



### 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. Note this was our first year as a registered charity in England and Wales

The highlights of another very successful busy year were as follows:

#### Fundraising:

- a) Targets of £20,000, £30,000 and finally £40,000 were broken. Now replaced with a 2 year target of £80,000 for year ending April 2017
- b) We started with VHL Awareness Month May with 2015 Claire Hobson and team climbing Ben Nevis, Scotland and raising over £10,000
- c) We ended with Dave O'Brien + 10 others raise over £7,600 in Wicklow Goal Break 10km
- d) In between there were lots of smaller fundraising events
- e) Vixstar Summer Ball raised over £6,000 which we shared with the Alzheimer's Society
- f) Awarded £1,000 by the Community Directplus Donation Scheme run by the charity's bank
- g) the eBay charity shop continued to be popular for pin badges, t-shirts etc. set-up by Roxanne Bonin

#### Donations and Key Outgoings

- h) Genetic Centres in UK and Ireland receive patient information packs
- i) £4,995 donation for a L20001 Luna FL Automated Fluorescence Cell Counter to the Department of Medical Genetics, Cambridge
- j) First Support Group Meeting held in Guy's Hospital, London
- k) We have been active in negotiating with Professor Eamonn Maher on our next donation for either more equipment or to help fund a specific piece of research. We have agreed to continue raising funds this coming year to maximise the donation impact.

#### Other Activities

- l) Progressing charity registration in Ireland. We submitted an application in July which has been reviewed favourably. We are waiting final approval of our constitution from the CRA's legal department.
- m) Progressing a new website design using WordPress which will make it easier to maintain and be easier to use from smart phones and tablets