



# PTEN Patient Day

24<sup>th</sup> November 2018

# Welcome & Thank you

- Objectives
  - To enable patients to **network** with other patients and health professionals
  - To **provide updates** from health professionals, researchers and PTENUKI on the help available
  - To **share** patient and carers' stories and consider what additional **support** the charity and health professionals can provide

# Introduction



- Thank you to all our Volunteers and Helpers
- Health & Safety
  - Emergencies & Evacuation
  - First Aid
  - Toilets
- Location
  - Atrium, kids room, meeting rooms, lunch area, mindfulness room
  - Please stay on the 29<sup>th</sup> floor
  - Please look after your children
  - Re-entry to the building
- Photographs & Video

# Patient Day Etiquette

- Be mindful of all ages and levels of knowledge / experience
- Start with a basis of trust and good intent
- No information shared by patients should be taken as medical advice
- Be kind and respectful with your words and thoughts
- Do not share from here people's personal/sensitive information

# Agenda



Time	Description	Organisers
10:00	Welcome, Updates & Patient Story	PTENUKI Trustees & Charlie
11:00	Breakout sessions <ul style="list-style-type: none"><li>● Female</li><li>● Male</li><li>● Parents</li><li>● Newly Diagnosed / PHTS Overview</li></ul>	All <ul style="list-style-type: none"><li>● Ellie</li><li>● Mike &amp; David</li><li>● Mark &amp; Kelly</li><li>● Katherine</li></ul>
12:15	Q&A Panel: Letting the patient voices be heard	Experts & Patient panel
13:00	Lunch	All
13:45	Patient Story	Yvonne
14:00	Speed Dating	All (yes, all !!)
14:30	Information Zones <ul style="list-style-type: none"><li>● Research &amp; Trials</li><li>● Fundraising</li><li>● Clinical / Medical</li><li>● Care &amp; Support</li><li>● Patient Group &amp; Awareness</li></ul>	All
17:00	Close	



# PTENUKI UPDATES



# PTENUKI Charity Update



- PTEN UK and Ireland Patient Group
- Registered Charity: 1172205
- Founded: March 2017
- Aims:
  - Patient Support
  - Improve Healthcare
  - Research

[www.ptenuki.org](http://www.ptenuki.org)

# Our Trustees



**IAN STOCK**  
CHAIR OF TRUSTEES



**ELLIE COLLINS**  
TRUSTEE (PROMOTION & AWARENESS)



**KELLY KEARLEY**  
TRUSTEE (FUNDRAISING)



**DR KATHERINE LACHLAN**  
TRUSTEE (MEDICAL ADVISOR)



**MIKE COLLINS**  
TREASURER AND TRUSTEE



**JOHN PEMBERTON**  
TRUSTEE (TECHNOLOGY)



**COLETTE KNIGHT**  
TRUSTEE (CARE & SUPPORT)



# Awareness & Comms



## Private

### PTENUK Private Group

Closed Group

Interacting as PTEN UK & Ireland Patie...

About

Discussion

Members

Events

Videos

Photos

Files

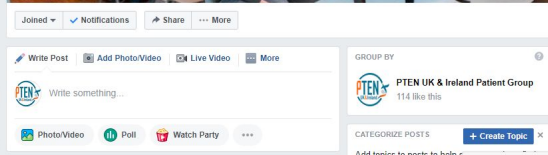
Group Insights

Moderate Group

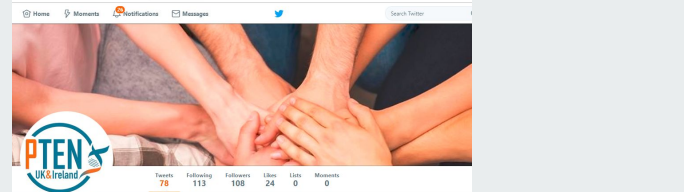
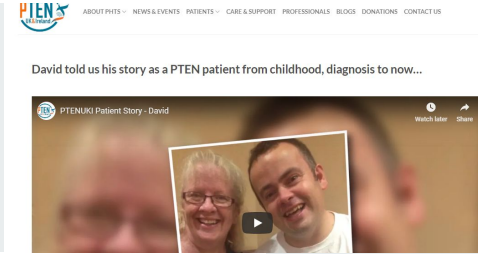
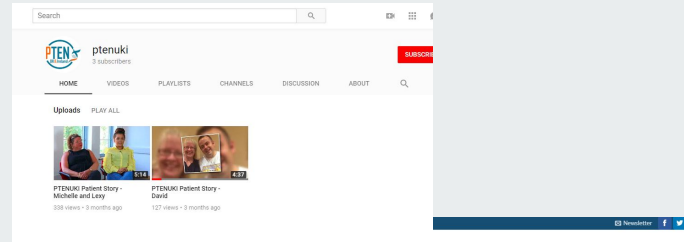
Search this group

Shortcuts

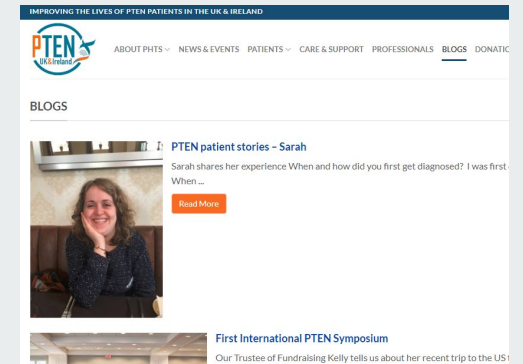
Oxford PharmaGen...



## Public



## Share your story



PTENUK Patient Story - David  
127 views



# Fundraising



The journey so far.....

- Since the launch of the PTEN UKI charity we have raised just over £11,000 from:
  - Corporate sponsors - places of work
  - Jeans for Genes grant
  - Local fundraising events
  - My Donate Page – community activities and personal achievements
- This has enabled us to set up our support system so we can reach families affected by a PTEN gene change in the UK and Ireland by:
  - Designing our logo and creating our brand
  - Building our website
  - Filming patient stories



# Fundraising & Raising Awareness

- Goes hand in hand
- People will only donate if they understand what the cause is
- Lots of people from the PTEN community raising awareness on a local level will help raise awareness on a national level
  - Local media coverage
  - Local event
  - Local Reps

# How you can help PTENUKI

- Volunteering as a local rep to help raise awareness
- Hold a local fundraising event - car boot sale, cake sale, coffee morning
- Ask your Employer to make our charity its charity of choice for 2019
- Set yourself a personal challenge and raise money through our My Donate page: <https://mydonate.bt.com/charities/ptenuki>
- Buy your shopping online through their SMILE website which raises money for charities:
  - <https://smile.amazon.co.uk>
  - Click on 'PTEN UK and Ireland Patient Group'

# The Future of PTEN Fundraising



- There are many avenues that we are looking to raise funds in 2019 and beyond...
  - Applying to large charity organisations – such as the National Lottery, Children in Need etc...
  - Applying to large corporate sponsors
  - Recruiting local reps
  - Attend RARE Fest in 2019 to raise the profile of PTEN - <https://camraredisease.org/rarefest/>



# Why do we want to raise funds?

The Charity's mission is to improve the lives of patients/parents/carers by:

- Providing better support:
  - Continue to develop the website with up to date medical content and patient stories
  - Build an online presence for the charity through social media
  - Help fund patients to attend the annual PTEN conference
- Increase awareness:
  - Design information booklets and other resources to reach out to genetic counselors and local GPs
  - Attend events such as Rarefest to raise the profile of the condition
  - Design and buy marketing material to spread the PTEN word
- Help Research:
  - Build an online patient registry to help further research

We are hoping all of this will lead to an increase in early diagnosis.

# Want to help?

If you would like to help raise money for this cause which is so personal to all of us, please contact me at:

[kelly@ptenuki.org](mailto:kelly@ptenuki.org)

07766 656157

# Medical Update



- Website
  - New pages for On diagnosis.
  - Links to useful websites e.g. explaining inheritance pattern, UK Clinical Genetics Services.
  - Clinical information
- Patient Registry
  - Funded by PTEN Foundation. Lead by Marc Tischkowitz
- GENTURIS

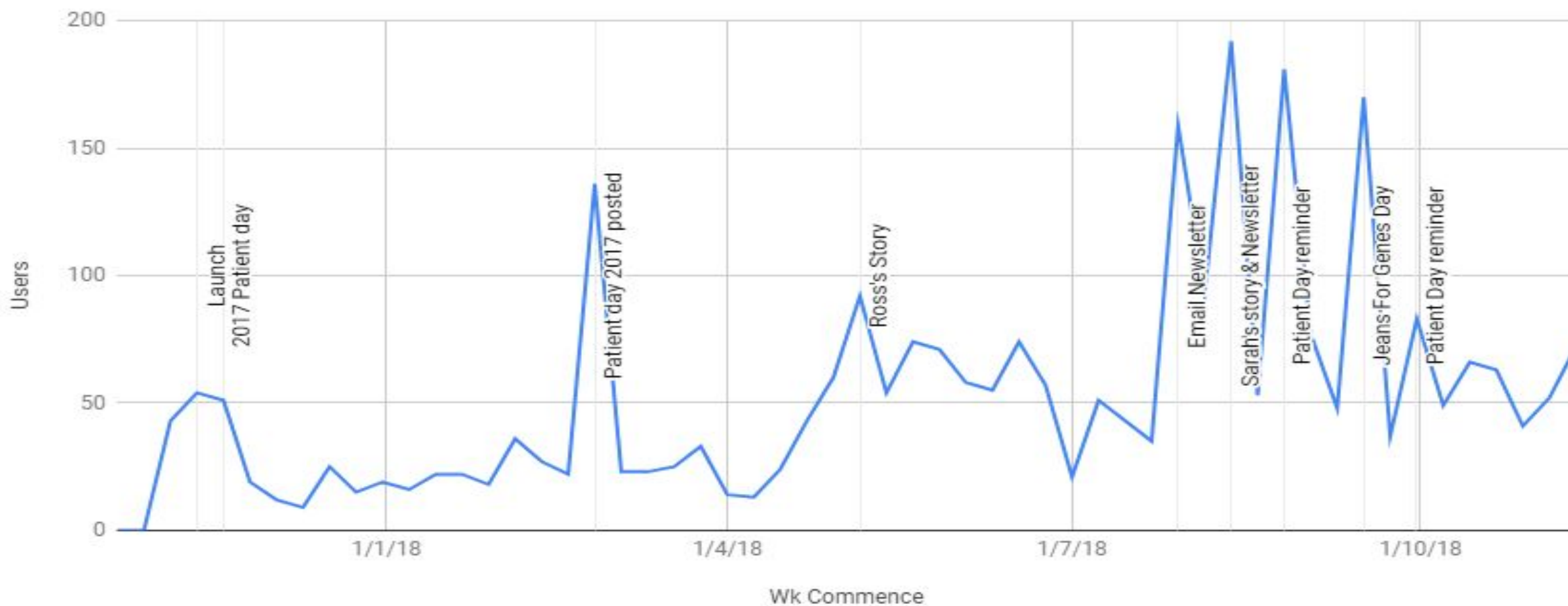
# Technology Update



- Website
- Email - Awarded Nonprofits enrollment Feb 2017
- Technical setup
- Next - Facebook donate button, Google advertising donation.

# Website

Users vs Wk Commence



# PTENUKI Buddy Scheme

PTENUKI are keen to set up a system whereby we can put patients and their families in touch with each other, to share information, stories and support.

## Objectives:

- Introduce you to fellow PTEN patients/families who are living with a PTEN diagnosis.
- We will try to match people whose experience is likely to be similar
- We will try to find a buddy who is further down the line with their treatment / diagnosis experience

## Goals:

- Your buddy will be able to give you a first-hand account into their experiences
- You will get insights into both what it practically and emotionally means having a PTEN diagnosis.

Please come and see **Colette** this afternoon at the Care & Support Information Zone

# PTENUKI - Local Reps/Meetup Groups



An objective very close to the heart of PTENUKI is to be able to reach out and be available as a source of information and support to patients, parents and carers of all ages, in the United Kingdom and Ireland, who are affected by PTEN genetic alterations.

PTENUKI would like to set up a system of local representatives, who can run their own meetups close to their geographical location. The frequency of meetups can be decided by the local group members.

We have got a **large map** available here today, and during the course of the day if you could pin your name and location onto the map where you live, that will give us a great snapshot of where we all live.

Please come along and see **Colette** this afternoon at the Care and Support zone to chat more, and register your interest as a participant or perhaps even an area rep!

# Patient Story



## Charlie Richards

# Breakout Sessions

- A chance to talk, to explain your journey and experiences
- Agree on 3 key questions or unmet needs to feed into the Q&A Panel
- Sessions
  - Female
  - Male
  - Parents
  - Newly Diagnosed / PHTS Overview

# Q&A Panel



- Sarah Plummer (PTEN Patient)
- Deborah Nash (PTEN Patient)
- Michelle Laver (PTEN Parent)
- Katherine Lachlan (Clinical Geneticist)
- Gill Crawford (Genetic Counsellor)
- Maria Whiteheard (PTEN Research)
- Ian Stock (PTENUKI Trustee)



**LUNCH**

# Patient Story



Yvonne Maureen

# Speed Dating

- Name(s)
- Area / Location
- Are you patient / family / carer / professional
- Why are you here today?
- Who are your professionals / patients?
- Who else do you know?

# Information Zones & Thank Yous

- Information Zones
  - Research & Trials
  - Fundraising
  - Clinical / Medical
  - Care & Support
  - Patient Group & Awareness
- Prize Draw
- Thank you to all our helpers, volunteers and attendees
- Sign up, check in, reach out, get involved

[www.ptenuki.org](http://www.ptenuki.org)



**THANK YOU**