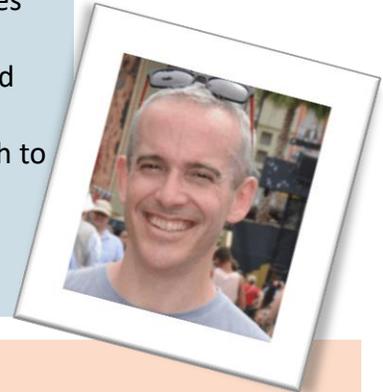


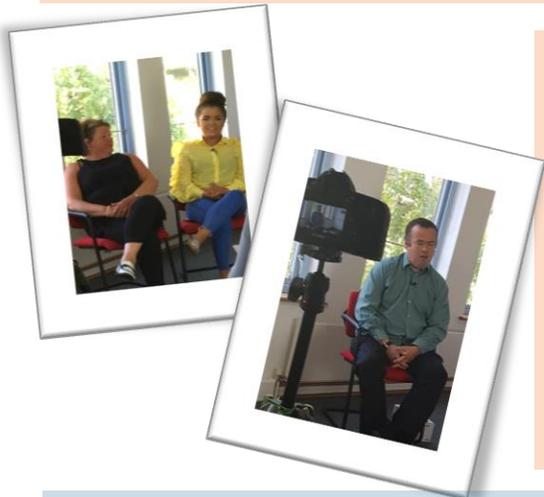
PTENUKI CHAIR OF TRUSTEES UPDATE

I am pleased to report that PTENUKI has been registered with the Charities Commission and we have appointed trustees. We have launched a new website <http://ptenuki.org/> where you can read who the trustees are, and the objectives we have agreed for the charity and much more. This is our first newsletter and I hope you will find the content of interest. If you wish to get more involved or have comments about the newsletter email info@ptenuki.org
Ian Stock



OUR VISION

The patient group's purpose is to improve the lives of patients, parents and carers of all ages, in the UK and Ireland, who are affected by PTEN genetic alterations, PTEN Hamartoma Tumour Syndrome (PHTS), Cowden Syndrome (CS), or Bannayan-Riley-Ruvalcaba Syndrome (BRRS) through better patient support, increased awareness, more accurate and accessible information, earlier diagnosis and intervention, greater research into treatment and prevention, and improved coordination of care.



PATIENT STORIES

You can now see our first patient video from David on our YouTube channel found [here](#). Shortly we will be adding to this with new video featuring Lexi and Michelle and providing shorter segments of the videos.

Hearing from patients and carers and building up support networks is a vital part of the charities role. If you would like to tell your story please let Ellie know at: ellie@ptenuki.org

PTEN RESEARCH UPDATE

It's been a busy year for the Foundation so far. We've changed our name to **PTEN Research** and have put the finishing touches to our **2018 strategy**. This draws together findings from our board meetings in London and Boston earlier this year, and sets out our vision for developing a targeted treatment for PHTS in the next 10 years. A public version will soon be available to download from our website. The results from our **2017-18 grant review** have now been finalised, and we will be announcing the recipients very soon. We are also planning substantial changes to our **website** - incorporating new content on PHTS, updates on our mission and current work, along with interviews with our grant recipients and partners. All this will be available soon. To find out more go to <https://www.ptenresearch.org/>

KELLY KEARLEY REPORTS ON THE 1ST INTERNATIONAL PTEN SYMPOSIUM IN ALABAMA

I had the honour of representing PTEN UKI at the first international symposium held in Alabama in March 2018. As a parent of a PTEN patient as well as a founding member of our patient support group, it was a fantastic experience. I felt I learnt all there is to know about PTEN, met some top medical experts in the field as well as meeting some amazing patients and parents that are also affected by the PTEN gene mutation on a daily basis. It was great to suddenly not feel alone, realising there are people affected by this condition all around the globe and also top medical professionals that are researching the condition to help people like ourselves - the future suddenly looked brighter!

To read Kelly's full report go to <http://ptenuki.org/first-international-pten-symposium/> The next International Symposium will be held at the Cleveland Clinic, Ohio on the 6 - 9th April 2019. If you are interested in attending, please register your interest by emailing info@ptenuki.org and we will be in touch as soon as we have more details.



Kelly and Austin



24 November 2018

PTEN PATIENT DAYS

In 2017 PTENUKI got 70+ patients, family members and professionals together in London for a day of learning, support, collaboration and looking to the future. To read a write up of what was covered go to <http://ptenuki.org/ptenuki-patient-day-nov-2017/>

For 2018 we will be holding the third Patient Day event at the Heron Tower in London on Saturday 24 November.

YOU CAN NOW REGISTER FOR THE EVENT
simply click here:

<https://goo.gl/forms/UXeXiN4riult6XLs2>

We do hope that many of you will be able to attend.

Want to write something for our next newsletter? Let Jenni know: jenni@ptenuki.org

