



Talk Lipoedema, we are committed to protecting your personal information. We value your support and respect your privacy. We take our commitment to you and your data seriously and as such this policy is written in accordance with the Data Protection Act 1998.

If you have any questions, or want to check, change or update your details at any time please contact our team:

- By Post: Talk Lipoedema, 16 Milton Bridge, Penicuik, Midlothian, EH26 ORD.
- By Email: [contact@talkipoedema.org](mailto:contact@talkipoedema.org)
- By continuing to use this Website you are agreeing to the terms of this privacy policy.

**Last updated: 18<sup>th</sup> March 2022**

## **OUR POLICY**

### **Who we are**

Talk Lipoedema is a UK-based charitable organisation that is active across the UK. It provides support to people with lipoedema, their families and carers. Talk Lipoedema initiates and participates in various projects to increase awareness of the disease, and improve research evidence.

Talk Lipoedema registered charity in Scotland (SCIO45490). Within the context of this policy 'we' means the charity.

### **Your data - what information do we collect?**

When you get in touch with us to make a donation, request information or otherwise support us, we collect and securely store the personal information you supply to us.

Typically this information might include your name, contact details, date of birth, and any preferences you have expressed to us about your interests and how you like to be contacted. Where you have made a generous gift to help us support patients with lipoedema, we collect the appropriate financial information from you to complete this transaction, and process your donation.

Some information on how people interact with our website is monitored. This information remains anonymous and helps us to make our website easier to use and more helpful to the people who visit it. We may also collect the number given to your computer or device on the internet, known as an Internet Protocol address when you interact with us online, and we may collect your device's advertising identifier when you use any Apps.

### **Information we collect from you on our social media sites**

The Talk Lipoedema Support Groups on Facebook, gives people the chance to share their experiences of living with lipoedema and ask any questions. We do moderate these groups to try to make sure it is a safe and supportive space. Please see our for more information on the individual group rule for more information.



When you visit our social media pages (including Facebook, Instagram, and Twitter), the owner of that site will usually place cookies on your device. You can choose whether to allow this by changing your social media or browser preferences – see our Cookie Policy for details.

Social media sites like Facebook, can also share your data with third parties, including us, depending on the settings you've chosen on those sites.

This means we can tailor our marketing to better suit your needs and aim to display ads that we believe are relevant to you. You can find out more about this type of activity in our Cookie Policy. You can change your cookies settings on our website or change your social media settings to prevent this type of activity.

Please note that even if you change your preferences with us, you will still see some content from us on social media, as the social media site will choose content for you based on other reasons. When you visit our social media pages (including Facebook, Instagram, Twitter), the owner of that site will usually place cookies on your device. You can choose whether to allow this by changing your social media or browser preferences – see our Cookies Policy for details.

We also may periodically offer you the opportunity to take part in user experience testing via our website. See user experience research for further details.

We may also receive information about you from third parties, for example from a friend who wants to send you a gift, information or make a donation in your name; or from service providers and reputable public data sources enabling us to provide you with a better supporter experience.

We do not usually collect sensitive personal data about our supporters unless there is a clear reason for us to do so. Sensitive information such as health information may be collected if you are participating in an event, so we can provide appropriate support and resources for you, if required. You may also wish to share health information with us if you decide to share your experience of lipoedema. If you choose to share this information with us, we will always treat it sensitively and ask you on every occasion if you are still willing to share it further in the form of case studies or media interviews.

### **How do we use this information?**

We use this information to:

- provide you with the service or information you have requested
- keep you up-to-date with our work and offer opportunities for you to get involved
- improve our service to you
- inform you with relevant information online
- tailor and personalise communications, marketing and notifications to you
- and further our charitable aims.

The use of your information enables us to keep you informed of how your support is helping to support, advocate and educate. You may receive communications from us about our work



which may cover our research, news, our appeals, fundraising activities, online shop and other initiatives you might want to hear about or get involved with.

Where you have provided us with your email address and have given us permission to contact you via this address, we may on occasion use your email address to communicate with you via social media sites.

If you want to hear more or less about the different areas of our work, please contact us at [contact@talklipoedema.org](mailto:contact@talklipoedema.org) and we will be happy to update your preferences.

We may also analyse your information and feedback to improve the services we provide. We use traffic analysis tools to evaluate website traffic in order to help us continually improve the design, content and layout of pages. If you enter your contact details in one of our online registration forms, we may use this information to contact you even if you don't "send" or "submit" the form. We will only do this to see if we can help with any problems, you might be experiencing with the form or with our websites.

Your input and support means a lot to us. If you would like to get involved, please contact us so we can keep you informed of opportunities.

#### **How long we keep your data**

As lipoedema is a long-term, chronic condition, we know that your needs for support and your relationship with us will change over time. We will normally keep your personal information only for as long as necessary.

We normally keep your details on our supporter database while we have an ongoing relationship with you. If we haven't heard from you for seven years, we will archive your data, which means we won't use it any more unless you decide to restart your relationship with us.

We keep financial records, Gift Aid records and details of any contracts we enter into with you for seven years after the relevant transaction, which is required by law. We do not keep your credit card details in accordance with payment industry standards.

#### **Protecting your data**

Data security and protecting your personal information is incredibly important to us. We take great care in the selection and implementation of appropriate security measures and controls, to keep your data protected and safe.

We do not sell, rent or share your information with external organisations. In the execution of our work, we do engage trusted partners and service providers to work on our behalf. Any partners or service providers working on behalf of Talk Lipoedema only have access to the information they need.

Our work is based in the UK, all information provided to us is stored securely, within the European Economic Area. (Where you have the same level of protection for you data as in the UK). From time to time, it may be necessary for us to use partners and service providers outside of the EEA, when this happens, we ensure that your information is held in compliance with the European data protection regulations. By submitting your personal information, you agree to this transfer, storing or processing at a location outside the EEA.

We take all steps reasonably necessary to ensure that your data is treated securely and in accordance with this privacy policy.



### **Your consent and accessing your data**

When you register with us, you are stating that you are over 18 years of age, or a minor acting with parental consent. You agree that any information you provide to us about yourself upon registration or at any time is true.

By providing us with your personal data you consent to the collection and use of any information you provide in accordance with the purposes set out in this privacy statement.

You have the right to request to see all personal data that we hold about you. The law permits us to charge you a fee of £10 for providing this information. If you would like to exercise this right, or have any concerns about the personal data held on you, please let us know. We will generally supply any information you ask for within 30 days unless it is a particularly complex request. Any personal data that you inform us is incorrect will be amended or deleted, as appropriate.

You can check, change or update your details and preferences with us at any time using the contact details at the top of this page.

### **Integrating third party services**

We will sometimes launch digital initiatives that allow or enable you to login in via third party services such as Facebook or Twitter, to integrate your user experience or take payment information such as PayPal and Stripe. To do this, we will ask you to login to said relevant third-party service. When you do this, we collect relevant information to enable our initiative to access that Third- Party Service and your data contained within. You will always be asked before we access any information held in the Third-Party Service, but we are not responsible for how Third-Party Services use, store and disclose your information, and will not accept responsibility for the privacy practices or other actions of any Third-Party Services.

We also cannot be held responsible for the privacy of data collected by websites not owned or managed by Talk Lipoedema. Please ensure you check the privacy policies of the individual sites.

### **COOKIE AND ONLINE PRIVACY POLICY**

'Cookies' are small pieces of information sent by a computer's web server to a web browser, which enables the server to collect information from the browser. A cookie essentially takes the form of a small text file deposited on your computer's hard drive. We may place a cookie on your machine to help with the gathering of the above website data or, where necessary, to ensure that pages where you log in function correctly. We do not access any information stored in cookies placed on your machine by other websites.

If you would like to prevent our cookies from being stored on your computer in future, you can do so by referring to your Internet browser's instructions. You can do this by clicking on the Help menu. Please note however that if you disable our cookies, you may not be able to access certain services or facilities on our site and your use of our site may be limited. Further information about deleting or controlling cookies is available at [www.aboutcookies.org](http://www.aboutcookies.org). One way to control cookies is through Google Analytics opt-outs for the web tool.