



## Trustees Annual Report

01 January 2023 – 31 December 2023



Charity name Lipoedema UK

Other name the charity uses Lip UK

Registered charity number 1181312

Charity's principal address Foxfield House, Chichester Road, West Wittering,  
West Sussex PO20 8QB

[www.lipoedema.co.uk](http://www.lipoedema.co.uk)  
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Founding Member of the  
Lipedema World Alliance



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## Introduction

This report has been compiled by the Trustees to provide an update of activities in 2023 for members & funders, and to comply with the charity's reporting obligations to the Charity Commission. We would like to thank everyone who donated or supported our activities through sponsorship as they made all these activities and achievements possible.

As trustees we understand that public benefit is part of what it means to be a charity. We took account of the Charity Commission guidance on requirements for public benefit in determining our purposes and activities when our charity was set up, and we are aware of the existence of the guidance on running our charity in a compliant manner to deliver public benefit. We refer to this guidance as our charity evolves and grows, to ensure that we remain appropriately focussed and managed.

We have taken account of the Charity Commission guidance on public benefit reporting in the creation of this annual report and in consideration of our other communications to beneficiaries and potential funders.

## Purpose of Lipoedema UK

To relieve the needs of people with Lipoedema, in particular, but not exclusively, by the provision of services, advice, information and support; and to advance the education of the public, in particular those involved in the diagnosis, treatment and care of those suffering Lipoedema.

## Main Activities of Lipoedema UK

- Provision of services, advice information and support
- Advance the education of the public
- Advance the education of those involved in the diagnosis, treatment and care

This report has been approved by the Board of Trustees, and is signed on their behalf on 15th October 2024 by:



Sharie Fetzner, Chair



Kate Forster, Treasurer & Secretary

## Our Team

### Trustees

Role	Trustee
Chair	Sharie Fetzer
Secretary & Treasurer	Kate Forster, Chartered FCIPD
Trustee	Suzanne Evans, BA (Hons)
Trustee	Kris Jones, RGN
Trustee	Sara Percival, MSc

Our trustee recruitment comes from our membership and our advisory teams. All our current trustees have a personal connection to lipoedema.

### Patrons, Clinical & Medical Advisory Teams

Role	Name	Contact Address
Patrons	Professor Peter M. Mortimer MD FRCP Dr Kristiana Gordon MBBS MRCP MD(Res) CLT	St George's NHS Trust, Blackshaw Road, Tooting, London, SW17 0QY
Nurse Consultants & Clinical Advisors	Mary Warrilow RGN, BSc(Hons), QN  Kris Jones RGN, ENB931, ENB N34, Post Graduate Diploma Lymphoedema Practice  Rhodri Harris RGN  Sara Percival MSc  Clare Anvar BSc(Hons), MSc MLD, Clinical Massage Specialist	Care of Lipoedema UK  Lymphcare UK, The Lodge, Mary Stevens Hospice, 221 Hagley Road, Stourbridge, DY8 2JR  Care of Lipoedema UK  Care of Lipoedema UK  Care of Lipoedema UK
Medical Advisors	Dr Sarah Pledger FFSRH, MRCGP, MBBS, DRCOG  Dr Vaughan Keeley PhD, FRCP	Care of Lipoedema UK  Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE

## Key Activities In 2023: Delivering Our Aims & Purpose

2023 provided another challenging environment as Lipoedema UK's support and advisory activities continued to experience increased levels of demand. Patients continued to find it frustratingly difficult to access previously traditional primary care services such as appointments with their GPs and referrals to other primary care providers such as Lymphoedema clinics.

We witnessed continuing strains of loneliness and isolation from our UK members, so our team increased our focus on increasing ways of alleviating the lack of face-to-face contact and difficulties in obtaining a diagnosis or professional advice.

Fortunately, 2023 witnessed a slow return to events for healthcare professionals both in the UK and abroad, these became increasingly important to the members of our team as they opened up many opportunities to grow affiliations with new organizations and international medical expertise. The major event of the year was the first World Congress for Lipedema held in Potsdam, Germany which created an optimistic and enlightening experience for both patient organizations and healthcare professionals from all around the globe.

### Weekly Webinars for Lipoedema UK Members

Following the 2020 launch of our on-line Health & Wellbeing community, in 2023 we continued to increase the content of medical advice and motivational support, along with the opportunity to 'meet' in a safe and secure environment where patients could obtain expert information and ask questions about their own situation and concerns. Our Nurse Consultant/Clinical Advisor team of Kris Jones, Sara Percival, Rhodri Harris and Mary Warrilow was strengthened by the addition of Clare Anvar, Clinical Therapy Advisor for Lipoedema UK who brings a deep knowledge and experience in post-operative treatments for lipoedema from her private clinical work.

Regular members told us our sessions continued to be a lifeline on how to manage their symptoms and as a support mechanism.

### International Collaboration

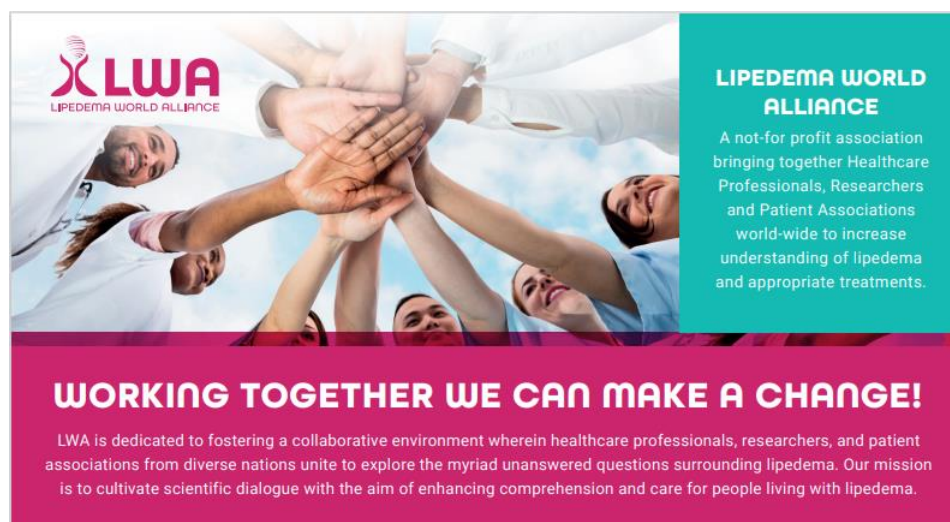
The provision of government provided healthcare services worldwide continues to frustrate patients and healthcare providers alike, most patients experience similar challenges in accessing lipedema diagnosis and treatment, despite different healthcare systems and countries. However, following the 2022 NICE review the UK has experienced a devastating drop in availability for patients to access surgery for lipoedema, at the same time as there is a growing awareness of the potentially transformational benefits of surgical treatments. Consequently, 2023 saw a constant stream of UK patients going abroad and funding their own surgical treatment.

In 2023, Lipoedema UK continued to strengthen its ties with other international patient organizations, surgeons and healthcare experts. We now regard international collaboration as an essential part of our work, to raise awareness of the experience of patients in the UK and to share information within the UK on the activities of international healthcare professionals and researchers.

We approach all our work with our goal in mind that #TogetherWeCanBeatLipoedema and believe that it is essential to have the voice of UK patients not only heard, but also involved in addressing the challenges of living with lipoedema and determining research priorities both in the UK but also worldwide.

### Membership of Lipoedema World Alliance (LWA)

The Lipoedema World Alliance, an international not-for profit association, was registered on 22 July 2022. Lipoedema UK is represented by two of our trustees, Sharie Fetzer and Kate Forster on the Board of the LWA.



The Lipoedema World Alliance Board brings us together with several of our sister lipoedema associations and a range of international lipoedema practitioners/researchers:

Sandro Michelini (President), Karen Herbst (Vice-President), Manuel Cornely, Gabriele Faerber, Isabel Forner Cordero, Mojtaba Ghods, Philipp Kruppa, Serena Michelini, José Luis Simarro, Thomas Wright, and then two representatives from each of: LIO Lipoedema Italia, Lipoedema UK and andLINFA.

Working with the LWA was a significant activity for us in 2023, culminating in our participation at the Lipoedema world Congress in October 2023.





## 2nd Lisbon International Lipedema Meeting

Our Chair was asked to speak about the work and challenges facing Lipoedema UK at a well attended professional event in Lisbon. Many international organizations continue to regard Lipoedema UK as the founder charity and seek our participation and advice on their own activities.



NICE Interventional Procedures Guidance: Liposuction for chronic lipoedema [IPG721]  
Published 29 March 2022

The National Institute for Health and Care Excellence (NICE) carried out a rapid review of the evidence into the provision of liposuction for lipoedema in the UK in 2021-2022.

The final recommendations published by NICE were:

*1.1 Evidence on the safety of liposuction for chronic lipoedema is inadequate but raises concerns of major adverse events such as fluid imbalance, fat embolism, deep vein thrombosis, and toxicity from local anaesthetic agents. Evidence on the efficacy is also inadequate, based mainly on retrospective studies with methodological limitations. Therefore, this procedure should only be used in the context of research.*

*1.2 Further research should report:*

- patient selection, including age, effects of hormonal changes (which should include effects seen during puberty and menopause) and the severity and site of disease*
- details of the number and duration of procedures, the liposuction technique used (including the type of anaesthesia and fluid balance during the procedure), and any procedure-related complications*
- long-term outcomes, including weight and body mass index changes*



- *patient-reported outcomes, including quality of life.*

*1.3 Patient selection should be done by a multidisciplinary team, including clinicians with expertise in managing lipoedema.*

*1.4 The procedure should only be done in specialist centres by surgeons experienced in this procedure.*

*This classification of a procedure as only to be used in the context of research is defined by NICE as: NICE consider there to be unresolved uncertainties or that a procedure is still considered experimental, so they recommend clinicians only carry out the procedure in formal research studies which were approved by ethics committees.*

NICE's 2022 recommendations above have effectively stopped almost all liposuction operations in the UK creating a void which has forced patients to seek surgery outside the UK. Many of the international surgeons have a wealth of experience and are leading experts in their fields so most patients have extremely good outcomes from their surgery. However, cost is a major obstacle and as the demand grows there is the potential for less experienced and 'cheaper' practitioners to enter the field and we are concerned about the obvious potential dangers for UK patients.

Lipoedema UK continues to campaign and seek more evidence to present to NICE at their next review in March 2025, or earlier, and continues to communicate with NICE and their patient facing activities.

### Social Media Activities

Social media continues to be an effective way to reach new members and raise awareness amongst women who may not be aware that they have undiagnosed lipoedema. Our social media reach continues to grow along with our presence on other organisations' social media as we become more integrated in a wider lipoedema network.

During June, Lipoedema Awareness month we spread word of our international initiatives and shared webinars, including live streaming them on Facebook and You Tube. As part of our collaboration with LIO and andLINFA, and thanks to the support of a range of sponsors, we were able to have sessions streamed with live translation so that people could hear the presentations in English, Portuguese or Italian, and we were also able to translate presenters who were not presenting in English, such as Dr Simarro who gave an update in Spanish on his work in Spain.

Using a variety of social media to stream these sessions helped us all reach a range of healthcare professionals and patients, and generated some useful discussions and participation.

### Updating our website: [www.lipoedema.co.uk](http://www.lipoedema.co.uk)

Our website continues to provide a wealth of information for both patients and health care patients seeking information on symptoms and treatments and is referenced by other reputable websites such as that of the NHS.

As our access to newer information increases we feel expenditure on our website is a top priority and our aim is to make it a trustworthy and impartial source of information for anyone searching the internet.

### Healthcare Professional Events

Lipoedema UK attended and exhibited at several significant Healthcare Professional events in 2023, including The British Journal of Community Nursing Lymphoedema conferences in London and the British Lymphology (BLS) Conference in October. We also exhibited at the Primary Care Event at the

NEC in October which provided an opportunity to distribute leaflets on lipoedema to over a thousand nurses, doctors and other primary healthcare professionals from our stand outside the diabetes theatre.



### Legal structure & compliance

We are incorporated as a Foundation Charitable Incorporated Organisation since 20 December 2018, building on our work as an unincorporated charity, Lipoedema UK 1157716, founded in 2012.

Our trustees are recruited from within our wider membership and all currently are people living with lipoedema, and/or providing services to those living with lipoedema. Our structure is a simple one with a small group of trustees and a larger team of volunteers.

### Principal risks facing us as a charity

**Resources.** We remain significantly constrained by volunteer capacity and our finances. As our reputation grows we are asked to speak at more and more events or participate in working groups, all of which involve expenses for us or our volunteers.

In order to take full advantage of all the opportunities that are increasingly available to us, we need to increase our income and our pool of suitably skilled people able to participate on our behalf.

## Finances

### Member Fundraising

We are always profoundly grateful for fundraising from our members and supporters and acknowledge and celebrate their fundraising on our social media and in our news emails to members. Our membership fees and members fundraising has grown along with our activities and support for individuals, although as lipoedema is a chronic condition it frequently impinges on a patient's earning power. Lack of NHS support for treatments continues to leave patients forced to fund their own, often expensive, treatments, which has become more complex since the NICE review. We continue to seek indirect funding through sources such as Give as you Live and other fundraising platforms.

### Membership

By providing our online sessions as closed zoom calls to our members, we maintain the investment of our resources into these sessions for those who join us as members, both making the space safer for them and helping encourage enquirers to become members.

Our members provide us both with important funds for our work and with their stories and experiences, and we appreciate the value of these non-financial and financial contributions.

### Sponsorship

We are extremely grateful to the loyalty and support shown to Lipoedema UK from our core sponsors. Sponsorship and other income was reduced from the previous year due to the fact we did not hold a conference. Compression garments companies remain a crucial part of our financing and we value our partnership with them and their willingness to develop new products to alleviate specific symptoms. They also provide links, connections and partnerships for awareness raising with healthcare professionals.

### Review of Accounts

Our financial position is outlined in our attached accounts. Activities in historical prior years are captured in the accounts of the unincorporated charity Lipoedema UK, registered charity number 1157716.

The increasing number of live events for healthcare professional in 2023 enabled us to return to one of our core activities of raising awareness amongst the medical profession of the symptoms of lipoedema and their role in identifying the condition as early as possible. It has been encouraging to note interest in helping lipoedema patients from increasing numbers of GPs and nurses and primary care givers and their own frustrations in the lack of care pathways and referral services.

In this new environment the content on our website has increased in importance as an educational tool and resource for both healthcare professionals and patients researching the symptoms and treatments for lipoedema.

Our aims are to increase our future income in order to increase our resources available to deliver projects to support healthcare professionals and people with lipoedema. Running a national charity from a volunteer base is always challenging and especially as demand for our support activities becomes more complex. We are not limited by our ambitions but by our resources, both financial and people.

### Investment and Reserves

We monitor our annual income in order to ensure we can meet commitments as they arise. Our funds are managed through our bank account. We do not invest funds elsewhere as our cash reserves are relatively small and we use our income to meet our expenses, rather than investing for the long term.



Lipoedema UK

A Charitable Incorporated Organisation Number 1181312

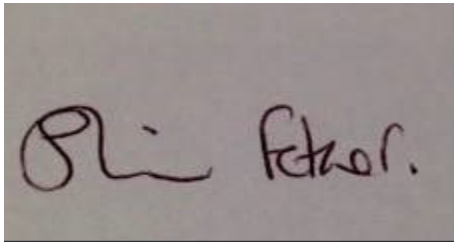
Accounts

31 December 2023



**Approval statement**

I approve the accounts which comprise of the Income and Expenditure Account, the Balance Sheet and the related notes. I acknowledge my responsibility for the accounts, including the appropriateness of the applicable financial reporting framework as set out in note 1, and for providing with all information and explanations necessary for their compilation.

A photograph of a handwritten signature in dark ink on a light-colored surface. The signature is written in a cursive style and appears to read 'Sharie Fetzer'.

Sharie Fetzer  
Chair  
6 August 2024

**Lipoedema UK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2023**

	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
<b>Income</b>		
Sponsorship & Donations	37,578	32,032
Membership	22,255	15,472
Publications	1,321	1,775
	<u>61,154</u>	<u>49,279</u>
<b>Expenses</b>		
Design and Print	7,155	5,035
Administration Expenses	4,418	2,150
Conference and AGM	-	3,177
Healthcare Professional Awareness Events	13,409	2,967
Membership and Healthcare Professional Support	21,668	17,227
CRM & IT Systems	5,809	6,888
Website	4,117	3,586
Accountancy, Insurance and other professional fees	2,087	1,688
	<u>58,663</u>	<u>42,718</u>
<b>Surplus</b>	<u>2,491</u>	<u>6,561</u>

**Lipoedema UK**  
**Balance Sheet**  
**as at 31 December 2023**

	<b>2023</b>	<b>2022</b>
	<b>£</b>	<b>£</b>
<b>Assets</b>		
Bank/building society balances	25,263	22,772
	<u>25,263</u>	<u>22,772</u>
<b>Liabilities</b>		
Other liabilities and accruals	600	600
	<u>600</u>	<u>600</u>
	<u>24,663</u>	<u>22,172</u>
<b>Net business assets represented by</b>		
Capital account:		
Balance at start of period	22,172	15,610
Net Surplus	2,491	6,562
	<u>24,663</u>	<u>22,172</u>

**Lipoedema UK**  
**Notes to the Accounts**  
**for the year ended 31 December 2023**

**1 Accounting basis**

The accounts have been compiled on a basis that enables a deficit or surplus to be calculated in accordance with UK Generally Accepted Accounting Practice and that provides sufficient and relevant information to enable the completion of a tax return.

## **Independent examiner's report to the trustees of Lipoedema UK**

**Charity Number 1181312**

I report on the accounts of the Trust for the year ended 31<sup>st</sup> December 2023, which are set out on pages 1 to 4 in the attached financial statements.

### **Respective responsibilities of trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed. It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act
- to follow the procedures laid down in the general Directions given by the commission under section 145(5)(b) of the 2011 Act
- to state whether particular matters have come to my attention

### **Basis of independent examiner's report**

My examination was carried out in accordance with the general Directions given by the Charity Commission.

An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

### **Independent examiner's statement**

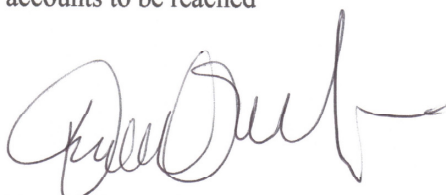
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached



Name: Donald M MacKenzie BSc CA

52 Crown Drive, Inverness, IV2 3QG

6<sup>th</sup> August 2024



Lipoedema UK

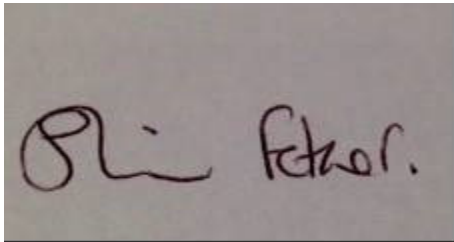
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Accounts

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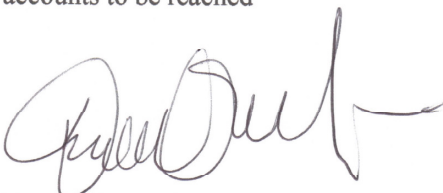
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