

# Processing of personal data Reference document

## Purpose of the document

The purpose of this document is to specify which personal data are processed by the Fragile X International (FraXI) and the conditions under which such processing is carried out, in accordance with the provisions of European Regulation 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data.

## Purpose of the processing carried out

1. Maintain the register of FraXI Members and Affiliate Groups, in accordance with the Belgian Company Code.
2. Have contact details of members and former members; families; as well as a number of organizations and people active in the disability sector; as well as grant funders, foundations, donors and other non-profits; as well as contact details obtained via forms on our website, eg. for newsletters, donations, sponsorship, research, volunteering, or any other information or requests, in order to be able to send them:
  - A letter (by letter or e-mail);
  - FraXI's newsletter (electronically);
  - Any other emails;and, if necessary, to be able to contact them by phone.

## Nature of the data collected

For each person or organization the following data may be collected:

- For representatives of an organization:
  - o The name of the organization
  - o The position of the person
  - o The organization's website address
  - o The organization's email address
- The address of the person's or the organization's registered office: street, number, postal code, locality, country
- Phone number
- The date of payment of the yearly membership fee

## Nature of the processing carried out

Collection, maintenance and use of data, for the purposes listed above.

## Treatment Process

### Data collection

The data is collected either by

- using the registration form sent by e-mail to any Member of Affiliate Group candidates. The completion of this form entails the formal and spontaneous acceptance of the candidate members, as required by the European regulation.
- Any contact forms on our website being filled in by said person and received by us.
- An email exchange with said person.

## Keeping data up-to-date

The data are kept up to date on an empirical basis, based on information received either from the data subjects themselves or from the post office (return of mail with the mention "No delivery at the provided address").

Occasionally, but not always, the validity of the data is verified by sending a copy of it to each person, together with the request for verification and reporting of any possible anomalies.

## Use of data

The use of the data is limited to:

- Generating lists of contact names;
- Generating an e-mail list for sending e-mails or newsletters in electronic form.

## Disclosure of data

The data collected is not communicated to anyone or to anybody, except the data subject himself.

## Data Retention

The data is stored on FraXI's Google Drive. This is kept securely and only accessed by authorised persons.

## Data Controller

The *Admin as directed by the Board* of the Association is responsible for data processing. Only the Admin or board member enters data into the contact file, corrects it if necessary and makes selections as needed.

Note: If consent is necessary, ensure that the consents obtained are:

- Freely given
- Specific and informed
- Unambiguous and clearly distinguishable