

NEWSLETTER ARTICLE:

“APPEAL FOR FOCUSED ULTRASOUND” (PAGE 6)

Here are a few websites of potential interest:

INFORMATION ABOUT IMPERIAL COLLEGE HEALTHCARE CHARITY TRUST AND FOCUSED ULTRASOUND

<https://www.imperial.nhs.uk/research/about-our-research/mr-guided-focused-ultrasound-for-essential-tremor>

DONATIONS

<https://www.imperialcharity.org.uk/donate/donate-to-an-appeal/tremorlifeline>

DR GEDROYC PROFILE

<https://www.fusfoundation.org/news/1673-investigator-profile-q-a-with-wady-gedroyc>

NEWSLETTER ARTICLE:

“TO ALL NEWSLETTER RECIPIENTS: PLEASE READ THIS MESSAGE ABOUT DATA PROTECTION” (PAGE 1)

GENERAL DATA PROTECTION REGULATION ADVICE FROM PARKINSON'S UK

By Douglas Smith, Parkinson's UK

Parkinson's UK and each of its Local Networks are strongly committed to protecting the privacy of personal data that we maintain about supporters, volunteers, clients, donors and other individuals. The introduction of the new General Data Protection Regulation (GDPR) has resulted in organisations making changes to ensure they meet the stricter rules this new law brings.

What do we mean by data protection?

Everyone has a basic right to privacy and to protect their information from misuse. The law sets stronger standards around things like consent, so people have more control and understand what we do with their info.

Why is legislation changing?

The world has changed since the original data protection law was introduced. The revised regulation provides extra protection essential in a digital era – and improved protection for our own personal data.

What is GDPR?

GDPR came into force on May 25, 2018. It aims to give people the power to say how their personal information is used, and keep it safer. GDPR is an important change in government legislation that provides an update to the Data Protection Act, with new requirements and increased penalties. The new legislation means Parkinson's UK has to tighten up the way it stores, collects and uses personal data. Personal data is information such as bank details, home addresses or medical details. If we don't make the necessary changes, Parkinson's UK could face damage to its reputation and be fined tens of thousands of pounds. We are making changes now, but our work to ensure we are GDPR-compliant will continue beyond this date.

The law requires us to produce a Privacy Notice that explains what we're doing with personal data, how we're taking care of it, and how long we're holding it for. This applies to personal data right across Parkinson's UK – from membership to just giving. Please take some time to read our new privacy policy which can be found at parkinsons.org.uk/about-us/privacy-policy-9-may-2018. If someone isn't clear or you don't manage their data according to the policy, you can increase the risk of breaching data protection laws.

What do I need to do?

Unless you're holding personal data or sending out information on behalf of the charity/branch, then you probably don't need to do much. But if in doubt, do get in touch with our Branch Secretary, Trish Carn (see page 8 of the

newsletter). If you do hold or share information on behalf of the charity, think about how you're storing the data. If it contains sensitive or personal information, such as a list of email addresses, make sure it is secure. For example, if it is held in a spreadsheet or other electronic document, ensure you have password protected it, and think twice before sharing it with anyone else. Also think about whether you really need to hold that data, and if you don't, destroy or delete it.

When sending messages via email to a group of people, blind copy (Bcc) all correspondents. If it includes any marketing data, or information about an event, be comfortable that all the people receiving the email would expect to receive it. If in doubt, check back with Trish that we hold good consent for the individuals. If we don't, then you should seek consent, recording the name and date that the individual has agreed to receive marketing information from you. Then share that consent record back with Trish.

If you are posting any document that contains personal data, think before you send it, and ask: does it really need to be posted? If it does, then it's advisable to send it recorded delivery. Finally if you hear of any potential data breaches, report them immediately to dataprotection@parkinsons.org.uk.