

Privacy Policy

FSHD Global Research Foundation Limited

FSHD Global Research Foundation Limited (ABN 79 128 037 614) (**FSHD Global, we, us or our**) operates website fshdglobal.org and mobile application '[Find The Cure](#)' (together, the **Site**).

This Privacy Policy (**Policy**) explains how we collect, hold, use and disclose personal information we receive from users of the Site.

By providing personal information to us, you consent to FSHD Global collecting, holding, using and disclosing your personal information in accordance with this Policy.

Collection

When registering to use our Site, and when using our Site, we will ask you to provide us with certain personally identifiable information that can be used to contact or identify you. Personal information may include, but is not limited to, your name, email address, phone number, address, and credit card details.

Personal information is also collected directly through the Sites and also through givenow.com.au – an embedded third party within our Sites, with the core purpose of processing donation and payments. Donor details are stored in Giftworks database and spreadsheets saved on internal server(s). Client database details are saved via Google Drive using email client, Mailchimp for EDM's. All information is backed up daily to hard drive and saved on FSHD Global Server. All computers are password protected. Offices are accessible with electronic cards. Any credit card details that are recorded are deleted or destroyed after use. Credit card details are not saved within local database.

Use

The FSHD Global Research Foundation is an Australian not-for-profit organisation dedicated to finding a treatment and cure for Facioscapulohumeral Dystrophy (FSHD).

The FSHD Global Research Foundation has been solely formed to fund medical research projects in Facioscapulohumeral Dystrophy (FSHD). These research projects aim to create a better understanding of, and find appropriate treatment and a cure for FSHD. Donations received are used to fund medical research.

Information is collected for fundraising activities, including but not limited to, events and donations. Personal information may be shared with corporate donors who aid in fundraising activities. FSHD staff and volunteers have access to donor details as part of their day-to-day work at FSHD. Outside IT support staff have access by way of hosting website and supporting staff.

If you register for our newsletters, attend an event, or donate via our Sites, the personal information that you choose will be collected. We may contact you or provide information in order to gather more details about your donation or to inform you of upcoming events.

We may also use your personal information to communicate with you about improvements, updates on medical research and new versions and features of the Site, and new services

offered on the Site. You may “opt out” of receiving these communications at any time by using the “unsubscribe” link in emails, or by contacting us at the email address below.

Disclosure

We will not generally disclose personal information to third parties, other than for a purpose directly related to our activities.

In order to deliver our services to you, we may need to disclose personal information to agents and contractors who support the operation of our business, such as credit card processors and service providers for the purposes of email distribution.

Protection of Personal Information

We maintain standards and security procedures to prevent misuse, interference and loss, unauthorised access, modification or disclosure.

Personal information is held electronically on the information technology systems of FSHD Global and may only be accessed by its authorised employees and contractors who may require access in connection with the purposes described in this policy.

Access to Personal Information

If you are a user of the Site, you may access personal information we hold about you, subject to a small number of legal restrictions.

If you wish to access the personal information we hold about you or request correction of it, most personal information can be updated and corrected directly by logging in to your account details on the Site. If there are aspects of personal information that cannot be updated directly, then you can request access and correction of your personal information by clicking on the “Contact Us” link on the Site.

Complaints

If you wish to make a complaint about how we have handled your personal information, you should forward a written complaint to:

[Privacy Officer](#)
FSHD Global Research
PO Box A296
Sydney South NSW 1235
Sydney NSW 2000

By email: admin@fshdglobal.org

FSHD Global will respond in writing within 30 days of receiving the complaint.

If the complaint remains unresolved, you have the option of notifying the Office of the Australian Information Commissioner (OAIC). Contact details can be found at OAIC's website: oaic.gov.au

Changes to our privacy policy

FSHD Global may amend this policy from time to time. If FSHD Global makes substantial changes in the way it collects, holds, uses or discloses personal information via the Site, it will publish an updated privacy policy.