



## Trustees Annual Report

01 January 2021 – 31 December 2021



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**

[info@lipoedema.co.uk](mailto:info@lipoedema.co.uk)

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## Introduction

This report has been compiled by the Trustees to provide an update of activities in 2021 for members and funders, and to comply with the charity's reporting obligations to the Charity Commission.

We would like to thank everyone who donated to us, gave us sponsorship or donated their time and/or resources. This support made all these activities and achievements possible.

As trustees we understand that creating public benefit is integral to being 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, stakeholders and potential and existing 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 and medical community, 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 in relation to lipoedema
- Advance the education of healthcare professionals and the public
- Advance the education of those involved in the diagnosis, treatment and care of Lipoedema patients

This report has been approved by the Board of Trustees, and is signed on their behalf on 12 October 2022 by:



Sharie Fetzer, Chair



Kate Forster, Treasurer & Secretary

## Our team



*Volunteer Nicola Kenworthy, Chair Sharie Fetzer, Nurse Consultants Mary Warrilow and Kris Jones*

Our team comprises of our trustees, members, volunteers and our medical advisors. Together this team supports our member activities, deals with enquiries and provides input to our materials and website.

Members of our team also advocate for us, present at our conferences, deal with the press and work tirelessly to raise awareness of lipoedema amongst the general public and the medical profession.

Recruiting additional volunteers to respond to the opportunities and demands placed on us, and to deliver our charitable purposes, is a key activity and constraint, due to the debilitating effect that lipoedema has on many of our members.

## Trustees

Role	Trustee
Chair	Sharie Fetzer
Secretary & Treasurer	Kate Forster, Chartered FCIPD
Trustee	Suzanne Evans, BA (Hons)
Trustee	Kris Jones (appointed 23 September 2021)

Our trustee recruitment comes from our membership and medical advisors. All our current trustees have a personal connection to lipoedema. Two of our long-standing trustees, Lucinda Evans and Carmen Ziqoras resigned in September 2021 as they were no longer able to devote sufficient time to charitable activities and we thank them for their long-term support during the crucial first few years. In September 2021 we were delighted to welcome Kris Jones as a Trustee, one of our long-term members and an especially talented and experienced Lymphoedema Nurse who we are fortunate to have as a nurse consultant.



## Patrons and medical advisory team

Role	Name	Contact address
Patrons	Professor Peter M. Mortimer MD FRCP	St George's NHS Trust, Blackshaw Road, Tooting, London, SW17 0QY
	Dr Kristiana Gordon MBBS MRCP MD(Res) CLT	St George's NHS Trust, Blackshaw Road, Tooting, London, SW17 0QY
Nurse Consultants	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
	Sara Percival MSc	East Suffolk and North East Essex NHS Trust Mill Road Therapy Centre, Mill Road, Colchester. Essex CO4 5LJ
	Rhodri Harris RN, BSc (Hons)	Accelerate CIC St Joseph's Hospice, MareStreet, London, E8 4SA
Medical Advisors	Dr Dirk Pilat FRCGP, PgDipGP (Otago)	Care of Royal College of General Practitioners, 30 Euston Square, London
	Dr Sarah Pledger FFSRH, MRCGP, MBBS, DRCOG	Fitzalan Medical Group, Fitzalan Road, Littlehampton, West Sussex, BN17 5JR
	Dr Vaughan Keeley PhD, FRCP	Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE

## Key activities in 2021 – delivering our aims and purpose in times of Covid-19 and lockdown



*Our long-awaited members conference – finally held in after lockdowns lifted in 2021*

2021 proved to be a challenging year with continued restrictions on our activities due to covid-19 and lockdowns. There was also increased pressure on our support and advisory activities as patients found it increasingly difficult to access support from traditional primary care channels. Our conference was particularly stressful to plan with confidence with numbers, speakers and exhibitors difficult to predict.

Many plans to attend and present at healthcare professional events remained on hold and we continued to delay the introduction of our Ambassador programme designed to increase our trained team of volunteers. In addition to all our usual activities, we also devoted considerable resources to representing patient interests in the NICE review (see section: Nice Interventional Procedures Guidance).

As we witnessed continuing stress and strains on our members, the team adapted our activities and focus to find new ways of alleviating the isolation and lack of medical attention experienced by our members. One key new way of doing this was through the continuation of our weekly online health and wellbeing sessions – see below.

CLINIC



HEALTHCARE PROFESSIONALS SESSION

Thursday 9th December

LIVING WITH LIPOEDEMA

Drop In Clinic with Healthcare Professional Panel

Kris, Rhodri & Sara  
Nurse Consultants

6.30 - 7.15 pm

Join our experienced nurses for a special Drop In Clinic Session and the chance to put forward questions around your Lipoedema health concerns.

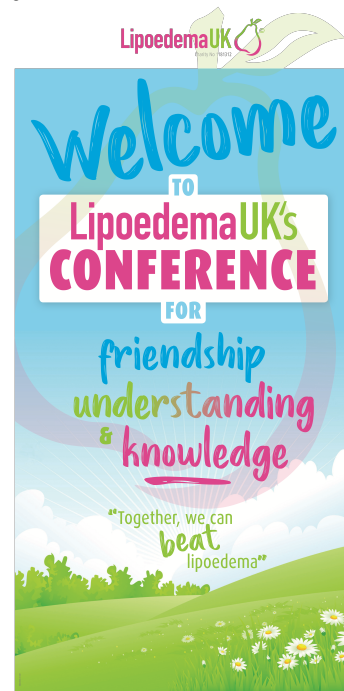
  
Lipoedema UK  
Charity No 1181372

### Weekly sessions of Lipoedema UK's virtual Health and Wellbeing Community

Following the 2020 launch of our on-line Health and Wellbeing community, in 2021 we evolved the format to increase content focussed on medical advice and motivational support, along with the opportunity for people to 'meet' in a safe and secure environment. Our Nurse Consultant team of Kris Jones, Sara Percival, Rhodri Harris and Mary Warrilow provided a regular feature of presentations and advice to approximately 50 members and the weekly session went from strength to strength during 2021. Many of our members told us that the sessions were a lifeline for them during lockdown and beyond.

### Members conference

Originally, we had planned to hold our biggest ever conference in June 2020 for 200 people. We hoped this would substantially increase our income and lead to relationships with new sponsors. Due to covid-19, we attempted to reschedule to October 2020, but had to cancel this date due to the second lockdown. However, we were heartened by the way that members chose to wait for the rescheduled dates rather than cancel their places. The two-day conference eventually took place in October 2021 and was highly successful and well supported by both members, expert presenters on lipoedema and exhibitors.



### NICE Interventional Procedures Guidance: Non-cosmetic liposuction in the treatment of chronic lipoedema IP1843

In 2020 NICE issued an invitation to Lipoedema UK to:

1. Provide an organisational submission to share views on the procedure by 01 May 2021
2. Publicise the [patient questionnaire](#) with our network to encourage people that have had the procedure to share their individual views and experiences
3. Comment on the draft guidance
4. Publicise the public consultation

Despite the restrictions of lockdown, the NICE review into liposuction was potentially the most significant initiative for UK Lipoedema patient care to date as it provided a great opportunity to present the wider case for provision of services for Lipoedema on the NHS. Out of necessity, it became the focus of a great deal of time and effort to respond in the most effective and appropriate way for significant part 2021. In order to gather the most wide-ranging evidence, Lipoedema UK devised an online patient survey. This had an overwhelming response with 902 responses received in just two weeks. The depth of this



## Non-cosmetic liposuction in the treatment of chronic lipoedema

### INTERVENTIONAL PROCEDURES GUIDANCE

By Mary Warrilow - Nurse Consultant, Lipoedema UK  
& Sharie Fetzer - Chair, Lipoedema UK

\*This document is based on Lipoedema UK's response to the National Institute for Health and Care Excellence (NICE) 2021 invitation to Lipoedema UK to contribute to the development of a piece of Interventional Procedures Guidance: non-cosmetic liposuction in the treatment of chronic lipoedema IP1843 (see page 12).

### INTRODUCTION & SUMMARY

**Lipoedema UK welcomed our involvement with NICE and the opportunity to comment on non-cosmetic liposuction (NCL) as a proposed interventional procedure for chronic lipoedema. In response, we have been proactive in capturing the views and experiences of individuals in the UK living with lipoedema and from those who have undergone non-cosmetic liposuction.**

In May 2021 Lipoedema UK launched our survey *Living with Lipoedema - Non-cosmetic liposuction and other treatments*. The response from members and non-members was overwhelming, with 933 responses in total, from the UK and overseas in just two weeks. All respondents were female.

The findings highlight how lipoedema can have a negative impact on the well-being and quality of life of individuals and their families, both physically, psychologically, and from a socio-economic standpoint. It highlights the day-to-day issues and impact facing those living with this long-term condition and the views and

### NICE WERE INTERESTED TO HEAR ABOUT

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, including health-related quality of life)
- the acceptability of different treatments and how they are given
- expectations about the risks and benefits of the treatment

experiences of those who are considering or waiting for non-cosmetic liposuction and the outcomes to quality of life (QoL) for those who have undergone NCL surgery. Any advantages and disadvantages of non-cosmetic liposuction have been explored and also the risks associated with the procedure.

Our survey has also given a powerful insight into the massive lack of NHS service provision for this group of patients, the lack of clear Clinical Pathways and treatment options including non-cosmetic liposuction for lipoedema. The report brings attention to the impact of late diagnosis and intervention and the long-term negative cost implications to not just the health economy and NHS, but to the quality of life of individuals and their families living with this long-term condition. We await the outcome of NICE's Interventional Procedure Committee and their recommendations.

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

information enabled us to compile a detailed report not only of patients experiences of liposuction but also the wide ranging and often devastating effects that lipoedema has on a patient's quality of life. The survey data was analysed with specific reference to the format of the NICE review documentation. Lipoedema UK's Chair Sharie Fetzer and Dr Kristiana Gordon were called as the two 'expert witnesses' interviewed by the NICE Committee during the first public review.

Following the submission to NICE and the Committee meetings Sharie Fetzer and Mary Warrilow published a detailed review covering the data submitted to NICE. This is available as a download on our website: <https://www.lipoedema.co.uk/wp-content/uploads/2021/11/LUK-NCL-Bklt-Sept21-WEBv9.pdf>

## Diet and lifestyle research between De Montfort University and Lipoedema UK

Work continued with Dr Jessica Jin, Senior Lecturer in Nutrition, and Lipoedema UK on our joint research project to investigate the effect of diet and lifestyle on Lipoedema and to seek an optimal diet for Lipoedema. It is envisaged that this project will continue for several years and lead to publishing various papers on the methods and findings. We are in the process of recruiting a PhD student to assist with the project.

### Social media

Social media, especially our Facebook page, continues to be an effective way to reach new members and raise awareness amongst women who have developed lipoedema and may not be aware that it is a medical condition. Led by our Social Media Ambassador Tessa Sanderson, our social media figures are constantly growing and enable us to share up to date information and receive feedback on the most relevant issues.

## PHD STUDY IN LIPOEDEMA DIET & LIFESTYLE



Late stage Lipoedema. Body image issues and restrictions in mobility can lead to social isolation and mental anguish - all having a negative impact on a patient's quality of life

A unique opportunity for an ambitious and enthusiastic self-motivated student. Despite anecdotal evidence on benefits of certain diets in improving lipoedema, scientific studies are lacking. Currently there are no dietary guideline in the UK for lipoedema management.

### PHD ENTRY REQUIREMENTS

- a Masters of Science degree in Nutrition specialising in the clinical aspects or related, e.g. medicine, clinical medicine, medical science or pharmacy - awarded at minimum a Merit level
- knowledgeable in areas of anatomy and physiology, fat metabolism and metabolic disease
- competent in collecting and analysing dietary, biochemical and clinical data using relevant techniques, such as dietary assessment and analytical biochemistry techniques

### STUDY AIM

- research how dietary practice affects lipoedema management
- design dietary intervention and test its efficacy
- develop UK-based dietary guidelines for lipoedema management

### PHD STUDY OVERVIEW

- full-time/3-4 years
- suited to those pursuing a career in weight management, research in clinical nutrition, obesity, endocrinology, immunity, metabolic diseases and eating disorders/behaviour, public health nutrition
- a multi-disciplinary supervisory team comprising nutritionist academic, medical practitioners in lymphoedema and endocrinology

[www.findaphd.com/phds/project/dietary-intervention-and-efficacy-in-improving-lipoedema-symptoms-among-patients-in-the-uk/7p133563](https://www.findaphd.com/phds/project/dietary-intervention-and-efficacy-in-improving-lipoedema-symptoms-among-patients-in-the-uk/7p133563)



[lipoedema.co.uk](https://www.lipoedema.co.uk) [Facebook](https://www.facebook.com/lipoedema.uk) [Instagram](https://www.instagram.com/lipoedema.uk) [jessica.jin@dmu.ac.uk](mailto:jessica.jin@dmu.ac.uk)

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

Despite the lockdowns, our website continued to refresh content. We also created a new section where members could tell their own stories about the impact of lipoedema on their lives in their own words. We are aware that our website content is frequently accessed by people seeking a diagnosis who download information and take it to a wide range of appointments particularly patients seeking a diagnosis or denied access to medical services in their area.



Nurse consultant Mary Warrilow (left) manning the stand to help educate health professionals

### Healthcare professional events

Lipoedema UK did manage to attend a few significant Healthcare Professional events in 2021.

The first Lymphoedema/Lipoedema live and online event after lockdown was the British Journal of Community Nursing Lymphoedema conference on 10th June. Sharie Fetzer Lipoedema UK chaired the hybrid programme and gave a presentation on Lipoedema UK's latest patient survey on diet and Lifestyle. There was a noticeable sense of joy amongst the participants to be meet and attend an event in person after so long being restricted to video-conferencing or being in isolation.

On July 9th Sharie was back in London to speak on Hormonal Changes: Contraception, Pregnancy, Childbirth and Menopause, to the Margaret Pike Trust at the Royal College of Physicians.

In September, we had a stand at the British Dermatological Nursing Group conference in Harrogate.

In October, Lipoedema UK were featured in an online presentation to patients and healthcare professions in Stockholm.

The final event we were able to attend was the International Lymphoedema Foundation conference in Denmark in November. This is an important international event and we were able to meet representatives of many other patient groups and significant international experts on lipoedema.

### Legal structure and compliance

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

Our current trustees are people living with or treating Lipoedema who are all elected/ re-elected at our AGM by our Members. 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. We celebrate their fundraising on our social media and in our news emails to members. We hope to see this source of income grow further as more people become aware of lipoedema and the devastating effect it has on both patients and their families. As lipoedema is a chronic condition it frequently impinges on a patient's finances. This occurs in two major ways. First, issues related to the condition, such as pain or mobility issues, limit earning potential. Second, patients are forced to fund their own, expensive treatments, such as conservative therapies or non-cosmetic liposuction. This situation creates financial hardship for many of our members and means many have insufficient funds to provide much direct financial support. However, many choose Lipoedema UK as their charity of for indirect funding sources such as Give as You Live.

### Sponsorship

We are extremely grateful for the loyalty and support shown to Lipoedema UK from our core sponsors during the pandemic and very pleased to acquire new sponsors in 2021.

Compression garments companies remain a crucial part of our financing and we value our partnerships with them and their willingness to develop new products that will alleviate specific symptoms. They also provide links, connections and partnerships for awareness raising with the Healthcare profession.

### Review of accounts

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

Covid-19 and its related lockdowns meant we were unable to offer many physical events for healthcare professional in 2021. Instead, we increased patient support for members and



general enquiries to provide a lifeline for patients who were increasingly distressed and demoralised by the lack of support from their local primary care services.

Our spend on technology and website increased significant to provide an educational tool and support for both healthcare professionals and patients researching the symptoms and treatments for lipoedema.

We wish to further increase our income in the future, in order to increase the resources we have available to deliver projects to support healthcare professionals and people with lipoedema. Running a national charity from a volunteer base is a struggle as the opportunities for our participation challenge the resources we have available. It is also challenging to continue to staff an organisation when so many key roles – such as chairperson, treasurer and secretary – have been done voluntarily for so many years, and volunteers may find it challenging to continue providing such a high level of financial and practical support into the future.

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

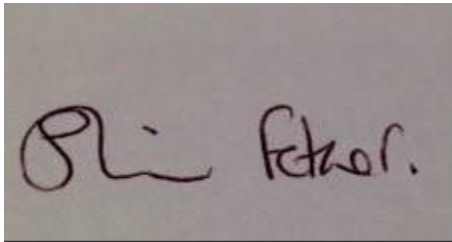
A Charitable Incorporated Organisation Number 1181312

Accounts

31 December 2021

**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 rectangular box containing a handwritten signature in dark ink. The signature appears to be 'Sharie Fetzer' written in a cursive, flowing style.

Sharie Fetzer  
Chair  
25th July 2022

**Lipoedema UK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2021**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
<b>Income</b>		
Sponsorship & Donations	40,891	26,205
Conference and Exhibitor payment	10,587	-
Membership	14,221	10,951
Publications	1,103	-
	<u>66,802</u>	<u>37,156</u>
<b>Expenses</b>		
Design and Print	3,876	1,555
Administration Expenses	1,002	533
Conference and AGM	13,505	2,070
Healthcare Professional Awareness Events	2,681	3,878
Membership and Healthcare Professional Support	26,838	12,903
CRM & IT Systems	6,019	5,841
Website	8,165	5,994
Accountancy, Insurance and other professional fees	1,453	827
	<u>63,539</u>	<u>33,601</u>
<b>Surplus</b>	<u>3,263</u>	<u>3,555</u>

**Lipoedema UK**  
**Balance Sheet**  
**as at 31 December 2021**

	<b>2021</b> £	<b>2020</b> £
<b>Assets</b>		
Bank/building society balances	16,210	17,582
	<u>16,210</u>	<u>17,582</u>
<b>Liabilities</b>		
Other liabilities and accruals	600	5,235
	<u>600</u>	<u>5,235</u>
	<u>15,610</u>	<u>12,347</u>
<b>Net business assets represented by</b>		
Capital account:		
Balance at start of period	12,347	8,791
Net Surplus	3,263	3,556
	<u>15,610</u>	<u>12,347</u>

**Lipoedema UK**  
**Notes to the Accounts**  
**for the year ended 31 December 2021**

**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 1157718**

I report on the accounts of the Trust for the year ended 31<sup>st</sup> December 2021, 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

31<sup>st</sup> August 2022

Lipoedema UK

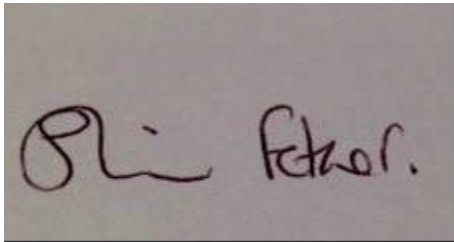
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Accounts

31 December 2021

**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.

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Sharie Fetzer  
Chair  
25th July 2022

**Lipoedema UK**  
**Income and Expenditure Account**  
**for the year ended 31 December 2021**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
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Sponsorship & Donations	40,891	26,205
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**Lipoedema UK**  
**Balance Sheet**  
**as at 31 December 2021**

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<b>Assets</b>		
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<b>Net business assets represented by</b>		
Capital account:		
Balance at start of period	12,347	8,791
Net Surplus	3,263	3,556
	<u>15,610</u>	<u>12,347</u>

**Lipoedema UK**  
**Notes to the Accounts**  
**for the year ended 31 December 2021**

**1 Accounting basis**

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

### **Charity Number 1157718**

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

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- examine the accounts under section 145 of the 2011 Act
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### **Independent examiner's statement**

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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

31<sup>st</sup> August 2022