



Trustees Annual Report

01 January 2024 – 31 December 2024



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

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info@lipoedema.co.uk

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 2024 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 18th October 2024 by:



Sharie Fetzer, 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

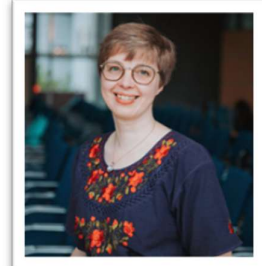
Sharie Fetzer
Chair



Suzanne Evans,
Trustee/Founder



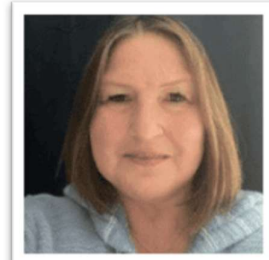
Kate Forster,
Secretary & Treasurer



Kris Jones,
Trustee and Clinical Advisor



Sara Percival,
Trustee and Clinical Advisor



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	Care of Lipoedema UK
	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	Care of Lipoedema UK
	Kris Jones RGN, ENB931, ENB N34, Post Graduate Diploma Lymphoedema Practice	Lymphcare UK, The Lodge, Mary Stevens Hospice, 221 Hagley Road, Stourbridge, DY8 2JR
	Rhodri Harris RGN	Care of Lipoedema UK
	Sara Percival MSc	Care of Lipoedema UK
	Clare Anvar BSc(Hons), MSc MLD, Clinical Massage Specialist	Care of Lipoedema UK
Medical Advisors	Dr Vaughan Keeley PhD, FRCP	Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE
	Dr Nicki Mazey, GP	Care of Lipoedema UK

Key Activities In 2024: Delivering Our Aims & Purpose

2024 continued to be challenging and exciting for us.

Lipoedema UK's support and advisory activities continued to experience increased levels of demand. People with lipoedema continued to find it difficult to access primary care services such as appointments with their GPs, and although we increasingly receive anecdotal reports that their GP was aware of lipoedema, this is not yet universal. Even where GPs or other primary care providers were aware of lipoedema there were often constraints in obtaining referrals to secondary care providers such as Lymphoedema clinics. In many areas patients were unable to locate a suitable local service with experience in treating lipoedema.

Whilst we prepare for NICE to carry out their next review on lipoedema reduction surgery (liposuction for lipoedema), we have continued to see some of our members travelling overseas for self-funded surgery. In 2024 we received increased enquiries about the use of GLP-1 Receptor Agonist medication and the role it may play for people with obesity and lipoedema.

NICE are aware that recommendations for the treatment and management of lipoedema are severely lacking and we continued to engage with them in 2024. We were delighted to be described as a trailblazing organisation by them for our level of engagement with their assessment of liposuction for chronic lipoedema, and that we stood out for "following research so avidly".

We received a significant grant in 2024 from the VTCT Foundation and appreciate their support for our work. We look forward to reporting on the activities funded by the grant in our next Annual Report.

We invested significantly in our website in 2024 to reflect the ongoing requirements for comprehensive online information and have received positive feedback on the credibility of our materials from both lay people and healthcare professionals.

Weekly Webinars for Lipoedema UK Members

Our online webinar programme for members went from strength to strength in 2024; we offered our members more online sessions this year than before, with simultaneous live attendance at sessions often at 50 or more people. Our national and international networking (including our part in the Lipedema World Alliance) enabled us to bring in new speakers as well as welcome back long-standing collaborators.

The regular input from our Clinical Advisors (Kris Jones, Sara Percival, Rhodri Harris and Clare Anvar) continues to be highly beneficial both to newly diagnosed members and those

who are not newly diagnosed but are seeking support with self-care issues such as compression garments where they have been unable to optimize them through local NSH support.

Part of our website enhancements include the ability for our members to access recordings of webinars via their online accounts. This enhancement is providing very popular and enables us to provide repeat and secure access to members' sessions whilst also providing some publicly available material which we continue to place on our YouTube channel or those of our presenters/collaborators where appropriate.

Our Clinical Advisors

Webinar Highlights

Sandra Slaughter



Professor Alexandre Amato



LIVE CONVERSATIONS Living with lipoedema

Dr James Kinross



Professor Peter Mortimer



Professor Manuel Cornely

Awareness Raising and Research

This year we were able to introduce our members to further ground-breaking research projects, from Mental Health and Visible Difference studies, in partnership with Appearance Matters at the University of West of England, to the UK National Pain Survey.

Pain is currently under-researched in lipoedema so we actively seek out opportunities to raise awareness around the experiences of pain and chronic pain amongst people living with lipoedema.

We also participated in mainstream media awareness raising including Lipoedema UK member Vanda Lima who shared her late diagnosis story with the Mirror newspaper, and Dr Lesley Steinitz, Head of Research at Lipoedema UK, who discussed weight loss injections with The Mail on Sunday.



Awareness and Research



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.

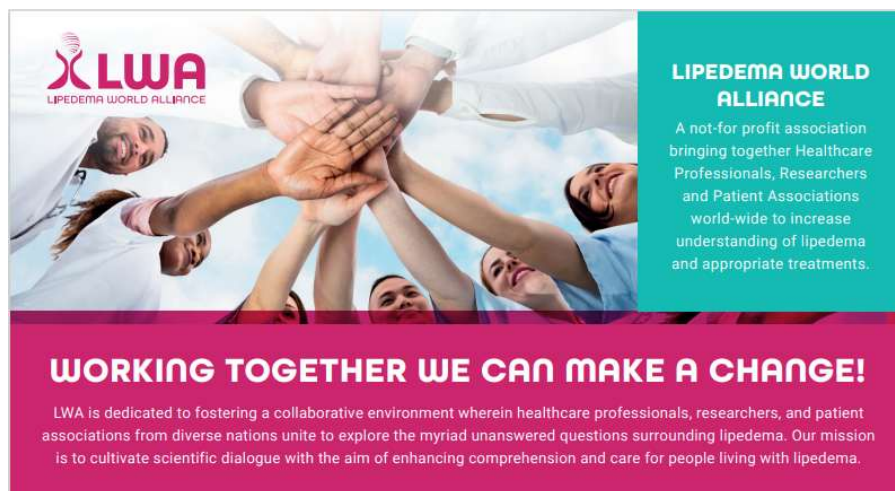
We regard international collaboration as an essential part of our work, to raise awareness of the experience of patients in the UK and to share information within the UK on publications and activities outside the UK that are adding to the knowledge base on lipedema diagnosis and treatments. We seek to continually refresh and strengthen our connections with international patient organizations, healthcare professionals and researchers to facilitate this, primarily through our membership of the Lipedema World Alliance.

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 in the UK and worldwide.

(When we write about lipoedema for an international audience, without specific references to our organization, we use the more common spelling of lipedema, as in the section that follows on the Lipedema World Alliance).

Membership of Lipedema World Alliance (LWA)

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



In 2024 as part of the Lipedema World Alliance we helped launch the inaugural Lipedema Manifesto, securing support from 20 different organizations including Lipoedema UK, uniting around 9 distinct calls for action to increase knowledge about lipoedema and improve the quality of life for people living with lipoedema.

In their LWA Board roles, Kate and Sharie provide the patient perspective to a variety of initiatives and organizational activities, including organizing and hosting the LWA webinars as part of Lipedema Awareness Month. Those webinars have had over 2,000 views at the date of this report, and our role in organizing/leading these activities helps keep Lipoedema UK high in the consciousness of current and future collaborators.

Membership of Pain Alliance Europe (PAE) and Pain UK

Many of our members find it hard to explain to others that their fat is painful, as that is not the case for other fatty tissue in obesity for example, and along with lower levels of awareness amongst healthcare professionals this can lead to miss-diagnosis with fibromyalgia or other conditions instead of lipoedema.

We feel it is crucial to increase understanding about the specifics of pain in lipedema both as a diagnostic criteria and in terms of quality of life for those living with lipedema, as well as raising awareness of lipedema within the international community who diagnose and treat patients with chronic pain.

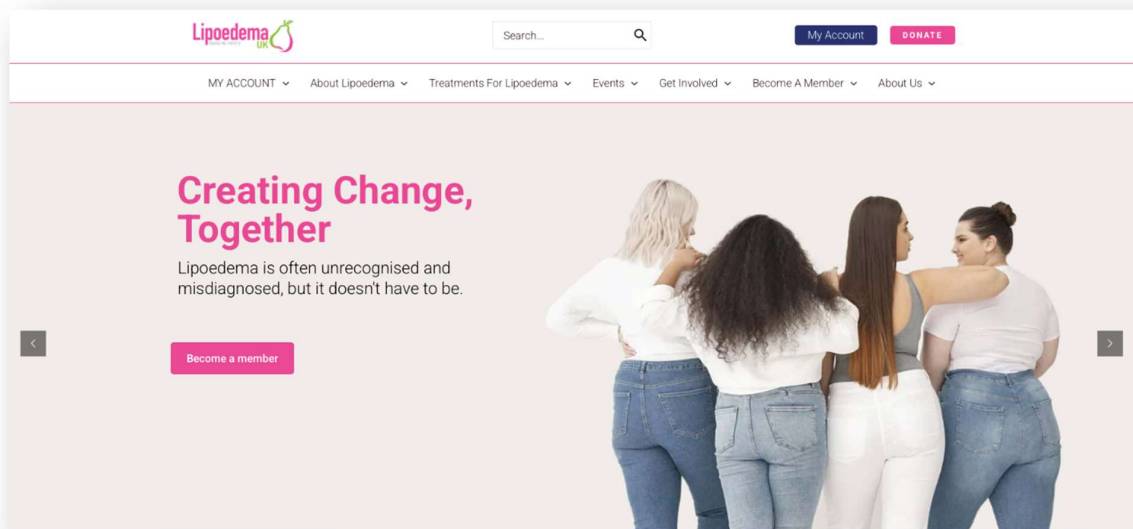
As part of our commitment to raising awareness around the experiences of pain amongst people living with lipoedema and calling for increased research into lipoedema pain, in addition to our ongoing membership of Pain UK, the UK umbrella charity for pain organizations, we joined Pain Alliance Europe in 2024 at the encouragement of Pain UK. At the end of 2024, our Trustee Kate Forster was asked to join the PAE Board to expand the pain conditions represented therein.

Social Media Activities and Website Rebuild

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 promoted not only our regular Members Webinars and activities but also our international initiatives and shared webinars, including our collaboration in the LWA events.

We also launched and promoted the Lipedema Manifesto in the UK.



We invested significantly in our website in 2024 to provide greater access to resources and information for our members, creating a secure area for self-service account management and access to recordings of members' webinars. We also refreshed the content of our public pages on the site.

Healthcare Professional Events

Raising awareness amongst healthcare professionals is crucial to improving care for people living with lipoedema in the UK. As part of that Lipoedema UK was represented at a number of events in 2024 including the National Lymphoedema Conference, BLS Conference, University of the West of England's Appearance Matters Conference, Journal of Community Nursing Study days around the UK, the 47th Congress of European Society of Lymphology in Istanbul, Turkey and the Primary Care Show in Birmingham among others.



The Primary Care show in Birmingham is a significant event for GPs and other Healthcare professionals. We were able to share information with hundreds of them, with our stand in a prime position next to one of the GP Lecture Theatres, giving us high levels of passing traffic throughout the event. We were also surrounded by a great collection of other organisations such as Diabetes UK, enabling cross-pollination of visitors between us all and provoking much interesting debate.

Dr Nicki Mazey, General Practitioner at Brownlow Health Central and Tier 3 Weight Management Lead, gave a really well-attended talk on lipoedema which generated extra visitors to our stand to keep talking to her and the rest of our team.



Primary Care Show NEC



Sharie and our Nurse Consultant Mary Warrilow presented the award for Chronic Edema Nurse of the Year at the British Journal of Nursing Awards in London. We are passionate about the impact that great nursing can have on the lives of people living with chronic conditions and are delighted to continue to be involved in these awards.

We were thrilled to be offered the opportunity to attend Brazil's 1st Lipedema Congress in Sao Paulo. Representing Lipoedema UK, Kate Forster met with Dr Paula Frederichi who lives with lipedema as well as running a specialist lipoedema clinic, along with the Board of ABRALI, our sister association for lipedema in Brazil. The congress was attended by hundreds of healthcare professionals who were keen to learn about lipedema. Kate, along with Manuela Lourenço Marques, Chair of andLINFA the Portuguese Lipoedema Association and a fellow Board Director of Lipedema World Alliance, presented on the LWA's Delphi project and patient representative involvement. ABRALI are a very inspiring and active organization, and it was wonderful to meet so many of their members and see so many of our fellow LWA Board members in attendance to support this groundbreaking Brazilian event.



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 and/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.

One of the most unusual fundraising activities in 2024 was when our member Lisa swam naked in a leisure centre, raising over £1,000 for us and raising awareness of lipoedema at the same time. We appreciate Lisa's willingness to raise funds in a distinctive way and appreciate all the funds that our members raise to enable us to carry out the activities described in this report.

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.

We were pleased to grow our membership in 2024, showing that people are increasingly becoming aware of lipoedema and are getting diagnosed. Having a growing and vibrant community of people living with lipoedema in our membership helps us share many different perspectives and stories with others, and also in the absence of statistical population data, it helps us indicate levels of lipoedema in the UK and the growing need for better NHS services.

Sponsorship

We are extremely grateful to the loyalty and support shown to Lipoedema UK from our core sponsors. 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.

Our attendance at this wide range of healthcare professional events enabled us to carry out 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, nurses and others in primary care, and to hear their own frustrations in the lack of care pathways and referral services.

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. The significant expenditure on that this year has attracted positive feedback as described earlier in this report.

We were fortunate to receive a grant in 2024, the majority of which was carried forward for spending in 2025. This grant and the subsequent carry forward of funds is shown as restricted income and expenditure in our accounts. This grant will enable us to carry out some significant work and position us well as we prepare for the next NICE review on 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 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.



Receipts and payments accounts

for the year ended 31 December 2024

Receipts and payments

	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 £
Receipts				
VTCT Foundation Grant	-	62,400	62,400	-
Sponsorship and Donations	28,179	-	28,179	37,578
Membership	27,610	-	27,610	22,255
Publications	-	-	-	1,321
Total receipts	55,789	62,400	118,189	61,154
Payments				
VTCT Foundation grant expenses	-	7,968	7,968	-
Design and Print	6,543	-	6,543	7,155
Administration Expenses	4,733	-	4,733	4,418
Healthcare Professional				
Awareness Events	10,563	-	10,563	13,410
Membership and Healthcare Professional Support	24,419	-	24,419	21,668
CRM and IT Systems	3,559	-	3,559	5,809
Website	15,869	-	15,869	4,117
Accountancy, Insurance and other Professional fees	1,309	-	1,309	2,087
Total payments	66,995	7,968	74,963	58,664
Net of receipts/(payments)	(11,206)	54,432	43,226	2,490
Cash funds last year end	25,263	-	25,263	22,773
Cash funds this year end	14,057	54,432	68,489	25,263

Charity Number: 1181312

		Unrestricted funds £	Restricted funds £
Cash funds	Bank and Paypal	14,057	54,432
	Total cash funds	14,057	54,432

		Amount due
Liabilities	Accruals	650

1. No guarantees were given by the CIO where potential liability under the guarantee is outstanding at the date of the statement
2. There were no debts outstanding at the date of the statement which are owed by the CIO and secured by an express charge on any assets of the CIO

Date of

Oliver Fether

18-Aug-25

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 31st December 2024, which are set out on pages 1 to 2 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

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Name: Donald M MacKenzie BSc CA

52 Crown Drive, Inverness, IV2 3QG

20th August 2025