



Trustees Annual Report
01 January 2020 - 31 December 2020



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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Introduction

This report has been compiled by the Trustees to provide an update of activities in 2020 for members & funders, and to comply with the charity's reporting obligations to the Charity Commission. We hope you will enjoy reading about our year as much as we enjoyed experiencing it. We would like to thank everyone who donated to us or gave us sponsorship as it made all these activities and achievements possible.

The start date for this report reflects our incorporation as a Foundation CIO which took effect in December 2018. In this report any references to activities prior to our incorporation as a CIO in December 2018 refer to activities undertaken by our team in previous years, as part of the unincorporated charity Lipoedema UK, registered charity number 1157716.

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 24 September 2021 by:

Sharie Fetzer

Sharie Fetzer, Chair

Kate Forster

Kate Forster, Treasurer & Secretary

Our Team



Chair Sharie Fetzer, Trustee Suzanne Evans & volunteer Nicola Kenworthy

We rely on volunteers. From our Trustees to our Medical Advisors to the many people who help us support our member enquiries, provide input to our materials, advocate for us, present at our conferences and events or on our behalf and give their time in so many other ways.

Without volunteers we would not be able to operate. In this report we list many (but not all) of the events we have presented or exhibited at. That is only possible thanks to our network of volunteers, giving their time so generously.

Recruiting additional volunteers to respond to opportunities and demands placed on us, and to deliver our charitable purposes, is a key activity and constraint.

Trustees

All our initial trustees from our incorporation served for the whole of 2020.

| Role | Trustee |
|-----------------------|-------------------------------|
| Chair | Sharie Fetzer |
| Secretary & Treasurer | Kate Forster, Chartered MCIPD |
| Trustee | Suzanne Evans, BA (Hons) |
| Trustee | Lucinda Evans, BSc (Hons) |
| Trustee | Carmen Zgouras |

Our trustee recruitment comes mainly from our membership. We encourage potential trustees to volunteer with us first, to get to know more about us. All our current trustees have a personal connection to

lipoedema. All new trustees meet with the Chair for face to face briefings and support. They are also given access to: the constitution, latest annual report and accounts and recommended to consult the Charity Commission guidance to understand their role and responsibilities.

Patrons & Medical Advisory Team

| 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 | Mary Warrilow RGN, BSc (Hons), QN Kris Jones RGN, ENB931, ENB N34, Post Graduate Diploma Lymphoedema Practice | Care of Lipoedema UK Lymphcare UK, The Lodge, Mary Stevens Hospice, 221 Hagley Road, Stourbridge, DY8 2JR |
| Medical Advisors | Dr Dirk Pilat FRCGP, PgDipGP (Otago) Dr Sarah Pledger FFSRH, MRCGP, MBBS, DRCOG Dr Vaughan Keeley PhD, FRCP | Care of Royal College of General Practitioners 30 Euston Square, London Fitzallen Medical Group, Fitzalan Road, Littlehampton, West Sussex, BN17 5JR Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE |

Key Activities In 2020 – Delivering Our Aims & Purpose in times of Covid and Lockdown.

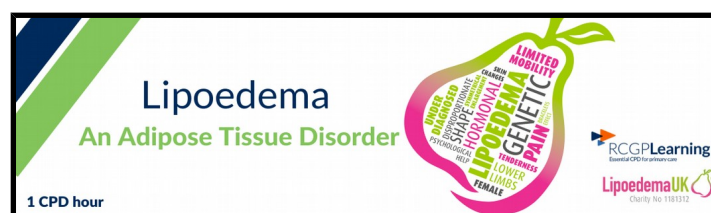
Like all other organisations and charities 2020 turned out to be quite different to what we had imagined. Our original plans included attending and presenting at a wide range of healthcare professional events and the introduction of an Ambassador programme to train and develop a much larger team. All these had to be abandoned with the introduction of lockdown.

During the lockdown, and throughout 2020, we became aware of the increased stress and strains lockdown was creating for our members and so changed our focus to increase ways of supporting them and alleviating some of the isolation and lack of medical attention they were experiencing.

Review of NHS website page on Lipoedema

Lipoedema UK were actively involved in the review of the NHS webpage on Lipoedema. The designer acknowledged that there was quite a low awareness, recognition and understanding of lipoedema among both patients and clinicians and wanted to make some substantial changes to the lipoedema page, including some good quality images to clearly show the characteristic symptoms. Lipoedema UK were able to provide several images from our membership and honoured to help with the revised page.
<https://www.nhs.uk/conditions/lipoedema/>

Review of learning Lipoedema



the RCGP course on

The Royal College of GPs updated the learning course that Lipoedema UK had originally sponsored in 2014 and also updated the logo for the course with Lipoedema UK's latest colours. The course is still a flagship for Lipoedema and continues to provide a credible source of information for GPs and all healthcare professionals.

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

In October 2020 Lipoedema UK were invited to help NICE in the following ways:

1. **Provide an organisations submission** to share your views on the procedure, see attached template for completion. Please submit by **01 May 2021**
2. **Publicise the patient questionnaire** with your network to encourage people that have had the procedure to share their individual views and experiences
<https://nice.researchfeedback.net/IP1843> by **01 May 2021**
3. **Comment on the draft guidance** – this will be made available on the NICE website following committee meeting one
4. **Publicise the public consultation**, once open, on your website, social media streams, newsletter etc.

This was seen as a great opportunity to present the case for liposuction on the NHS and so it became the focus of a great deal of time and effort to respond in the most effective and appropriate way which continued into the whole of 2021.

Diet and Lifestyle Research De Montfort University and Lipoedema UK

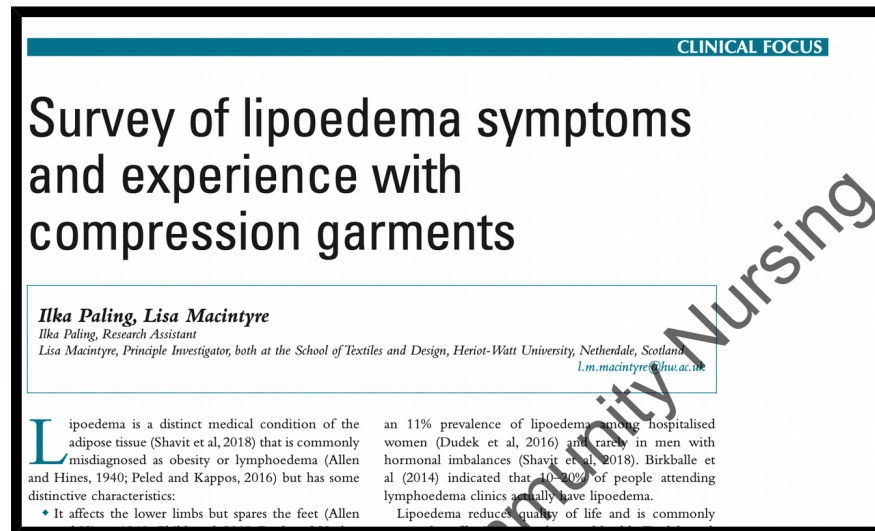
Following meeting Dr Jessica Jin, Senior Lecturer in Nutrition, at the Primary Care Event at the NEC in 2019, Lipoedema UK embarked on a join research project to investigate the effect of diet and lifestyle on Lipoedema and to seek an optimal diet for Lipoedema. It is envisaged that this project will continue for several years and lead to publishing various papers on the methods and findings.

Social Media

Unsurprisingly in 2020 Social media became a lifeline for many people and our Instagram and Facebook accounts continued to raise awareness amongst women who have developed lipoedema and may not be aware that it is a medical condition. Social Media Ambassador Tess, who leads on our activities and tirelessly answers many questions and has a big following with her positive posts on dealing with life's challenges. Our social media figures are constantly growing and enable us to share up to date information and receive feedback on the most relevant issues.

Compression Garments Research

A report by Ilka Paling of Heriot Watt University on her co-operative piece of research with Professor Lisa Macintyre of Heriot Watt University, Jobskin and Lipoedema UK was published in the British British Journal of Community Nursing.



Women in Dire Need Reports

In 2019 we launched our series of four focus group reports; Women in Dire Need, available for download from our website.

The focus group reports, conducted and written by Amy Fetzer MSc, expose the in depth effects of this chronic disability on the lives of patients, by showcasing their collective personal experiences.

In 2020 a combined report on the findings of all the focus groups was published in the British Journal of Community Nursing.

Cancellation of our Members Conference

Originally we had planned to hold our biggest ever conference in June 2020, which would have substantially increased our income and led to relationships with new sponsors. Due to covid we attempted to reschedule it to October 2020, but had to cancel this date due to the second lockdown. However, we were heartened that so many of our members

chose to wait for the rescheduled dates rather than cancel their places. The conference will now take place in October 2021.

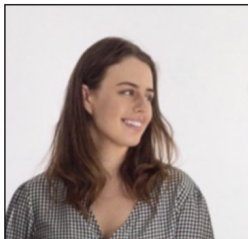
Updating our website

Despite lockdown our website continued to attract a lot of new views and we felt it was time to refresh some of our content and also increase the depth of subjects, so that patients who were denied access to medical services could obtain a wider range of reliable medical information
www.lipoedema.co.uk

Launch of Lipoedema UK's virtual Health & Wellbeing Community

Our major initiative in 2020 was the launch of our Health & Wellbeing

Launched August 2020



Lipoedema UK Health & Wellbeing Community!

Once a week - Zoom meeting for members

**Sandra, Tess, Joella, Georgina
and our Nurse Consultant Team**



community. Created to provide a mix of serious medical advice, motivational support, exercises and an opportunity for people to 'meet' in a safe and secure environment of like minded people. Our Health and Wellbeing community went from strength to strength during 2020.

Structure & Governance

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 membership so all currently are people living with 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 all fundraising that our members and supporters do. We have celebrated their fundraising on our social media and in our news emails to members. We are always happy to support those who are raising funds for us and awareness of lipoedema. We hope to see this grow further as more people become aware of lipoedema. As lipoedema is a chronic condition that frequently impinges on a patient's earning power, and as there are few NHS resources available, patients are forced to fund their own, often expensive treatments, such as non-cosmetic liposuction. This situation creates financial hardship for many of our members and so many have insufficient funds to donate directly, but many are choosing Lipoedema UK as their charity of preference for indirect funding sources.

Sponsors

Our industry sponsors, who are mainly manufacturers and retailers of compression garments, remain a crucial part of our financing. Their sponsorship is our main source of income and essential to our survival and operation. They also provide links, connections and partnerships on awareness raising and other activities.

Our main sponsors had their own challenges, but maintained the same level of financial support. In addition we have always appreciated their moral support and encouragement when needed.

Review of Accounts

Our financial position is outlined in our attached accounts. 2019 was our first full year following our incorporation as a CIO in December 2018.

Activities in prior years are captured in the accounts of the unincorporated charity Lipoedema UK, registered charity number 1157716.

Following our incorporation, the funds remaining in Lipoedema UK, registered charity number 1157716 were transferred to the control of this CIO, as reflected in the accounts. That one-off transfer accounted for £11,794 of our 2019 income and so the “true” income for that year was closer to £50k than £60k. As such, the comparable decrease in income was around £12k when comparing 2020 to 2019.

The main reason for the decrease in income was the lack of sponsorship and donations, which was around £11k. We did not hold a face to face conference in 2020 and anticipate that doing so would have brought in that additional sponsorship/donations from exhibitors at the conference. Our conferences are not a profit making activity so if we had received that additional income we would have expected an increase in expenditure to run the conference.

Whilst in 2019 we held a very simple conference/AGM, we did attend far more events with healthcare professionals. The lack of these events in 2020 meant that we spent around £11k less by not attending these, not incurring costs to attend and exhibit at events, nor to produce materials to give away to healthcare professionals at these events.

We continued to invest a comparable amount year on year in supporting our members and responding to enquiries from healthcare professionals as these kept coming in.

We held a relatively simple members meeting alongside the AGM of the unincorporated Lipoedema UK. We did not apportion costs between the two charities as the costs were nominal and separate events would have been more costly.

Our spend on technology was significantly reduced from our 2019 website expenditure, whilst remaining an important part of enabling our awareness raising and supporting our members.

We wish to further increase our income in the future, 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 challenging as the opportunities for our participation challenge our resources available.

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

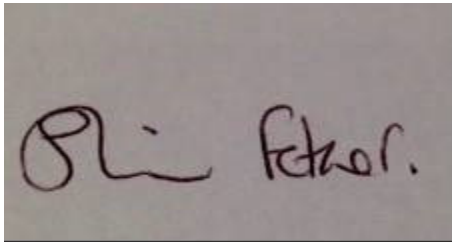
A Charitable Incorporated Organisation Number 1181312

Accounts

31 December 2020

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
26 June 2021

Lipoedema UK
Income and Expenditure Account
for the year ended 31 December 2020

| | 2020 | 2019 |
|--|---------------|---------------|
| | £ | £ |
| Income | | |
| Sponsorship & Donations | 26,205 | 37,656 |
| Conference and Exhibitor payment | - | 315 |
| Membership | 10,951 | 9,895 |
| Donations Being transfer from Lipoedema UK 1157716 | - | 11,794 |
| Publications | - | 1,302 |
| | <u>37,156</u> | <u>60,962</u> |
| Expenses | | |
| Design and Print | 1,555 | 2,400 |
| Administration Expenses | 533 | 3,188 |
| Conference and AGM | 2,070 | 855 |
| Healthcare Professional Awareness Events | 3,877 | 15,573 |
| Membership and Healthcare Professional Support | 12,903 | 11,978 |
| CRM & IT Systems | 5,841 | 4,277 |
| Website | 5,994 | 12,527 |
| Accountancy, Insurance and other professional fees | 827 | 1,374 |
| | <u>33,600</u> | <u>52,172</u> |
| Surplus | <u>3,556</u> | <u>8,790</u> |

Lipoedema UK
Balance Sheet
as at 31 December 2020

| | 2020 | 2019 |
|---|---------------|--------------|
| | £ | £ |
| Assets | | |
| Bank/building society balances | 17,582 | 9,191 |
| | <u>17,582</u> | <u>9,191</u> |
| Liabilities | | |
| Other liabilities and accruals | 5,235 | 400 |
| | <u>5,235</u> | <u>400</u> |
| | <u>12,347</u> | <u>8,791</u> |
| Net business assets represented by | | |
| Capital account: | | |
| Balance at start of period | 8,791 | - |
| Net Surplus | 3,556 | 8,791 |
| | <u>12,347</u> | <u>8,791</u> |

Lipoedema UK
Notes to the Accounts
for the year ended 31 December 2020

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

Charitable Incorporated Organisation Number 1181312

I report on the accounts of the charity for the year ended 31st December 2020, 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

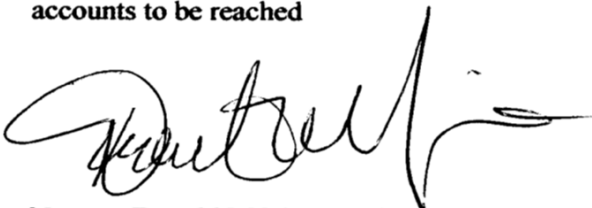
In connection with my examination, no matter has come to my attention:

(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

28th June 2021

Lipoedema UK

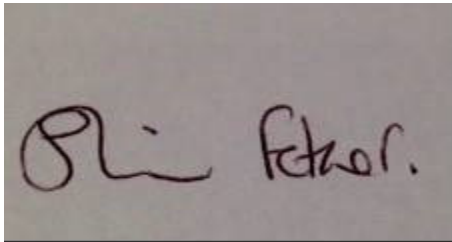
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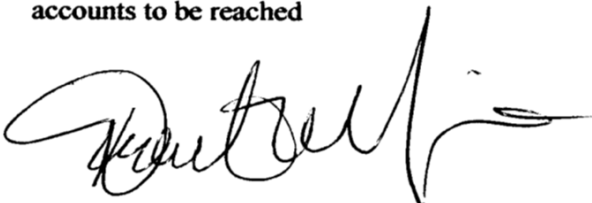
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