Cambridge Stem Cell Institute

UNIVERSITY OF CAMBRIDGE

Help shape research on BRCA breast cancer prevention

We're forming a patient advisory group

In 2013, actress Angelina Jolie announced that she had surgery to remove her breasts as a preventative measure against cancer. Jolie found out through family history and genetic diagnosis that she had a fault (mutation) in a gene called BRCA1 which meant she had an 80% chance of developing breast cancer – 10 times the risk of the general population. Her openness led to an increase in awareness and in the number of double mastectomies (breast removal surgeries before cancer develops). However, breast removal is a serious medical procedure which then raises the question: is there an alternative way to prevent breast cancer in BRCA1 carriers without having to undergo surgery?

What we are doing:

Our research group at the University of Cambridge has been studying how BRCA1 mutations affect breast cells before any cancer is detected. In 2021 and 2024, we published studies that identified the earliest changes caused by BRCA1 mutations. Some of the changes we found could potentially be treated using drugs already available or under development. We have now been funded by Cancer Research UK to test six of these drugs in a lab model of BRCA1 breast cancer to see if we could prevent cancer development. A blood test developed in the lab could also identify who would benefit the most from these drug treatments. By the end of this project, we hope to have strong evidence to support testing the use of these drugs as prevention therapeutics in a clinical trial.

Why we want to form an advisory group:

People with lived experience of, and affected by, BRCA1 mutations, breast cancer and treatments have valuable perspectives that we want to hear. Our patient advisory group will help shape our research and engagement plans and ensure they are relevant and beneficial beyond the lab. We seek a small group with diverse experiences to work with researchers to exchange knowledge, review proposals and develop future activities. Members of our patient advisory group will be compensated for the time and expenses incurred working as partners on the project.

Who we are looking for:

- people with lived experience of breast cancer
- people who have undergone drug or surgical treatments similar to those we are testing
- people from backgrounds underrepresented in biomedical research

for this project, we are particularly interested in meeting and will prioritise:

- people who carry the BRCA1, BRCA2 or PALB2 genes, their families and carers
- people who have had, considered, or are considering, preventative breast surgery

What your role would be:

- attend closed meetings, usually online, to discuss and provide feedback on project progress
- review documents and summaries in advance of meetings
- offer personal and community insights to ensure our project addresses patient needs
- share ideas and practice that you see elsewhere and training you would find valuable
- participate in discussions about wider communication, engagement and involvement plans

What you need to be able to do:

- work as part of a team and respect the views of others
- demonstrate honesty and integrity, including with confidential information
- be comfortable sharing your opinions and personal experiences of cancer
- have IT skills and internet access, or work with us to put in place alternatives
- commit up to 2 hours per month (paid at £25 per hour with all reasonable expenses covered)

How to get involved:

We want to hear from people interested in joining our advisory group. We are using a short online survey to collect contact details and understand your background, experience and genetic risk of BRCA1 breast cancer. Follow this link to the form at www.stemcells.cam.ac.uk/engage/brca1

A background or training in biology or medical research is not required for this role. If you have difficulty with any online documents or forms, please let us know using the details below.

If you have questions, you can contact Sara Pensa by email at sp580@cam.ac.uk
You can also contact us by post: CSCI PPIE team, JCBC, Puddicombe Way, Cambridge, CB2 0AW

Who we are:

Sara Pensa
Project Lead and Postdoctoral Researcher

Walid Khaled
Principal Investigator and Professor

Greg Palmer
Patient and Public Involvement and Engagement Manager

Interested? Meet the team behind this research project, share your views, and help create our advisory group…

Get in touch if you would like to find out more and visit us at the Cambridge Biomedical Campus on Friday 6 December.