



**We hope that everyone is safe and well and our thoughts go out to all of our contacts across the world during this difficult time.**

At PTEN Research it is our goal to improve the lives of the patients and their families living with PHTS (PTEN Hamartoma Tumour Syndrome) by funding research into better understanding of the condition, and into the development of potential future treatments.

**Thank you for continuing to support us.**

**- The PTEN Research Team**

**If you would like to read more about us please visit our website or email us at [contact@ptenresearch.org](mailto:contact@ptenresearch.org)**

## OUR RESEARCH

At PTEN Research we fund projects with leading experts in the field of PHTS at institutions around the world. It is through this approach that we generate the most valuable scientific research with the leading scientists in the field. Our formal application and external review processes ensure that we only fund work of high scientific value.

**If you would like to find out more about how we fund research, or apply for a research grant please [click here!](#)**

## NEWS AND EVENTS



### **Foundation appoints new Director of Finance and Business Operations**

The Trustees are pleased to announce the appointment of Adam Bennett as the Director of Finance and Business Operations of the PTEN Research Foundation.

Adam is responsible for the Foundation's finances, legal activities, risk and compliance, human resources and IT.

Prior to joining PTEN Research, he had a career in investment banking and was afterwards head of Lord Rothschild's family office and more recently Chief Operating Officer of WHAM, an FCA-regulated firm that manages the investments of charitable foundations. He is a Fellow of the Institute of Chartered Accountants in England and Wales and graduated with an MBA from INSEAD.

**[Click here to find out more about the PTEN Research Team](#)**



Our thanks to the PTEN UK and Ireland patient group for inviting us to record a YouTube video to share on their channel. The video provides an overview of some of the Foundation's key activities.

**[Click here to watch the video](#)**

## ICD10 CODE CDC MEETING & IMPACTS

### **Application for International Classification of Diseases (ICD) code for PHTS**

The Foundation have been working closely with Charis Eng (Cleveland Clinic), Marc Tischkowitz (University of Cambridge) and other experts to develop and submit an application for an International Classification of Diseases (ICD) code specific to PHTS.

The ICD coding system is maintained by both the Center of Disease Control (CDC) and World Health Organisation (WHO) each of which have their own separate application processes.

Having such a code is important as it can be recorded in an individual's medical records as a clear and unambiguous identification of their PHTS diagnosis. This supports not only individuals with PHTS directly, but also their doctors and researchers in several ways including:

- Supporting access to appropriate medical care for PHTS patients, including cancer screening and surveillance programmes.
- Helping to better understand the number of patients who have a PHTS diagnosis.
- Helping to promote greater awareness of PHTS by doctors, which in turn should lead to better care and improved levels of diagnosis.
- Supporting PHTS research and potential future clinical trials.

On September 15th Prof Eng presented an overview of the application to the CDC and we hope to get feedback from them in the summer 2022. In the meantime, the WHO review is ongoing.

**[Click here to access the CDC meeting materials.](#)**

## CONTRACT RESEARCH UPDATE

Two collaborations initiated with contract research organisations in 2020 have made significant progress generating preclinical models of PHTS. The goal of this work is to enable assessment of repurposing of existing drugs for further evaluation in future PHTS clinical trials.

Initially the focus will be on assessing the many drugs developed for cancer applications that target the major pathway affected by PTEN mutations. These drugs may offer the shortest potential repurposing route given the wealth of information already available from their development to treat cancer.

Additionally, the collaborations will aim to gain a better understanding of the underlying consequences of PTEN mutations in neurological, vascular, and tissue overgrowth aspects of PHTS. Insights from the collaborations will complement those made through the Foundation's academic collaborative network to increase our knowledge of PHTS and identify additional potential therapeutic approaches.

**It goes without saying that 2021 has been another challenging year for patients and families as well as our academic and industry collaborators alike. Despite this, we are very proud and appreciative of all of the hard work and continued progress that has been made across our supported research projects.**

**On behalf of everyone at PTEN Research we would like to extend our thanks and appreciation for the ongoing partnerships and collaboration.**



**[If you would like to make a donation to support our work please click here](#)**

**PTEN RESEARCH**

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