

# PRIVACY NOTICE

## Irish Haemochromatosis Association

### 1. What is Personal Data?

Personal data relates to a living individual who can be identified from that data. The processing of personal data is governed by the EU General Data Protection Regulation (the “GDPR”) and the Data Protection Acts 1988-2018

### 2. Who are we?

The Irish Haemochromatosis Association (IHA) is the data controller (contact details below). This means it determines how your personal data is processed and for what purposes.

### 3. How do we process your data?

IHA complies with its obligations under the “GDPR” by keeping personal data up to date; by storing and destroying it securely; by not collecting or retaining excessive amounts of data; by protecting personal data from loss, misuse, unauthorised access and disclosure and by ensuring that appropriate technical measures are in place to protect personal data.

We use your personal data for the following purposes: providing you with information and resources about haemochromatosis, treatments for and research into the condition, advising you about forthcoming events, fundraising and administering the business of IHA including membership applications and renewals. We will only use your information to inform research and develop better services for haemochromatosis patients. For research purposes, patient information is always anonymised and patient names and identifiers are never used.

### 4. What is the legal basis for processing your personal data?

We process personal data (your identification, location and financial data where applicable) based on your consent and, in the case of data relating to your health, explicit consent.

### 5. Sharing your personal data

In certain circumstances, we need to share personal data in pursuit of our legitimate interests, for example the use of processors to manage communications, surveys or the secure storage of your data. We may also share your data with individuals or organisations who are processing information on our behalf, for example website, newsletter and CRM/database management and IT suppliers. We may also use statistical information (without personal identification) for future research on the prevalence of haemochromatosis in Ireland and will tell you when we plan to do so. Information used for research purposes into haemochromatosis will be anonymised and will not have personal identification information.

### 6. International Transfer

[All personal data is stored within the European Economic Area or countries whose data protection regimes have been designated as adequate by the European Commission. We will not transfer any data to a third country or international organisation without your explicit consent and without appropriate privacy safeguards in place.

### 7. How long do we keep your data?

We keep data in accordance with the guidance set out within our formal records retention policies (ie 5 years) and do not maintain data beyond what is absolutely required or where otherwise required by law.

### 8. Your rights and your personal data

You have the following rights with respect to your personal data: -

- The right to request a copy of your personal data, which the Irish Haemochromatosis Association holds about you.
- The right to request that the Irish Haemochromatosis Association correct any personal data if it is found to be inaccurate, incomplete or out-of-date.
- The right to request your personal data is erased where it is no longer necessary or lawful for the Irish Haemochromatosis Association to retain such data.

- The right to request that the Irish Haemochromatosis Association provide you with a copy of your personal data and, in certain circumstances, to transmit that data directly to another data controller.
- The right, where there is a dispute in relation to the accuracy or processing of your personal data, to request a restriction is placed on further processing.
- The right to object to the processing of personal data.
- The right to lodge a complaint with the Data Protection Commission.

## 9. Further processing

If we wish to use your personal data for a new purpose, not covered by this Privacy Notice, then we will provide you with a new notice. The new notice will explain the new use of your personal data prior to commencing the processing. It will set out the relevant purposes and processing conditions.

## 10. Contact Details

To exercise all relevant rights, queries or complaints please in the first instance contact the Executive Director of the IHA by email or phone.

TEL: +353 00 (1) 873 5911 or MOBILE: 087 2853907

EMAIL: [info@haemochromatosis-ir.com](mailto:info@haemochromatosis-ir.com)

The Irish Haemochromatosis Association, The Carmichael Centre, North Brunswick Street, Dublin 7

## 11. Complaints

You have the right to make a complaint to the Data Protection Commission which you can contact by phone: +353 (0761) 104 800; via email [info@dataprotection.ie](mailto:info@dataprotection.ie) or by writing to:

The Data Protection Commissioner,  
Canal House,  
Station Road,  
Portarlinton,  
Co. Laois,  
R32 AP23.