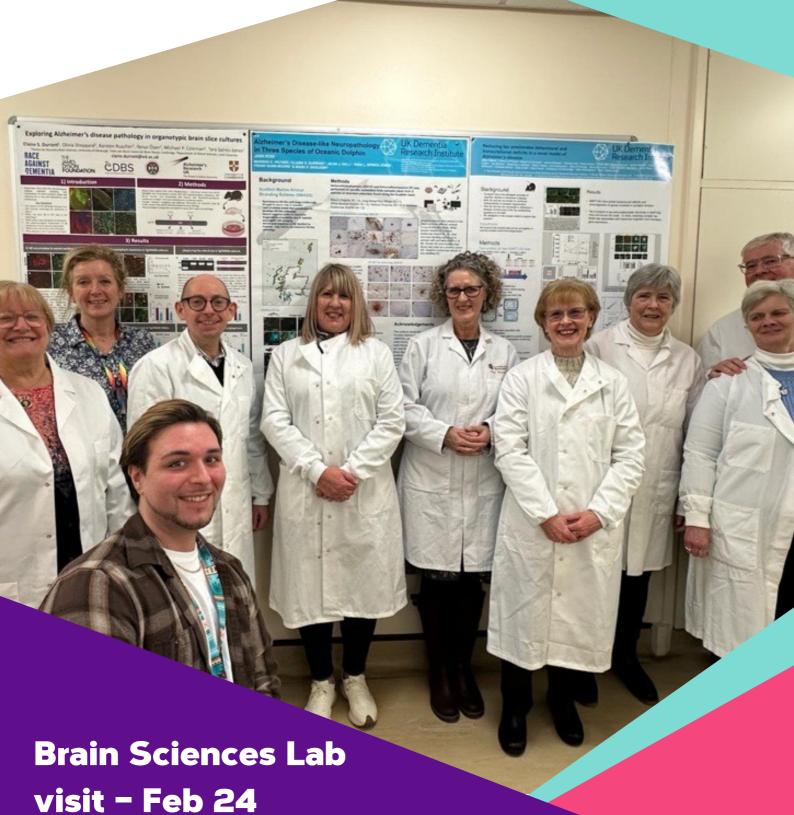


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National Dementia Carers
Action Network





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The Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN) are proud partners in research, supporting purposeful dementia related research by bringing their personal experiences to help shape and inform the aims and objectives of research projects; volunteering as research participants; and being kept informed of activity within the dementia research world.

Members have established a strong relationship with the Centre for Discovery Brain Sciences at Edinburgh University, meeting with its deputy-director Professor Tara Spires-Jones and students to discuss the work of the Centre and touring the facility to see, first-hand, the work that is taking place there.

At the start of February 2024 six SDWG and NDCAN members had the pleasure of visiting the Centre, the second such visit in just a few months. From hearing about "living" tissue brain research and fruit fly brain research; to trying out some of the state of the art microscopes and learning about the ethics and protocols applied in the Centre – the members have shared their thoughts on the fascinating and inspiring visit.

(ommitted people doing inspiring work

I feel so privileged to have been part of the tour of the Brain Science Lab in Edinburgh University. The first impressions from our meeting with Tara, Claire and their students and listening to everyone's enthusiasm while giving very brief summaries of their work was inspiring. Their commitment to research into dementia was heartwarming and they understood the importance for their generation to find answers, effective treatments and perhaps a cure for generations to come.

The lab tour itself was fascinating. Hearing about their strict ethical collection and use of small pieces of "living" brain tissue from brain tumour operations, as well as post-mortem tissue was inspiring.



It was just incredible to be told how much they could do with absolutely tiny pieces of brain tissue the size of a crumb, and thin slices which could be layered into even thinner slices then combined again.

The different kinds of microscopes being used for different kinds of tests was really interesting too. Kris and other students working with tiny fruit fly brains to research, analyse and report on their findings were so enthusiastic about the comparisons with the human brain. Creating tiny "hybrid" flies from embryos was like something out of science fiction!

They are all using state of the art technology so expertly – I was just overwhelmed with their knowledge and skills, and their ability to explain all about their work in lay terms that we could all understand and appreciate.

Mind boggling research

The experience and welcome from everyone at the lab was something very special from start to finish and thoroughly deserving of thanks and appreciation.

We started off the visit in the kitchen-lounge area for tea and coffee and general introductions, with everyone, researchers and Active Voice members, giving a little background about themselves. Professor Tara Spires-Jones was there, described her work, the research being done there, and she also baked some incredible cookies that I will remember as simply delicious. She is Wonder Woman personified!

Then we toured the labs dressed in white lab coats... brought back memories of Beaker from the Muppet Show.





The range and depth of the research is mind-boggling and that's besides the fact that my mind is already boggled. The machinery is so very expensive, sophisticated and specialised and lucky us got to peer into microscopes, see slides and learn about the exciting progress that's being made.

The tiny size of the tissue samples and fruit flies was a surprise and then being shown how they are handled and used to progress the research made a big impression, as did the cataloguing and care taken with the samples. Everything is so wee. It's like dicing a pin head.

For me, learning about the collection and usage of the access tissue donated by folk having a brain tumour removed was very special. That and the respectful approach and delicate handling shown by the researchers in all aspects of what they do is amazing. Thank you all for the warm welcome and wonderful afternoon.

Rynagh Flynn, SDWG

Dissecting the brain of a fruit fly is mind blowing!

I was invited along to Edinburgh University to see around the brain laboratory by Professor Tara Spires-Jones. We met lots of post graduate students, each assigned different roles in brain research. It was fascinating to hear their enthusiasm and admire their intelligence at such young ages. They were especially inspired listening to the experiences of people with dementia.

We were shown around each laboratory by the lab manager Jane Tulloch and Kris who explained, in plain English, what we were viewing via microscopes.

We learned about using live brain tissue from post operative patients, incubating it and nourishing it to survive for 28 days. This allowed scientists to view the live electrical and chemical exchanges on specialist equipment.

We learned about the life cycle of fruit flies and how this aids learning on diseases such as Alzheimer's. Dissecting the brain of a fruit fly is mind blowing!

What was very noticeable to me was the constraints of the old building that the staff are working in with curtains for darkness.





Dementia is the leading cause of death in Scotland, but we are not looking after our brilliant genius scientists.

It was apparent that they desperately need funding. The expensive equipment is squeezed into spaces not purpose built for it. Scotland has the ability to be at the forefront of research. It feels as though we are so close to a breakthrough, but we must look after our researchers better.

Elaine Deehan, ND(AN

They are all stars!!

It was so generous of the staff and researchers to give us the time to get to know the specifics of what they were each working on. Also, to be reassured about the stringent protocols in place due to the understandable ethics of humans, as well as animals of whatever form.

I thoroughly enjoyed the trip - it was just truly phenomenal to see and hear what all the young researchers are working on and then be able to ask questions. It is tremendous to think young researchers are carrying forward the great research of the past.

Oh to be a millionaire or billionaire to support all the great work of Alzheimer's Scotland, Brain Health, Brain Sciences, UWS ASCPP.



Margaret Mc(allion, SDWG



"Enabling and promoting the diverse voices of people with dementia and carers to campaign for, promote and uphold rights and drive change."