

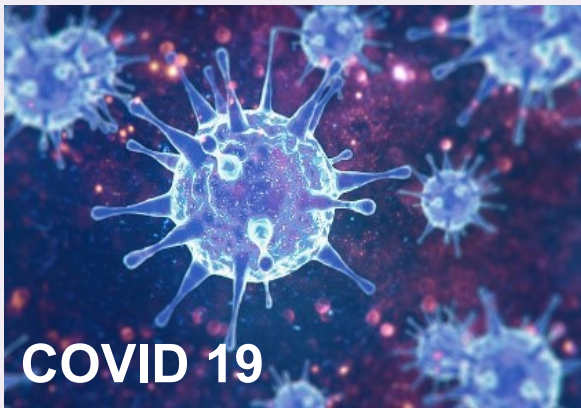
BDR NEWS



Brains for
Dementia
Research

Brains for Dementia Research Newsletter

Summer 2020



The global pandemic COVID-19 has dominated the news over the last few months affecting virtually every aspect of our lives, including research.

From mid-March, BDR Centres based in hospitals and universities started to close and the long-awaited BDR engagement events due to be held in Cardiff and Bristol had to be cancelled. In general, the research community had no choice but to respond to this catastrophic event by bringing many of their studies to an abrupt halt. So, in these unprecedented times, how did BDR fare? Not surprisingly, study progress slowed, but it did not stop. Instead, the study has been able to keep going principally because of a feature of its design – the capacity to carry out assessments remotely. Although some of our BDR research staff were drafted to help support the NHS during this difficult period and a few staff members were furloughed, most

continued to work on BDR, albeit from home. Instead of making face-to-face visits, we made all our contacts by phone and with the generous support of you, our volunteers, this has meant that we have been able to keep pretty much on track. It has not been possible to gather all the information that we would have liked (you cannot assess grip strength or blood pressure over the phone!) but through your continued support, we have been able to gather valuable data. Similarly, we have not been able to assess everyone by phone as for some participants this is just not possible, but in these cases we will try to catch-up in person, once restrictions around contact are lifted.

There have been few positive aspects to this period, but as the assessment teams will comment, many of our BDR participants lead busy and interesting lives taking them out of the house, so at least at the moment when we call, there is a good chance of finding people at home!

BDR supporting researchers

As well as continuing with assessments, we have also continued to receive and respond to data requests. We recently approved an application from a prominent, national research consortium. BDR data will be used together with data from other large studies to address the genetic variability of dementia. The research team intend to link genetic information with clinical presentation, establishing a technological platform and best practices for national collaboration between clinicians, geneticists, statisticians, data scientists and lab scientists which promises to be a huge step forward.



Brain Donations

Not surprisingly, corona virus has had an impact on the number of donations that we have been able to accept. We are immensely grateful to all our donors and their families for offering to make this generous gift but because of lockdown, the increasing demands on mortuary staff and the inherent risks relating to the virus, we have been unable to accept all donations. However, we would still encourage families to contact their local team when potential donors have passed away so that we can update our records and ensure that we don't make inappropriate contacts in the future.

During this unprecedented period of lockdown, the global economy has been severely affected and our funders, the dementia charities, Alzheimer's Society and Alzheimer's Research UK, have not been immune to this. The charities have closed their shops and because of cancelled sporting events, monies which would have been pledged through sponsorship, have taken a bit hit. Despite these pressures and in recognition of the importance of BDR, the charities have approved funding beyond the current end-date of April 2021. **They have agreed to fund the study and the associated brain banks for a further 5 years until April 2026, offering a grant of five million pounds!** We are delighted to receive this news and are immensely grateful to the charities for recognising the significant contribution BDR has made to dementia research.



www.brainsfordementiaresearch.org.uk



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[@brains4dementia](https://twitter.com/brains4dementia)



What's happening in your local BDR?



**Dementias
Platform^{UK}**
Medical Research Council

<https://www.dementiasplatform.uk/>

How BDR members can help change the story of dementia

Dementias Platform UK (DPUK) brings together anonymised information from a whole range of health studies. This data is held within the DPUK Data Portal and is stored in a single, secure, environment so researchers can only access anonymised data following application and approval from the original owners of the data. In other words, if a researcher wants to look at anonymised BDR information, before gaining access, they must apply to the BDR Access Committee outlining exactly what information they want and for what purpose. This keeps the data secure and access controlled, but having access to a large number of data sets also offers great benefits, as it allows researchers to address key scientific questions in a much more rigorous and rapid way, than would otherwise be possible thereby accelerating our understanding of neurodegeneration and the development of new treatments.

To make the best use of and expand the data resources, DPUK have collaborated with BDR so that those **BDR participants and Study Partners who have expressed an interest in taking part in future research** may be invited to participate in additional brain health research.

The projects promoted by DPUK are **GREAT MINDS** and the **CLINICAL STUDIES REGISTER**.

Where appropriate, **your local study team will be contacting you directly** about these initiatives although we would like to emphasise that all invitations for additional research are of course **optional**. If you have any queries about our partnership with DPUK, or if at your last assessment, you expressed an interest in future research, and now wish to **opt-out**, please contact your local study team at the contact details given below;

BDR Centre	Telephone / Email
Bristol	0117 4147823 / bdr-brainbank@bristol.ac.uk
Cardiff	02920 688042 / adresearch@cardiff.ac.uk
London	02078 480626 / kamara.t.israel-mcleish@kcl.ac.uk
Manchester	07787 002 307 / Brain-bank@manchester.ac.uk
Newcastle	0191 208 1231 / nbtr@ncl.ac.uk
Oxford	1865 234608 / bdr.oxford@nhs.net

NOTE: If you have previously registered interest in future studies and are keen to be involved, you do not need to contact us. Any invitations will come from your local team.



What's happening with our Engagement Events?

The Cardiff and Bristol teams planned to host events in the spring of 2020 and were so disappointed to have to cancel them following the outbreak of Corona virus. The teams in Newcastle and Manchester have also been busy planning similar events for the spring of 2021. Will they go ahead and if so when? At the moment, we are not sure. We will follow Government guidance and if we can reinstate the cancelled events and proceed with the proposed plans for next year then we certainly will. We'll keep you posted!

The Cardiff team interview one of their Study Partners



We spoke with Julie, a study partner who has been greatly involved in BDR for the last few years. Julie's parents both signed up to participate in the Brains for Dementia Research project in 2012. Since then her mum has sadly lost her battle with Alzheimer's Disease and has donated tissue to the project. Her father continues to support the project and acts as an advocate for individuals with dementia, raising awareness and funds in the process.

We asked Julie for her thoughts about the project and what taking part means to her:

"When Dad first told us they were going to sign up I was initially quite interested, but also felt quite emotional at the thought of it happening. Knowing it's going to a good cause and the research can go forward is a great feeling.

As a family we discussed the idea of brain donation and once my sister and I knew this was what they wanted we were on board quite quickly. We didn't hesitate, we wanted to respect Mum and Dad's wishes.

On the practical side of things, we thought about losing a part of Mum and Dad's body, but we had already lost Mum to Alzheimer's. It was a long emotional rollercoaster and whatever happens, you don't forget about them once they've donated brain tissue. They're still your family and their spirit lives on through research.

My hope for the future is obviously a cure, but even if we could slow down the effects of dementia I would be happier. Until then we will all keep researching, keep fundraising and carrying on. That's what we do."

We always enjoy hearing your views, so if you would like to contribute to future newsletters, please contact your local study team.

Engaging the future generation of dementia researchers

One of our BDR funders, Alzheimer's Research UK, are supporting a project from **MindTorch** which takes a hands-on approach to inspiring and informing young people from low socio-economic backgrounds about neuroscience and the important role of dementia research. A workshop was held in London and more are planned for the other BDR Brain Banks. The aim is to give students the opportunity to visit the brain banks, speak to researchers at the cutting-edge of dementia research and to learn about research progress and how to develop a career in science.

<https://www.alzheimersresearchuk.org/grants/inspire-fund-public-engagement-grant/>