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|  | **The Data Protection Law is Changing…** |

Due to changes in data protection legislation, soon NPUK won’t be able to contact you about any of our services or activities unless you explicitly give your consent.

In other words, if you would like to continue to use our services, receive our updates and information about our services, research and clinical trials, our events, details of fundraising activities or other items relevant to our work, we will need your explicit permission to keep in touch with you.

**What are my options?**

We would love to keep in touch with you about our work, but you will only hear from us in the ways you wish to - whether that is by post, phone, email, SMS, Messenger, Whatsapp, or other social media platforms.

You can choose all of the options listed below or just one or two of them if you prefer – it is up to you.

You can also change your mind at any time – you will find further details about how to do this below.

* Post
* Phone
* Email
* SMS, Messenger, WhatsApp and other social media messaging platforms
* Face to face (or using the methods stated above) interaction with our Care and Support Team, including our Clinical Nurse Specialist, Senior Families Advocate, Project Families Officer or Central Office Team

You can choose how you would like to interact with us, use our services or receive information on the subjects important to you.

Information you receive may include; our NPUK Newsletter, details of our events such as our Annual Family Conference & Interactive Workshop, informative literature and publications relating to Niemann-Pick disease, updates regarding research, clinical trials and other items relevant to our work and services.

What will happen if I don’t tell you my contact preferences?

*If you don’t let us know how you want to hear from us, we will not be able to contact you or share information with you once the new regulations come into effect. This may also affect access to our services. Therefore, if you would like us to keep in touch with you, please choose at least one option. Please let us know how you would like to hear from us as soon as possible so that you don’t miss out on any of the contact information you’re used to receiving from NPUK.*

**Why is NPUK making this change now?**

We are updating our processes and practice to ensure that we comply with the new General Data Protection Regulation (GDPR), which comes into effect in 2018 and replaces the Data Protection Act (1998).

However, by making this change and only contacting you in the ways you choose, we will be able to communicate with you more effectively and ensure you are receiving the information you want in the way you want to receive it.

**How do I tell NPUK my preferences?**

* [Fill in our short online form – visit www.npuk.org](http://Fill in our short online form – visit www.npuk.org )
* We can send you a form by post or email, simply contact us by email info@npuk.org or call 0191 415 0693
* Call us on 0191 415 0693 and we can assist you in completing a form
* Whenever you contact NPUK, you can review the ways in which you use our services or receive our information and make changes at any time. Visit [www.npuk.org](http://www.npuk.org) for further information
* If you change your mind about your choices, you can update your preferences by contacting us at any time.

**I am already in contact with NPUK - how do I update my preferences?**

It is quick and simple, just follow the steps above to complete our short form, contact us by email info@npuk.org or call 0191415 0693.

Even if you have previously told us how you would like to hear from us and/or you have supported us for many years, the new legislation requires you to renew your preferences and give your **explicit** consent in order for us to continue to contact you in the ways that are important to you.

**What can I do if I change my mind or don't want to hear from NPUK anymore?**

If you change your mind about your choices, you can update your preferences at any time and by any of the following methods:-

* To unsubscribe completely email us at info@npuk.org
* To change your preferences, complete our short online form, visit [www.npuk.org](http://www.npuk.org)
* We can send you a form by post, simply contact us by email info@npuk.org or call 0191 415 0693
* Call us on 0191 415 0693 and we can assist you in updating your preferences.
* Write to us at: NPUK, Suite 2 Vermont House, Washington, NE37 2SQ
* We will update your contact preferences on our systems within one month of receiving your request.

**Another family member would like to hear from NPUK - how do we tell you?**

If someone else in your family (e.g. your partner or child over 13) would also like to opt in to our communications, please ask them to complete our short form with their own details and contact preferences.

**Please note:**

* We are unable to accept forms completed on someone else's behalf - every person opting in must give us their own contact preferences and consent.
* We require parental consent for children aged 13-15 opting in to our communications. If a child aged 13-15 completes the form, we will contact their parent/guardian to gain consent. Parental consent is not required for those aged 16+.
* It is our policy to send one copy of mailings (e.g. NPUK Newsletter) to anyone living at the same address in order to keep our postage costs down.

**Your Details Are Safe With Us**

Privacy Statement

*We will always store your personal details securely. We will use them to provide the service(s) that you have requested and communicate with you in the way(s) you have agreed to. Your details may also be used for analysis purposes, to help us provide the best possible service. We will not pass on your details to anyone else and we will only share them if required to do so by law.*

***For more information, please visit: https://www.gov.uk/government/news/government-to-strengthen-uk-data-protection-law***