**Changes to Local Group Reports**

**Frequently asked questions**

**What is GDPR?**

GDPR stands for the General Data Protection Regulation and is new legislation that supersedes the old Data Protection Act. This legislation gives stricter rules around how we use and store people’s personal details – and how we share this information.

**Why is it important that Parkinson’s UK complies with GDPR?**

We are required by this legislation to ensure we have put appropriate security controls in place to protect people’s personal information.

If Parkinson’s UK is found to be in breach, we could be liable for fines of hundreds of thousands of pounds – if not more. It could also damage the charity’s reputation, and the confidence people we support have in us to protect their personal data.

**Why are you no longer able to send Local Group reports – also known as Membership Lists – in the post?**

To comply with GDPR and ensure security, these reports would need to be sent recorded delivery and require a signature on receipt. This would cost the charity thousands of pounds per year as a result. We believe this is not a good use of the charity’s money.

We also appreciate volunteers might find it inconvenient to receive recorded delivery letters on a routine basis. And, people living with Parkinson’s might find it difficult to sign for reports. For these reasons, the process had to be reviewed.

**Why were we not told earlier of these changes?**

Our Data Protection and Governance teams are working hard to evaluate all the different areas that will be affected by the new regulations.

The decision around the Local Group Reports has only recently been made following careful consideration of the impact any changes might have. We have let you know about this as soon as the decision was made and apologise if this causes you any inconvenience.

**What are the plans for Local Group Reports?**

Parkinson’s UK is currently reviewing the process for providing you with Local Group Reports. We hope to have the new system in place by the end of 2018, although this date may change.

Updates will be provided as part of our ongoing communication around data protection. We appreciate your patience while we carry out this review.

**How will I know when there are changes to the Local Group Report for my local group?**

We enclose the latest Local Group Report and will send you an updated report via recorded delivery in August, once the re-consenting campaign is complete.

**What is the re-consenting campaign?**

One of the requirements under these new GDPR guidelines is ensuring everyone has given their permission (consent) to continue hearing from Parkinson’s UK and their local group.

We know many of your group attendees will already have consented to contact them with information. However, to ensure we are compliant with the new GDPR guidelines, we need your support in capturing their consent again. Take a look at the Consent Guidance, included, which will provide more details.

**Can I still phone or email updates or changes to Supporter Services?**

You can still phone and check the status of a member’s details if you have their membership number. We are unable to advise on any new members joining your group without their name and address.

We will be able to confirm if a member is linked to your group via email, but will be unable to share their personal information with you as they may not have given consent for you to have it.

**How do I mail or email group members about what is happening in the group?**

Mailing lists you hold locally should be used to contact your group attendees. You can continue to use this mailing list while the re-consenting campaign is happening, but should delete people who have not re-consented by 31 July 2018.

**What’s the difference between an attendee and a member?**

Parkinson’s UK activities, including those run by local groups, are open to everyone affected by Parkinson’s. An attendee is a person who may attend your group meetings or activities, but has not joined the charity.

A member is someone who has joined the charity. A member has the right to vote at the charity’s Annual General Meeting (AGM), and if linked to a local group, has a right to vote at the group’s AGM.

**How does GDPR affect the Local Group Report I hold locally?**

The Consent Guidance enclosed gives more detail on how you can ensure your Local Group Report is kept securely and that your group attendees have given consent in line with GDPR requirements.

If you have any questions about how you use the information you hold, please contact your local volunteer co-ordinator or data protection officer Douglas Smith at [dataprotection@parkinsons.org.uk](mailto:dataprotection@parkinsons.org.uk) or on 020 7963 9388.

**What do I do now?**

If you need any further information or guidance in relation to this communication contact your local volunteer co-ordinator.