping stone from which to move on with our aims and objectives in 2015-16.