

## DEBRIEF FORM

**Title of Project:** An investigation into the impact of diet and lifestyle on the management of lipoedema.

**Names of Investigators:** Dr Jessica Jin; Dr Louise Dunford, Hana Hussain; Sharie Fetzer and Mary Warrilow.

Thank you for taking part in this study. The aim of the study is to gain an understanding of the self-reported dietary and lifestyle impact on the efficacy of management for lipoedema conditions through an administration of an online survey questionnaire to a UK population with lipoedema. Your data will be kept confidential at all times. Raw data will be kept on password-protected computers, which will only be accessible to the named researchers. Raw data will be destroyed after five years in accordance with DMU ethics policy.

Below is provided the brief introduction about Lipoedema UK and all supports you may obtain from them and other resources should any need arises throughout the study.

### **Lipoedema UK**

Lipoedema UK is a small national charity that was founded in 2012 by medical professionals and patients at St George's University Hospitals NHS Foundation Trust in London. Our aim is to increase the awareness of lipoedema among medical workers in the UK. We focus on educating doctors, healthcare workers, patients, and the public, by publishing information leaflets, reporting on the latest research, commissioning our own research, hosting events for patients and medical professionals, and attending appropriate healthcare conferences. We team up regularly with other international experts and patient organisations to help make a worldwide impact. Our Patrons are the UK's leading lipoedema expert, Professor Peter Mortimer, Professor of Lympho-vascular and Dermatological Medicine to St George's and Dr Kristiana Gordon, Consultant in Dermatology also at St Georges, London. We also have a friendly team of skilled and experienced Nurse Consultants that have worked in the field of lipoedema / lymphoedema for many years and are able to offer the charity clinical and medical advice and support on a voluntary basis. All our nurses are Registered with the National Midwifery Council (NMC).

### **Support and Advice from Lipoedema UK**

*"Lipoedema UK are very experienced in providing advice and support for patients who are distressed by their condition - we provide information for patients to share with their GPs and other healthcare professionals and are particularly aware of the distress and anxiety that often accompany receiving a diagnosis of lipoedema. Our website, literature and other research such as our Focus Group reports are acknowledged leaders in the field."*

Sharie Fetzer – Chair, Lipoedema UK.

Lipoedema UK will endeavor to offer advice and support during the study time from our professional team.

We understand that some of the questions within the survey itself can be sensitive and probing and may cause scenarios of upset or distress.

The Nurse Consultants team are highly professional and very experienced in dealing with patients distressed by their condition. And they are here at hand to offer support and give advice to participants if necessary. Our friendly and approachable Nurse Consultants will be able to discuss confidentially any concerns or issues that have arisen from the survey questions.

Lipoedema UK offers all their members a Membership Pack comprising booklets and information on managing lipoedema plus the option of a GP Information Pack which many members find extremely helpful when discussing their condition and symptoms with their GP and other healthcare professional.

For non-members, they can access the Lipoedema UK website which is a very good source of similar information.

We are therefore well equipped to help with any questions, concerns or issues raised by you from participating in this study.

You can contact us via the email address [support@lipoedema.co.uk](mailto:support@lipoedema.co.uk) and we will contact you by return email or phone call to confidentially discuss any issues.

### **Other supporting resources**

#### **Lipoedema UK**

[www.lipoedema.co.uk](http://www.lipoedema.co.uk)

#### **Lymphoedema Support Network**

<https://www.lymphoedema.org>

#### **Samaritans**

The Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout the United Kingdom and Ireland, through their telephone helpline, email, writing, or face-to-face services.

1A Elmfield Avenue, Leicester LE2 1RB

T: 0845 790 9090

E: [jo@samaritans.org](mailto:jo@samaritans.org)

W: [www.samaritans.org](http://www.samaritans.org)

**Thank you again for your participation.**

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