

# PARKINSONS IRELAND PRIVACY STATEMENT



April 2022

## Introduction

The Parkinson's Association of Ireland ("PAI") is a charity, registered in Ireland as CHY 10816, with its head office at **Carmichael House, North Brunswick Street, Dublin 7, Ireland**, email: [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie).

The aim of this Privacy Statement is to give guidance as to the implications of the General Data Protection Regulations (GDPR) (2016/679) (the Regulations) to all staff and members of the Association on how personal data is managed by the PAI. The Regulations aim to safeguard the rights of living individuals in regard to how information about them is processed. It does this by placing obligations on people and organisations that control personal data and process personal data.

The objectives for which Parkinson's Ireland exists are:

- to facilitate people with PD to control their lives and environment, to live with dignity and participate in the community,
- to provide support for the families and carers of people with PD,
- to co-operate with the medical, scientific, social and caring professions to promote scientific research into the cause of, cure for and management of PD, and the alleviation of medical and social symptoms PD,
- to exchange and disseminate information relating to PD, and
- to provide an identifiable focal point by developing an efficient, effective and caring organization to serve the needs of people with PD.

PARKINSONS IRELAND is committed to protecting the privacy of people who use our services, employment candidates and current employees, contacts, fundraisers, business partners, and other third parties we deal with, such as family members.

This Privacy Statement details how PARKINSONS IRELAND collects, uses, discloses, transfers and stores your personal information. It applies to personal data about you that we collect, use and otherwise process in connection with your relationship with PARKINSONS IRELAND.

# **PARKINSONS IRELAND as Controller of your Personal Data**

PARKINSONS IRELAND is a nationwide charity that operates from its headquarters in **Carmichael House, North Brunswick Street, Dublin 7, Ireland**. PARKINSONS IRELAND also has a network of Voluntary Branches, each of which processes personal data submitted to it directly and/or through a client's consent when he or she has ticked the "*I would like my details sent to the nearest Voluntary Branch*" on PARKINSONS IRELAND's Yearly Membership Form. Any personal information processed by PARKINSONS IRELAND in connection with this Privacy Statement is ultimately controlled by a PARKINSONS IRELAND as the "data controller" as provided for under the General Data Protection Regulation ("GDPR"), the Irish Data Protection Acts, 1988 to 2018, and the Data Protection Commission (DPC) Guideline for the Charity and Voluntary Sector.

The elected Secretary of each Voluntary Branch is the controller of the personal data processed in that branch.

You may request information about the personal data that PARKINSONS IRELAND holds about you by emailing us at [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie) or writing to us at **Carmichael House, North Brunswick Street, Dublin 7, Ireland**.

Please note that throughout this Privacy Notice the word "website" refers to <https://www.parkinsons.ie>.

## **Collection and Processing of your Personal Data**

### **INFORMATION COLLECTED BY USING PARKINSONS IRELAND WEBSITE**

1. You are not required to provide any personal information to access public areas of PARKINSONS IRELAND's website.
2. However, when you visit the PARKINSONS IRELAND website we record your IP address and details of your visit, including the date and time. An IP address is an assigned number, similar to a telephone number, which allows your computer to communicate over the internet. In addition to your IP address the following technical information will also be collected: your login information, browser type and version, time zone setting, browser plug-in types and versions, operating system and platform, information about your visit including the full Uniform Resource Locators (URL), clickstream to, through and from the website (including date and time), pages viewed, download errors, page interaction information (such as scrolling clicks) and methods used to browse away from the website.
3. PARKINSONS IRELAND uses this IP information for its legitimate interests to compile statistical data on the use of our website and to track how users navigate through our website in order to enable us to evaluate and improve.
4. Personal information such as names, addresses, email addresses, telephone numbers, and other personal data relating to services that we are providing to you will only be collected from users of the website who voluntarily input such information.
5. ilikecake Limited website designer in Palmerstown, Dublin acts as a data processor for Parkinson's Ireland in relation to the PARKINSONS IRELAND website. In this

capacity, ilikeake has sight of data regarding: donations, staff, the personal information of clients (including names, addresses, email addresses), enquiries and memberships.

## **CONTACT SALESFORCE DATABASE**

We may retain information you have provided us with in PARKINSONS IRELAND's contact database. Information that we typically hold in our database includes:

1. your contact information, including your name; job title; organization's name; address; phone number(s), email address(es) and other identification information;
2. the area(s) that you have an interest in
3. historical fundraising activity for PARKINSONS IRELAND.

Once your details are included in PARKINSONS IRELAND's contact database we may also record details of any

- a. PARKINSONS IRELAND's mailing lists you have subscribed to or unsubscribed from;
- b. mailings (including services updates and event invitations) we have sent you;
- c. hyperlinks you have clicked in any mailing that we have sent you;
- d. meetings we have held with you;
- e. event invitations you have replied to; and
- f. events you have attended.
- g. your care records.

From time to time we may ask you by email to review your contact details and preferences, and update them as necessary. This not only helps us to keep the contact information we hold about you up-to-date, it also ensures that we only send you information that you have requested and/or is relevant to you.

## **INTERACTIONS WITH PARKINSONS IRELAND**

We retain personal information relating to interactions between PARKINSONS IRELAND and people who use our services, clients, job applicants and current employees, contacts and business partners, including information relating to the services that we provide. We only retain information that is necessary for the purposes set out in this Privacy Statement.

## **PROCESSING OF YOUR PERSONAL INFORMATION**

PARKINSONS IRELAND, in the head office, and throughout its network of Volunteer Branches, will only collect and process personal information where it has a legal basis for doing so.

PARKINSONS IRELAND uses personal information which we have collected from you in order to:

1. provide you with a more tailored and effective service and/or care;
2. perform analysis aimed at improving our products, services and technologies for people with PARKINSON'S

3. communicate with you through certain mandatory service communications such as welcome letters.
4. ensure compliance with regulatory requirements and applicable law;
5. provide updates and newsletters, including our PARKINSON'S News magazine by mail and our electronic newsletter, and invitations to events and meetings;
6. carry out administrative purposes (including within the PARKINSONS IRELAND regional offices and the network of Voluntary Branches), which may include, for example, accounting and billing, auditing and identification checking;
7. undertake system testing, maintenance and development in order to ensure network and information security;
8. to let you know ways you can get involved in our fundraising and campaigns; when you are making a donation, registering for a campaign or event, as appropriate, you may be asked to provide personal details such as name, email address, postal address, phone number or payment information as needed 9. prevent fraud; and
10. market our services and products to you where PARKINSONS IRELAND has a legitimate interest or you have consented to us doing so and in accordance with your preferences.

PARKINSONS IRELAND will only collect, use and otherwise process information revealing racial or ethnic origin, political opinions, religious beliefs or relating to your health or sexual orientation or otherwise which is treated by applicable data protection laws as a "sensitive" or "special" category of personal information, where and only to the extent that you have given your explicit consent unless we are otherwise permitted or required to collect, use and process such information under applicable data protection laws, including but not limited to where this is necessary in connection with providing our agreed services to you.

Any data collection that is optional will be made clear to you. However, PARKINSONS IRELAND may need to collect and process personal information for certain legal compliance purposes or in order to perform certain services for you, including compliance with legal requirements relating to our anti-fraud, anti-money laundering or 'know your customer' obligations. If you choose not to give us this personal information then it may delay or prevent PARKINSONS IRELAND from meeting PARKINSONS IRELAND's obligations or it may mean that PARKINSONS IRELAND cannot perform certain services for you. PARKINSONS IRELAND will advise you if this is the case.

## **MARKETING and INFORMATION COMMUNICATIONS by PARKINSONS IRELAND**

We may wish to use the personal information that we collect about you to provide you with relevant marketing communications. This may include sending tailored direct marketing and information e-mails and other communications relating to our services or those of our PARKINSONS IRELAND head office or Voluntary Branches, and sending you invitations to seminars and other events related to the care of yourself or your family member.

We shall only send such marketing communications to you to the extent that doing so is in the legitimate business interests of PARKINSONS IRELAND or where you have consented to us doing so. As set out in the Data Subjects Rights table below, you may withdraw that consent at any time by contacting us at [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie). In addition, each electronic communication that you receive shall have a very clear "unsubscribe" option, which will allow you to stop receiving similar communications in the future.

## **EXCHANGE OF INFORMATION**

- a) PARKINSONS IRELAND shares data between our head office and our Voluntary Branches, where necessary, for the purposes outlined in this Privacy Statement.
- b) PARKINSONS IRELAND ensures that your personal information is shared in accordance with applicable data protection laws, at all times providing protection to your personal information and your rights.
- c) PARKINSONS IRELAND has relationships with third parties in order to provide services for people with PARKINSON'S, such as medical professionals. In some instances, we may disclose your personal information to third parties where this is necessary to perform the services for which you have engaged PARKINSONS IRELAND or otherwise in furtherance of an outsourcing or other data processing arrangement. In those circumstances PARKINSONS IRELAND will ensure that the third party is contractually bound to only process personal information in accordance with applicable data protection laws and with PARKINSONS IRELAND's specific instructions and requirements, and at all times in a manner that protects your rights under applicable data protection laws. Our suppliers and service providers will be required to meet our standards on processing information and security. The information we provide them, including your information, will only be provided in connection with the performance of their function. They will not be permitted to use your information for any purposes other than those outlined in this Privacy Statement.
- d) In relation to any other third parties, PARKINSONS IRELAND will only disclose or transfer your information where you have given your consent or where we are required to do so by law or other regulatory code or practice.

## **TRANSFER OF INFORMATION ABROAD**

**The Parkinsons Association will never transfer your data outside of the European Union.**

## **DATA RETENTION**

PARKINSONS IRELAND shall only retain your personal information for so long as there is a reasonable need to retain the information for the purposes set out in this Privacy Statement. The Parkinsons Association will delete your data 5 years after the end of the relationship.

## **PROTECTION OF YOUR PERSONAL DATA**

PARKINSONS IRELAND is committed to protecting the security of your personal information. We use a variety of security technologies and procedures to help protect your personal information from unauthorized access, use, or disclosure, across all of our

computer system Parkinson's, networks, website, mobile phones, regional offices and Voluntary Branches.

### **Data Subject Rights**

You have rights in respect of the personal data that we collect and process concerning you.

<b>Access</b>	<p>You are entitled to details concerning the processing of your personal data. This includes details of the data being processed, the purposes of the processing, any recipients of your data, the period for which the information is processed, the source of the information, any international transfers of the information and how we protect it. You may also request details of any automated decision making, including profiling, of your personal data.</p> <p>You are entitled to a copy of the personal data we process about you.</p>
<b>Corrections</b>	<p>You are entitled to have any incomplete and inaccurate personal information held by us corrected on request.</p>
<b>Right to be Forgotten</b>	<p>In some cases, you may request to have your personal data erased where the data is no longer necessary for the purposes for which it was collected and/or processed or you withdraw consent to our use of it.</p> <p>We may advise that we must continue processing your data if there are grounds other than your consent for processing your data, where processing is in compliance with a legal obligation, for reasons of public interest or for the exercise or defense of legal</p>
<b>Restrict Processing</b>	<p>You can ask us to restrict the processing of data PARKINSONS IRELAND holds about you if you dispute the accuracy of the data we process about you or if you have objected to the grounds upon which we process the information.</p> <p>Where you have asked us to restrict processing the information we shall only hold, process and erase the information as permitted by you or as permitted by the Data Protection Acts, 1988 to 2018 or the GDPR. We will advise you if we do not agree with your request.</p>
<b>Data Portability</b>	<p>Where processing of your data is carried out by automatic means, you are entitled to receive a copy of that information in a machine-readable format and for that to be provided to another data controller, where technically possible.</p>

<b>Object</b>	You may object to PARKINSONS IRELAND collecting, using and otherwise processing your personal data where the basis for the processing is PARKINSONS IRELAND's legitimate interests or the processing is in the public interest. In such circumstances we shall cease processing your personal information unless we are legitimately processing the information on a different basis, there are compelling legitimate grounds for continuing to process the personal information, or we are otherwise permitted to under applicable data protection laws, which PARKINSONS IRELAND will so advise.
<b>Withdraw Consent</b>	Where you have given us consent to process your personal data for any of the purposes outlined in this Privacy Statement and we have no other legal basis for processing, you shall be entitled to withdraw that consent.
<b>Right to Complain</b>	<p>If you have concerns or complaints regarding this Privacy Statement or the manner in which PARKINSONS IRELAND collects, uses and otherwise processes your personal data we would like to hear from you.</p> <p>If you consider that we have not processed your data according to these rights and we have not addressed your complaint in this regard, you are entitled to lodge a complaint in Ireland to the Data Protection Commission at <a href="http://www.dataprotection.ie">www.dataprotection.ie</a>.</p>

This Privacy Statement may be updated from time to time.

The current version of this Privacy Statement can be found on the PARKINSONS IRELAND website or may otherwise be requested at [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie)

## **COOKIE POLICY**

### **1. Policy Statement**

This policy covers the use of cookies on the Parkinson's Ireland website

### **2. Aim(s) of Policy**

This policy aims to inform Parkinson's Ireland website users that cookies are used on the website and how to go about opting out of cookie usage.

### **3. Scope of Policy**

This policy applies to all visitors to the Parkinson's Ireland website

## 4. Background and Opting out Procedure Cookies Overview

Cookies are small text files that are stored on your computer by the websites that you visit. Cookies enable some information about your visit to be recorded and enable websites to recognise a user anonymously based on the information stored in the cookie.

Most websites today use cookies. Cookies are really useful for website providers to monitor how their site is used and what information or content is the most popular. This can help improve content created and how navigation of the site is handled. It can also be used to tailor your experience and ensure that the most relevant information is presented to you based on your preferences. Some cookies are used to enable essential functionality of the website such as shopping or to remember your login details for later visits.

Cookies can be either 'session' or 'persistent'. Session cookies are only stored for the duration of usage of the site and are deleted once the browser is closed. Persistent cookies can remain on your computer for longer specified periods.

There are two types of cookies: First-party cookies that are set by the site you are visiting and Third-party cookies which are set by other sites that have features embedded on the site you are visiting – such as advertisements or YouTube videos.

### Cookie Details

Parkinsons Ireland uses both session and persistent cookies on our website. By using this website you are agreeing to the use of cookies as described in this privacy statement. Our cookies are not used to identify you personally but rather to improve your experience on our website.

#### We use the following local cookies:

- Google Analytics to track users as they navigate the website – these cookies are named: \_utma, \_utmt, \_utmb, \_utmc, \_utmz
- AddThis – provides access to social sharing buttons for Facebook, Twitter, etc
- Cookies to allow use of the shopping cart and to process payments **We also use**

#### **Third-party cookies:**

- YouTube to embed video content into our site
- DoubleClick and Google Analytics to allow us to advertise and monitor performance on Google

### Managing Cookies

You can choose not to allow cookies to be used on your machine or delete cookies that are already there. This may have a negative effect on your browsing experiences as a lot of website functionality requires the use of cookies and so some options may no longer work.

### Contact Information

If you have any questions in relation to this Privacy Statement please contact us at [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie).