

Let's discuss brain donation

From the start of BDR, with your support, we have successfully received over **1,000 donated brains**. There have been around 500 requests for this precious resource, leading to 45,000 tissue samples being dispatched to researchers around the world. Despite this success, plans for donation don't always come to fruition. So far, around 18% of potential donations were not successful. The reasons for this can vary widely and are often beyond the control of the BDR staff or of individual families, but we aim to take as many donations as possible, so let's focus on how we can maximise our chance of success. Your brain donations are vital for scientists looking to find badly needed treatments for dementia.

How can families help us with donations?



It is so important that potential donors discuss their plans for donation with their families. We want to ensure that there are no surprises at the time of a participant's death and realise the need for sensitivity. In addition, families need to be aware of a donor's wishes as we rely on the family or friends of the donor to inform us of a death as soon as possible - if we aren't aware or are informed too

late, then a donation can't go ahead. We encourage potential donors to have conversations with all those who may potentially be involved in the process. For instance, if a potential donor has changed their GP, their address, or perhaps moved into a nursing home, we encourage you to share the donor information as appropriate.

All donors are issued with a **donor card**. If you have mislaid yours or want additional copies, please contact your local BDR Centre as they will be happy to provide you with extra cards. Team members are also available to speak with families if they have any specific concerns.



COVID and brain donations

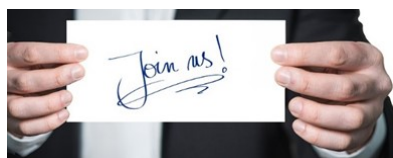
We have experienced some difficulties arranging brain donations during the pandemic. Initially, mortuaries only carried out donations where there was evidence that the donor was COVID-free. Now, some mortuaries will accept COVID-positive donations and others will not. One way that families might help us, is where feasible, to encourage their loved-ones to **undergo regular testing for COVID**. A recent negative lateral flow test will enhance the likelihood that a mortuary is able to accept a donation, enabling BDR to fulfil donors' wishes.

What happens when a donor dies?

Once a BDR team are informed of the death of a potential donor, they will do their utmost to make sure that the donation goes ahead. Ideally donations need to take place within the first 24 hours but we can still accept most donations up to 72 hours. It is important to be aware, that the donation process **should not delay the funeral arrangements**. **There are also no additional costs involved** as transport costs resulting from the donation, are covered by BDR.

To learn more about the donation process, the BDR team in Newcastle produced a film which can be viewed by going to <https://vimeo.com/241678921>

What's happening in your local BDR?



We hope that you enjoyed the online BDR event hosted by the Principal Investigators in Oxford, Professor Olaf Ansorge and Dr Vanessa Raymont. If you were unable to attend the live meeting, you can access a recording by going to

https://www.youtube.com/watch?v=2_VKC8mEVRE

The next event will be hosted in the springtime by the BDR team based at King's College, London. In the future, we hope to be able to return to having some in-person events, but while we are still limited by concerns around COVID, an online event is our safest way of engaging. We do hope that you have enjoyed them.



Dementias Platform UK
Medical Research Council

In the summer 2020 newsletter, we featured a piece about two new initiatives, "Great Minds" and the

"Clinical Studies Register". They were launched by the data portal, Dementias Platform UK (DPUK) and in 2021, a publication detailing progress, appeared in the British Medical Journal

<https://tinyurl.com/ywcad7zs>

To summarize, the authors describe the benefits of identifying those at potential risk of dementia early on, prior to the onset of symptoms. This is important as by doing so, it allows researchers to select exactly which people might gain the most by taking part in clinical trials for new drugs as they become available. So far, there have been few if any real successes in the search for new dementia medications, a fact which discourages pharmaceutical companies from investing in this area of drug development. One of the reasons given for the lack of progress, is the fact that it has been difficult to recruit participants with known backgrounds in terms of their cognitive, genetic, lifestyle and family histories. This is where a study such as BDR really excels. The repeated assessment data carried out in BDR allows researchers to identify which individuals may be at an increased risk of developing certain dementia pathologies. Recruiting these individuals into drug trials should lead to an increased probability of success thereby providing the pharmaceutical industry with a greater incentive to invest in this important area of drug development.

Would you like to learn more about dementia?

NEURA CLIN 2022

is a free, one-day, live-streamed, virtual event aimed at addressing one of the greatest challenges of our era:
dealing with dementia.

Presentations will be made by dementia experts and they are accessible and free to all. For further details including a link to join the event, go to:

<https://tinyurl.com/radhfz6f>



We would really like to know what you think about our communications. It is important to us that participants, study partners, friends and family feel involved.

If you have comments about the newsletters, the online engagement events, the website, or any other aspect of the study, we would love to hear from you.

You can give your feedback by clicking on the link here <https://forms.gle/c5CwksYX1jRSpe3J7> to complete a short survey. Alternatively, if you prefer to leave feedback with the coordinating centre, you can contact us by email at **BDR.coordinatingcentre@ncl.ac.uk** or telephone on **0191 208 2109**.

Many thanks.