

BRAIN Involve

Freepost BRAIN UNIT

Dear Sir/ Madam,

Many thanks for registering your interest in joining BRAIN Involve. Enclosed in this pack are an application form and an information sheet outlining the terms of reference for the BRAIN Involve group. If you have any questions or queries concerning BRAIN Involve please contact Jo Baker (brainunit@cardiff.ac.uk 02920688608).

We believe that active involvement from members of public leads to research that is more relevant and more reliable. BRAIN Involve aims to enable people affected by neurological diseases to play a role in informing and shaping research into neurological and neurodegenerative diseases. Being a member of BRAIN Involve is not about taking part in research but about using your experiences to help inform and develop research ideas and projects that are relevant to you. BRAIN Involve is part of the Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit. BRAIN is funded by Health and Care Research Wales ([www.healthandcareresearch.gov.wales](http://www.healthandcareresearch.gov.wales)) and aims to be a UK centre of excellence for developing and delivering novel therapies to patients with neurological and neurodegenerative diseases. Our Unit members range from lab-based scientists working on developing novel cell and drug therapies through to healthcare professionals working with patients with neurological diseases throughout Wales.

There are lots of ways you can contribute to research within BRAIN. For example, you may want to attend our BRAIN research events and/or provide us feedback on research grants, research study materials and patient leaflets. We understand that getting involved in developing research may seem daunting, but we have lots of support in place to help you become as active in the group as you want to be.

As we want to make sure BRAIN Involve members are provided with the appropriate training and support we ask that all BRAIN Involve members are also members of the Health and Care Research Wales Public Involvement Community. We believe that this is important for our BRAIN Involve members as the Public Involvement Community provide support and training opportunities for becoming actively involved in research and will often cover expenses incurred (e.g. travel to and from meetings) and reimbursement for involvement in the development of research (e.g. review research grant applications, review study materials for clinical trials). Further information about the network can be found here: [https://healthandcareresearchwales.org/public/help-research](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fhealthandcareresearchwales.org%2Fpublic%2Fhelp-research&data=04%7C01%7CBakerJ21%40cardiff.ac.uk%7C67c53ea3a2094c5b64fc08d88a5192bb%7Cbdb74b3095684856bdbf06759778fcbc%7C1%7C0%7C637411430252606204%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C1000&sdata=%2FWqKWuhbfoVl%2Ff%2BuLIL0H352%2BFLYUytWYsyHak7eBzE%3D&reserved=0)

If you are not currently a member of the Public Involvement Community we will ask the administrator to contact you directly to register for the Public Involvement Community.

Thank you again for taking the time to consider joining BRAIN Involve, please do not hesitate to contact me if you have any further questions.

Best wishes,

Mrs Jo Baker and Dr Emma Lane

BRAIN Research Manager and BRAIN Involve Package Lead

**Please provide us with the following information:**

|  |  |
| --- | --- |
| **Please let us know your full name**  |  |
| **Please let us know the name you would like us to use when we contact you**  |  |

|  |  |
| --- | --- |
| **Please let us know your contact details.**  | **Please let us know which contact details you would like us to use when we contact you** |
| **Email address** |  |  |
| **Home telephone number** |  |  |
| **Mobile telephone number** |  |  |
| **Postal address** |  |  |
| **If you have a carer and/or family member or friend you wish to include their details please list them below** |  |
| **Please let us know their full name** |  |  |
| **Email address** |  |  |
| **Home telephone number** |  |  |
| **Mobile telephone number** |  |  |
| **Postal address** |  |  |

|  |
| --- |
| **Our current remit concerns the following neurological diseases:** |
| **Multiple Sclerosis** |  |
| **Parkinson’s Disease** |  |
| **Epilepsy** |  |
| **Huntington’s Disease** |  |
| So we can ensure we are providing you with relevant information, we would be grateful if you could let us know whether you would like to receive information concerning research opportunities in one or all of these diseases (please tick all that apply) |

|  |  |  |
| --- | --- | --- |
| **Are you member of health and Care research wales Involving people network?** **Please tick** | **Yes** | **No** |
|  |  |

*Please note. If you are not a member of the Involving people network we will pass on your contact details to the Involving People network administrator. We will not provide the network administrators with any other information you have provided us with.*

Finally, please read the following statement below and if you are happy with the information provided, please sign and return this form to Cassy Ashman via our freepost system: Freepost BRAIN UNIT (please write BRAIN UNIT in uppercase, please note, you do not need to put a stamp on the envelope).

I understand that the information provided by me will be held confidentially, such that only the BRAIN Involve co-ordinators (Professor Monica Busse, Dr Cassy Ashman, Dr Emma Lane) and the director of the BRAIN Unit (Professor William Gray) can trace this information back to me individually.

I understand that if I am not currently a member of the Health and Care Research Wales Involving People Network the BRAIN Involve coordinators will pass my preferred contact details (e.g., email, telephone) onto the Involving People Network administrator. No other information I have provided BRAIN Involve (e.g., information concerning my interest in neurological diseases) will be passed onto the Involving People Network.

The information supplied by me will be stored on a Cardiff University networked computer drive with permissions set so that only those who require access (BRAIN Involve coordinators and the BRAIN director) to the database will be able to see it. Access to the networked drive will be password protected.

Any paper applications will be held in a lockable cabinet in a locked room within a key-entry only academic department at Cardiff University. The information within the database will be held by Cardiff University and will not be passed to any third party without referring back to the individual for their consent.

I understand that I can ask for the information I provide to be deleted/destroyed at any time and I can have access to the information at any time.

I, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (NAME) consent to join BRAIN Involve.

Signed:

Date: