Nurse, Karen

Turner

CANCER RESEARCH UK CLINICAL TRIALS UNIT

Patient and Public Involvement and Engagement (PPIE) Newsletter: Spring 2023



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International Clinical Trials Day is an important opportunity to share information with you all on our exciting clinical trials. So let's 'Raise our Voices', 'Elevate the Bar', 'Be for Everyone' and 'Inspire the Future' together!

This newsletter is for you and needs to be driven by what you would like to see, so please let us know at engage@trials.bham.ac.uk, and in the meantime, a massive thank you from us; we hope you enjoy reading this edition.

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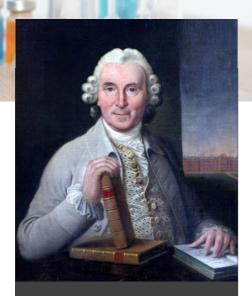
About CRCTU:

An internationally leading centre for the design and delivery of high-quality, practice-changing trials for children, young people and adults with cancer.

Our Mission:

Improve the lives of patients with cancer by developing innovative, efficient and biology-rich clinical trials, with a patientcentric approach to trial design and delivery.

INTERNATIONAL CLINICAL TRIALS DAY 2023



On the 20th May each year, Clinical Trials Day is celebrated around the world, inspired by what is generally considered to be the start date of the first ever randomised clinical trial.

On 20th May 1747 James Lind, a ship's surgeon in the British Royal Navy began a trial into the effects of different treatments on scurvy in sailors. Lind was not the first to believe that citrus fruits provided a cure for scurvy, but he was the first to test their effects in what he described as a 'fair test', alongside five other purported treatments, including cider, vinegar and sea water.

We will be promoting International Clinical Trials Day on our Twitter page. Click below, or find us at @CRCTU





Resources and more about how you can get involved in promoting International Clinical Trials Day can be found on the website of the Association of Clinical Research Professionals (ACRP).

BRAIN CANCER AWARENESS MONTH





JOIN THE BRAIN
TUMOUR CHARITY
THROUGHOUT MAY,
AND MARCH
TOWARDS A WORLD
WHERE EVERYONE
AFFECTED BY A
BRAIN TUMOUR CAN
LIVE A LONGER,
BETTER LIFE.

Stride towards a cure this Brain Tumour Awareness Month! The Brain Tumour Charity's flagship event, The Twilight Walk, is back! And, for the first time ever, they're holding it during Brain Tumour Awareness Month! This inspiring event sees communities across the world unite to propel progress towards a cure. Join in-person at the first ever London Twilight Walk, or stride out remotely and tackle a Twilight Walk Own Walk.

BERTI is a group for people affected by brain tumours, including patients, friends and family, health professionals and researchers. BERTI provides a forum to meet with other people affected by brain tumours and share experiences, understand the condition better and work with clinical staff and researchers to improve clinical care and facilitate research.

Run between the University Hospitals Birmingham NHS Foundation Trust and the University of Birmingham, BERTI meets 3 times per year for a formal talk explaining an aspect of brain tumour or a research idea, with time for discussion both as a whole group and smaller informal chats. There is no cost and no commitment – come along, join in and let us know what you think!







Brain tumour patient Baljit Mehat (who sadly passed away this year) previously sat down with the Chief Investigator of the study, Professor Susan Short, to ask some key questions.



LO GIC Core

LOGGIC Core is a European study for children and young people with a Low Grade Glioma (LGG). When a patient with a LGG has had surgery, this study will seek to find out as much information about the tumour as possible. To do this, we will carry out laboratory tests on the samples, some of which will identify if there are genetic mutations.

LOGGIC Core is currently in set-up in the UK and we are inviting applications from patients, parents/guardians of patients and the public to sit on the Trial Management Group. Meetings are held every 3 months and last for around 1 hour.



MaVeRiC

MaVeRiC is currently in development and will study the treatment of chronic lymphocytic leukaemia.

There are multiple opportunities for patient and public involvement in this study.

We are seeking a patient representative to provide a valuable patient perspective and contribute to the design of the trial.

Should the trial receive funding, we will also need:

- a representative to help develop the patient-facing documents
- representatives to sit on the Trial Management Group

FIND OUT MORE



HEM-iSMART

HEM-iSMART is a personalised medicine trial in which children with relapsed leukaemia or lymphoma will receive a treatment corresponding to the specific genetic alteration(s) present in their tumour. This is an internationally sponsored trial and we are seeking a representative to help develop the UK patient-facing documents required as part of our funding application.

FIND OUT MORE







We are seeking a patient representative to join the PRiZM+ Trial Steering Committee (held twice yearly).

PRiZM+ is a Phase 2 study of zanubrutinib in relapsed/refractory peripheral central nervous system lymphoma, a blood cancer that affects the brain. The trial includes patients who lack capacity to consent therefore we welcome people who have a particular interest in, or experience of, this area of care.

The trial has so far recruited 9 out of 20 patients to the current treatment arm; further treatment arms are planned for the future.

Involvement and
Engagement in Cancer
Research at Birmingham
(ICRB) are due to meet online on the 7th June 13:00
– 14:30. Local researchers
are invited to present
projects to the group for
feedback and to gain your
unique insight. If you
would like to join us in
June please email Karen
Turner to be added to the
distribution list.

REGISTER INTEREST



FIND OUT MORE

CCLG Functional Imaging of Tumours study

The world-leading UK consortium of children's cancer imaging experts is seeking the views of patients, parents and others in developing their future research ideas, building on the 20 years of success from the CCLG Functional Imaging of Tumours Study. They are looking at how to develop the existing research in areas of advanced imaging and MRI, data integration and sharing and the use of artificial intelligence.

They would love to hear your views at a meeting on Thursday 8th June, 15:00-17:00 in central Birmingham.





ALL EVENTS



FEATURED EVENT



The MAC (Midlands Arts Centre) - Foyle Studio Cannon Hill Park, Birmingham, B12 9QH, United Kingdom



The Science of Our Society



grown astronomically over the few years since two people decided to share their research in the pub. Although their mission has expanded, their core values remain the same: to provide a space for researchers and members of the public alike to come together, be curious, and chat about research in a relaxed environment outside of mysterious laboratories or daunting dark lecture theatres. They believe that everyone has a place at the table to discuss the research going on both on our doorsteps and far beyond. Their missions and visions are based around the people that matter most: their audience, volunteers, speakers, and the wider research community.

FIND OUT MORE





LEARNING FOR INVOLVEMENT

Now available – an interactive course for new and experienced reviewers of health and social care research, which has been produced by a team of public reviewers and patient and public involvement professionals with the NIHR.

The course is online and freely available. Each module is also available as an accessible version, to download as a pdf or as a PowerPoint version.

VISIT SITE



UNIVERSITY OF BIRMINGHAM PPIE WEBSITE



At the University of Birmingham, patients and the public are involved throughout our research. We work in partnership with people from all backgrounds to bring different perspectives to the way that research studies are designed, carried out and how the results are shared. We have lots of opportunities to get involved in all aspects of research, so there's something to suit everyone.

Here we signpost to training, support and resources for both public contributors and research teams. Find out more about PPIE in the College of Medical and Dental Sciences at the University of Birmingham.