

International Gaucher Alliance

Subject Access Request Procedure



1. Scope

This procedure covers all personal data that is processed by International Gaucher Alliance with the exception of personal data that is routinely requested by data subjects.

It is the right of all data subjects to ask International Gaucher Alliance the following:

1. What personal data International Gaucher Alliance is being processed about that person, if any;
2. To be provided with a description of the personal data processed International Gaucher Alliance about that person;
3. The purpose or purposes for which the personal data is being processed;
4. Confirmation of who will have access to the personal data; and
5. To be provided with a copy of the personal data, as well as a confirmation of where International Gaucher Alliance acquired that personal data.

2. Responsibilities

The Data Controller (“DC”) shall be responsible for the application and functionality of this procedure and shall handle all Subject Access Requests (“SARs”). The DC shall report to the Governance Committee/CEO on all matters relating to SARs.

3. Procedure

All SARs are made using form Subject Access Request Form 92017-C.

The data subject is required to provide evidence of his or her identity by way of a current passport or driving license and his or her signature must be cross-referenced with the signature provided on the Subject Access Request form.

The following information must be provided by the data subject on the Subject Access Request Form: the personal data that is being requested, whether specific data or all data held by International Gaucher Alliance and where it is being held.

International Gaucher Alliance is required to record the date on which the Subject Access Request Form, with the accompanying identification evidence, is submitted.

International Gaucher Alliance has one month from this date to provide to the data subject the personal data requested. Should International Gaucher Alliance fail to provide the requested information within the one-month window, this shall be in direct breach of the GDPR. No extension shall be allowed under any circumstances.

It is vital that the Subject Access Form is sent to the DC straight away, to ensure that the requested data is collected within the one-month window.

The DC will carry out data collection by one of the following steps:

1. Collecting the personal data requested; or
2. Carrying out a search of all electronic and hard-copy databases including manual files, backup and archived files as well as email folders and archives.

The DC shall at all times have access to a data map which sets out the location of all of International Gaucher Alliance's stored data.

At no time may personal data ever be altered or destroyed in order to avoid disclosure.

Responsibilities

The DC is responsible for the following:

1. Keeping a record of all SARs made, including the date on which the SAR was received;
2. Reviewing all the documents provided to a data subject pursuant to a SAR to check for the mention of any third parties and if a third party is mentioned, to prevent the disclosure of the identity of the third party to the data subject, or to seek written consent from the third party as to the disclosure of their identity.

Personal data exemption categories

The following data exemption categories apply, meaning that International Gaucher Alliance does not have to provide personal data covered below:

- The prevention and detection of crime;
- Negotiations with the data subject request maker;

- Management forecasts;
- Confidential references provided *by* International Gaucher Alliance however not references provided *to* International Gaucher Alliance
- Data covered by legal professional privilege;
- Data used for research, statistical or historical reasons.

Personal data provided by International Gaucher Alliance to a data subject pursuant to a SAR shall be in electronic format, unless the SAR expressly requests otherwise, and all items shall be scheduled, displaying the data subject's name and the date on which the data item was delivered.

4. Document owner

The Data processor is the owner of this policy document and must ensure that it is periodically reviewed according to the review requirements contained herein.

The latest version of this policy document dated 01/05/2018 is available to all employees of International Gaucher Alliance on the corporate intranet.

This policy document was approved by International Gaucher Alliance's Board of Directors and is issued by the Chief Executive Officer ("CEO") on a version-controlled basis.

Name of CEO: Tanya Collin-Histed

Date: 01/05/2018

Change history record

Issue	Description of Change	Approval	Date of Issue
1	Change of name from EGA to IGA	N/A	16/10/18
2	N/A	N/A	N/A
3	N/A	N/A	N/A