



INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

Focus
Document

A document in partnership with

LSN

THE LYMPHOEDEMA
SUPPORT NETWORK

because lymphoedema matters

ELEMENTS OF AN EFFECTIVE NATIONAL PATIENT ORGANISATION THE LYMPHOEDEMA SUPPORT NETWORK

The Lymphoedema Support Network has grown from a local group of seven individuals to a national charity. It is widely acknowledged to be the largest provider of information on lymphoedema in the country, and is the voice of the lymphoedema patient in the United Kingdom.

www.lymphoedema.org

www.lympho.org

Belong



Together



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1. Introduction

The LSN was asked to write our 'story' to inform and encourage international groups within the ILF community. This is not to imply that we know it all, always get it right or that we have completed our work, as none of these things is true. But what is true is that the hard work, dedication and expertise of everyone involved in the organisation since it began in 1991 has seen the LSN grow from a group of seven members with big ideas, to the UK's leading lymphoedema charity, still with big ideas! This is a précis of our work and a more complete record of how we have reached this point can be found on our website. We have tried to be true to the history and the heart of the organisation, but space limitations mean that there are pieces, events and people missing. We sincerely apologise, but would like formally to thank all those who have served the LSN, in any capacity, or who have supported us, over the past nineteen years, as we would literally not be where we are today without them.



Anita Wallace
LSN Chair



Karen Friett
LSN Chief Executive

The LSN team

Introduction



Professor Peter Mortimer

Message from Professor Peter Mortimer, Lymphoedema Support Network's Chief Medical Advisor

“In my view, the LSN is the best thing to have happened to lymphoedema and its management in the UK in the last twenty years. The introduction of Decongestive Lymphatic Therapy in the early 1980's created the opportunity for a structured approach to treatment but was hampered by a lack of awareness and a lack of acceptance for a treatment that did not use drug or surgical therapy. The founding of the LSN changed that. Through its campaigns and canvassing of politicians and commissioners, the NHS had to listen. Progress has been made through the skilful and targeted policies of the LSN in a way that would not have been possible by NHS professionals alone. The production of fact sheets has not just educated patients but professionals as well. The LSN provides patients with an information resource that gives them direction and hope.”



2. The Lymphoedema Support Network

“In the beginning, we certainly never hoped or expected such success on so many different levels.”

*Founder member,
Kathleen Harvey*

The first meeting of the LSN took place in 1991, instigated by Eunice Jeffs and Sian Thomason, lymphoedema specialist nurses at The Royal Marsden Hospital (RMH) in London and was attended by just seven people. Sally Harrison was elected chair, and a desk and filing cabinet in the RMH Appeal office became the first LSN office. By February 1993, the LSN had a formal Board of Trustees, obtained charitable status, 150 members, had held its first Annual General Meeting and had published its first newsletter. As the years passed, local groups were established, fact sheets produced, newsletters printed and members recruited. Talks about the condition were given across the length and breadth of the country and partnerships formed with industry, professional bodies and other charities. The aims and objectives of the group were constantly reviewed to reflect the needs of the membership and eventually staff were appointed and offices established. Today the LSN is recognised as the largest provider of information on lymphoedema in the United Kingdom. Despite a growing reputation and sphere of influence, those seven original members would still recognise the LSN, as it remains true to their aims of being an organisation run by lymphoedema patients for lymphoedema patients.

GROWING MEMBERSHIP

Our first meeting was attended by just seven individuals. Growing the organisation to 3,600 members was no simple task. Early members spent hours making posters and visiting surgeries, but it took nearly two years to reach 100 members. The LSN website helped support an increase of between 150 and 250 new members each year, reaching 1,000 in 1999. Fact sheet production raised our profile and, our

“I became a member of the LSN and look upon it as a safety net.”

The Lymphoedema Support Network

two thousand and first member was recruited in 2001.

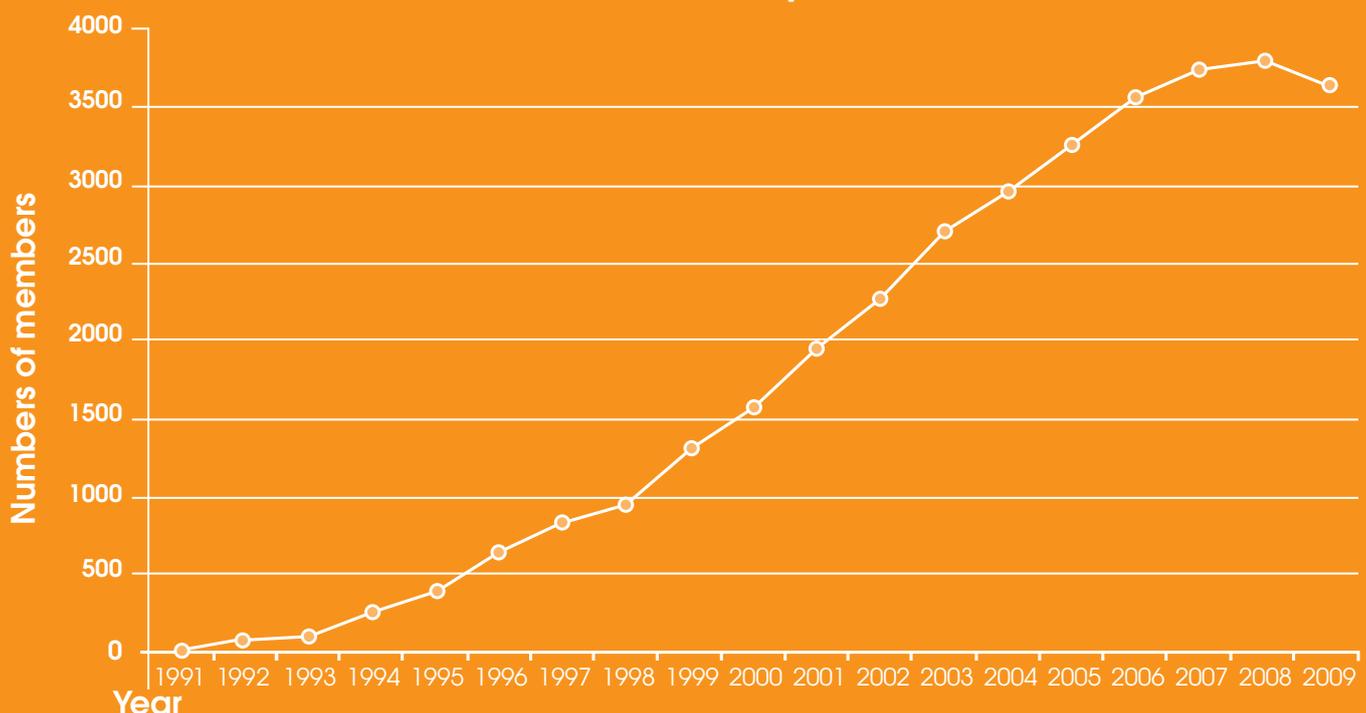
Many members are elderly or ill and inevitably we lose significant numbers each year. So, we not only have to grow our membership, but also maintain it. We use personalised renewal letters and reminders; integrated membership forms on fact sheets; posters in UK clinics; media opportunities; work with the British Lymphoedema Society (BLS); and the LSN website. This allows us to replace those members unable to maintain their membership and recruit a further 300 individuals every year.

The present financial climate has had an impact on the UK charity sector and we have noted an increase in those discontinuing their membership. This has led to the first ever year-on-year decline in membership. Although it is only a small number, we are, and will continue, to do all we can to reverse this.

Growing Membership

- It takes time to build up membership – be patient
- Use all tools at your disposal
- Protect people’s personal information

Membership



The Lymphoedema Support Network

MANAGING THE ORGANISATION

Initially managed solely by Trustees, it was decided that there would be advantages in registering the LSN as a charity. To do this, the organisation had to write a constitution, formally appoint Trustees, submit annual accounts to the Charity Commission and hold an Annual General Meeting. In March 1993, the LSN was registered as a charity in the UK. The LSN continued to grow in influence and efficacy, and in 1996 became an employer, necessitating formal contracts. The Big Lottery Fund grant application meant that the organisation was put under the microscope in terms of management as it only offered grants to organisations 'that are managed in such a way as to be lawful and promote sustainability'. The fact that the LSN received a grant is testament to what has been achieved. There are now routine strategic planning meetings, business plans, budgets and written policies and procedures reflecting key work. This allows us to optimise efficiency and provides checks and balances for what we do. Effective management is often not seen as a priority among busy work schedules, but not taking the time to ensure that an organisation is being run to best effect is short sighted and potentially dangerous. Weak governance can leave small organisations open to litigation, misuse of funds, inefficiency and ultimately discontinuation. The Trustees and staff of the LSN take this role seriously.

Managing the organisation

- Ensure your organisation works within legal and charity law guidelines
- Keep accurate records of all meetings
- Protect your organisation from risk by putting formal policies and procedures in place
- Respect the roles, talents and experiences of all members of your team

“As the National Clinical Director for Cancer, I am very aware of the need for condition specific support groups such as the Lymphoedema Support Network. They provide a level of individual support to patients and those affected by lymphoedema which can only enhance the care given by healthcare professionals. We are delighted that the LSN has allowed several of its fact sheets to be made widely available through the National Cancer Information Pathways and value its involvement in the National Cancer Survivorship initiative.”

Professor Sir Mike Richards, UK National Cancer Director

PARTNERSHIP WORKING

The LSN has developed many positive partnerships to achieve its aims and to support the work of others. For the 'Lymphoedema Families' research in 1993, research geneticists needed twenty families affected by lymphoedema, so the LSN advertised the study and liaised with participating families. The research led directly to the discovery of the gene responsible for Milroy's disease. As the LSN became recognised as the voice of the lymphoedema patient, more calls were made on it, including in 1997 writing

The Lymphoedema Support Network

a patient experience chapter in a lymphoedema book for healthcare professionals.

We continue to create positive partnerships in a National Health Service (NHS) where the patient voice is valued. The LSN is an organisation that gets things done, is realistic and proactive, and has a professional approach to all that we do. We are confident of the patient's right to influence services, policy and product development. We know what we want to achieve, how to achieve it and whose help we will need. Some partnerships are short-term and project based, others longer term, but all have specific strategic and operational objectives, and are based on agreed outcomes and honest communication. There are limitations to what we can, or should, try to achieve on our own and we value our partners and hope that they feel that working with us has furthered their objectives as well as supporting ours.

Partnership working

- Value the input you bring as an 'expert' patient
- Behave professionally at all times
- Seek out partnerships that benefit both organisations
- Don't be afraid to say no if it is not right for your organisation

The International Lymphoedema Framework

In 2000, the LSN become partners with the ILF in a piece of research to look at the prevalence and patient experience of lymphoedema. This partnership proved so successful that it was continued, leading to lymphoedema garments being available on prescription in the UK and two international lymphoedema conferences at which there has been concurrent patient conferences.

The British Lymphology Society

The BLS is a pivotal group in the UK. Last year, the BLS ran a lymphoedema awareness campaign and the LSN was happy to support them by taking telephone calls from members of the public resulting from magazine articles, etc. Many BLS members are instrumental in our fact sheet production. We will soon be producing joint information for healthcare practitioners on the LSN and BLS websites.

Leeds Lymphoedema Service

The LSN has worked with the Leeds Lymphoedema Service on the development and production of its 'How to manage your lymphoedema' DVDs. Both groups did a great deal of work on the project and both benefited in terms of kudos and a shared profit scheme.

The National Cancer Action Team

This Department of Health group, led by the UK's National Cancer Director, created information pathways to ensure that all those who receive a cancer diagnosis in the UK receive the correct information at the correct time. As a result of our work with this group, 11 LSN fact sheets are now available on the cancer network pathways, meaning that every patient in the UK who has treatment for a variety of cancers receives information about lymphoedema and risk reduction. It has also raised our profile in the Department of Health and sees us treated as equals alongside the major UK cancer charities.

3. Provision of information

FACT SHEETS

The production of quality information has always formed a large part of the work of the LSN. Our first fact sheets were produced in the late 1990s and became an invaluable resource. This work continues to be one of the cornerstones of our organisation; twenty-two fact sheets are now available, of which, 50,000 are purchased by hospitals, clinics, practitioners and hospices throughout the UK each year. In order to ensure that the information we provide is accurate and appropriate, a rigorous process is followed.

It takes sensitive editing and up to ten drafts to get each fact sheet right, particularly as some healthcare professionals find writing for patients challenging. We pay no fees to contributors but most consider being asked a professional compliment. All contributors are acknowledged and information is dated, includes our charity number and

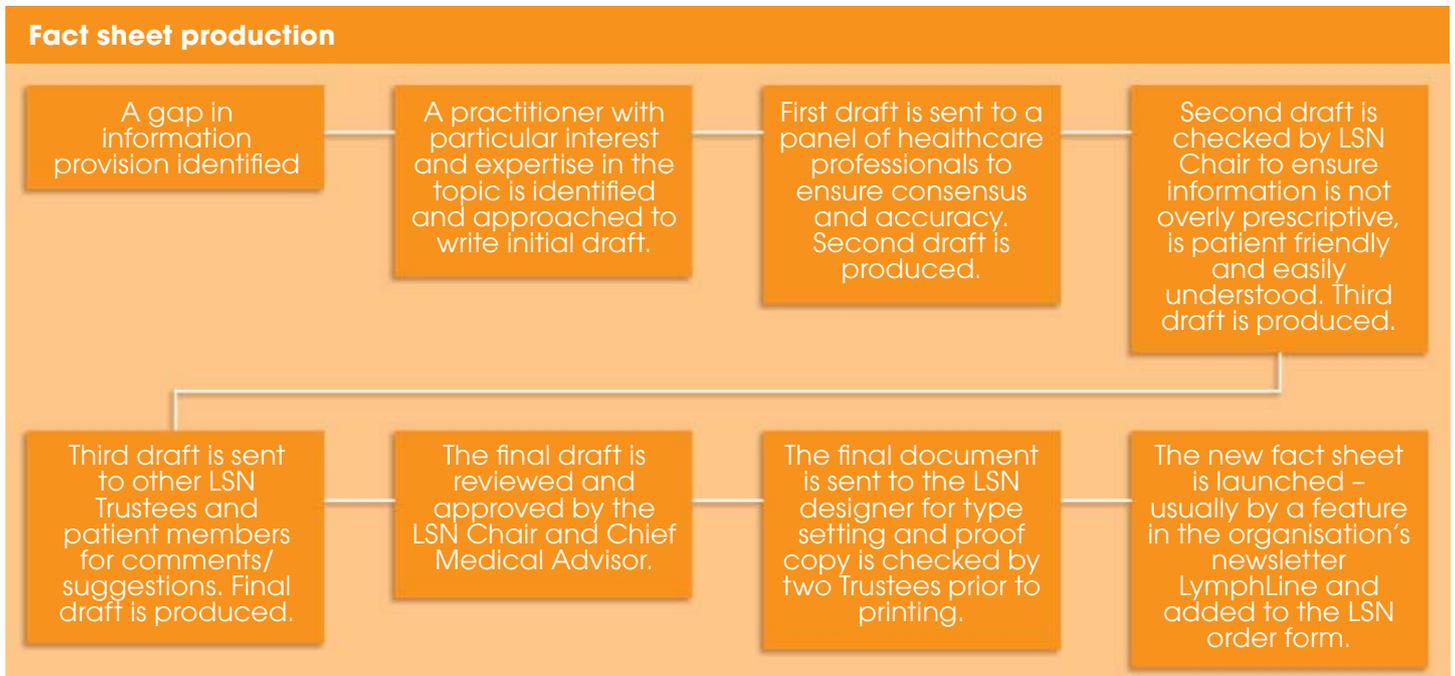
a membership application form. Information is reviewed and updated regularly. The LSN is constantly looking to develop our fact sheets and it seems that the more we produce, the more gaps are identified and the higher the quality expectation. We value the reputation we have built up and acknowledge that this is only possible because of the collaborative working between the healthcare professionals who write for us, our medical and nursing advisors, the LSN Chair, Trustees and members.

Fact sheets

- Always work with healthcare professionals
- Ensure the patient perspective is included
- Develop a relationship with key professionals



Provision of information



LYMPHLINE NEWSLETTER

'LymphLine' was first produced in 1993 and by 1997 there were four editions a year. LymphLine reaches patients and healthcare professionals and keeps members informed of our work. Content, quality and balance are managed by LSN Chair (Editor) and Trustee (Assistant Editor). A grant from medi UK covers a percentage of the publication costs of our twelve page, gloss finished magazine, with four colour pages. Articles reflect current issues, information about research studies, treatment developments, patient experience stories, fundraising events, support group news, tips and hints and news about LSN fact sheets or other merchandise. Some advertisements are included in LymphLine partly to generate income to cover production costs and also to keep members informed of current lymphoedema garments and other products. Information is accurate and of a high standard and has led to authors being keen to be asked

Newsletter

- Try to get a balance between advertising space, editorial and articles
- Do not be afraid to edit articles
- Allow plenty of time to source articles

Provision of information

“I find your newsletter a great comfort in what can sometimes be a very lonely and frightening condition.”

to write for what is seen as a prestigious publication. The LSN does not commission articles and does not pay author fees. LymphLine is currently distributed to 4,000 individuals and groups. The mail-out of the newsletter is organised by the LSN and a team of volunteers.

An electronic index of all articles printed in LymphLine is maintained at the LSN office and selected articles are published on the LSN website.

VIDEO/DVDS

“I think the DVD is brilliant – informative and understanding and hits just the right note.”

The first LSN video was produced with support from MLD^{UK} and demonstrated exercises and deep breathing. Little funding was available and whilst of use, it had limitations. Some years later Dr Jacqui Todd from the Leeds Lymphoedema Service and the LSN worked together to produce two videos, one for upper and one for lower limb patients, covering all aspects of self-management. The project was jointly funded and intended to supplement information already provided by clinics, although for those people not currently receiving care, how and when to use the activities was made clear, as was the fact that some people should not use the video without first seeking medical advice.

In 2008, the LSN and Jacqui Todd worked in partnership on new DVDs. Jacqui secured some funding from Macmillan Cancer Support and the preparation, filming and editing process took 18 months. Two DVDs were produced, one for arms and the other legs. LSN members demonstrated exercise, compression garments, simple lymphatic drainage (SLD) and skin care and recorded their experiences of adjusting to life with lymphoedema. These DVDs contain more information and include perspectives about the condition from Professors Mortimer and Moffatt. The LSN Patron, actor, Zoë Wanamaker CBE, gifted her time to carry out the voice-over. The DVDs have been universally well received by patients and healthcare professionals.

DVD

- Work with a healthcare professional that you trust
- Use people who really have the condition not models
- Producing a DVD is expensive, try to obtain funding for the project

Provision of information

Website

Technology is a vital information tool and one which the LSN utilises to reach a wider audience. In 1996, the first LSN website was set up and included information about the condition, the LSN, news and articles. In 2001, useful links to other organisations and related charities were added.

The LSN website continues to develop and is very well visited with over 2,500 hits each month. The information is categorised to help people find what they need quickly and includes medical articles, lipoedema, campaigning and advocacy, support group information, useful links and merchandise. All medical articles are checked by our medical advisor. Members value the patient experience section as a way for individuals to share the impact lymphoedema has on their lives and we encourage people to be honest about their challenges and successes. We are fortunate to have a Trustee who has the skills to maintain our website at no cost to the organisation, so we are able to ensure the contents are kept current and responsive.

A new LSN website is currently being designed and built as a gift to the organisation. It will include more information and give a truer representation of the dynamism of the organisation; some new features include the ability to make payments and donations online and comprehensive information specifically aimed at healthcare professionals.

Website

- Retain control of the website
- Make sure the information on your website is accurate and regularly updated

The screenshot shows the LSN website homepage. At the top left is the LSN logo with the text 'THE LYMPHOEDEMA SUPPORT NETWORK'. To the right is a 'Donate online' button and a 'Winner' badge. Below the logo is a navigation menu with links: HOME, ABOUT THE LSN, LIVING WITH LYMPHOEDEMA, LYMPHOEDEMA, INFORMATION FOR DOCTORS AND HEALTH CARE PROFESSIONALS, SHOP, SUPPORT US, and CONTACT US. The main content area starts with a welcome message: 'Welcome to the Lymphoedema Support Network website. If you have developed lymphoedema, you are not alone; it is estimated that well over 100,000 men, women and children in the UK are living with the condition. Although lymphoedema is a long term condition, with the right information, support and treatment there is much that can be done to improve both swelling and other symptoms.' This is followed by a paragraph about the LSN as a registered charity. Below this is a 'NEWS' section with three articles, each with a small image and a 'READ MORE >' link:

- Common sense rules at the RCoA**
By Karen Friett, LSN Chief Executive... READ MORE >
- £1 million New Funding for Lymphoedema Research**
By Dr Anthony Stanton & Professor Peter Mortimer... READ MORE >
- 'Lymphoedema Matters'**
Ribbons and wristbands launched... READ MORE >

4. Individual support

INFORMATION AND SUPPORT LINE

“When I telephoned the LSN there were no platitudes, thank goodness, just genuine help – invaluable.”

Being run by those living with lymphoedema means that the LSN appreciates how challenging it can be to learn you have a lifelong condition and that your body will never be the same. Meetings and written information are helpful but there are times when people need access to someone who understands. Initially, LSN members shared their telephone numbers so those interested in joining could access information, but soon, some were providing much more. There was a need for a telephone support line and for many years several people generously volunteered their time, expertise and home telephone numbers to man this service. Eventually, when the organisation had grown significantly, the telephone information and support line was run from the office and it continues to be an enormous source of support and information for those calling. It can be a difficult and challenging job dealing with callers who may be distressed, angry or frightened and it is vital that they understand we are unable to give medical advice. Often what people require is information about clinics or how to get an accurate diagnosis, but sometimes it is the opportunity to talk to someone who understands.

We have also written and produced a comprehensive information pack which we send out free of charge to callers which contains information about the condition and treatment options and the type of information the LSN can provide.



Information & support telephone line

- Never offer advice you are not trained in or qualified to dispense
- Have useful telephone numbers close to hand
- Protect the emotional health of those manning the line

Individual support

LOCAL SUPPORT GROUPS

The LSN began as a group meeting in London, but there was also a need for support for those in other areas of the country. Whilst the LSN ran its telephone support and information line, this was not the same as meeting with others with lymphoedema. Some people decided to start their own local groups and the LSN supported the initiative by producing 'how to' information. Each local group had their own team prepared to organise meetings and manage the money as well as access to a local healthcare professional. Trustees from the LSN spent many hours travelling to meetings explaining the practicalities and the boundaries of information sharing amongst patients. Some of these groups never got off the ground, wanting a level of support from the LSN that was just not possible, while others flourished, having monthly meetings, visiting speakers, social activities and fundraising events.

There are currently 67 local lymphoedema support groups across the UK. They remain very individual with some even carrying out fantastic fundraising events that raise enough money to support their clinics. The LSN continues to produce information on how to start a group and maintains a database so we can signpost new members to groups. The LSN values the individual support local groups are able to offer patients and will continue to promote their development and worth.

Local support groups

- Produce 'how to' written guidance
- Keep a database of groups and contact details
- Accept and embrace individuality

5. Income generation

CORPORATE SPONSORSHIP

Compression garments are manufactured by a few companies in the UK. The LSN realises the potential of working with industry to ensure that patients can influence product development and we can obtain funding for our work. It began with medi UK in 1997, who gifted an educational grant to sponsor our newsletter, LymphLine. As the LSN has grown, we have developed and formalised our corporate relationships as we need predictable income and access to key people in companies, our members need to be kept apprised of new products/developments and have a way of feeding back to product manufacturers, and companies need to demonstrate they are working with users and potentially have access to focus groups.

We currently have seven corporate sponsors, Activa Healthcare, BSN medical, Cosyfeet, Haddenham Healthcare, Juzo UK, medi UK, and Sigvaris and more are contacting us. Companies pay a fixed fee annually, allowing them a half page advertisement plus a 500 word advertorial in LymphLine, reciprocal website links and opportunities to sponsor our AGM and other events. We will continue to explore ways of working with industry that will benefit all, whilst being very aware that our reputation for professionalism has taken hard work to develop, and strict management of who we are associated with, regardless of the financial temptations involved, will continue to be a priority.

Corporate sponsorship

- Start small, seek funding for specific projects and build up to a corporate membership scheme
- Ensure both parties benefit
- Don't get greedy
- Develop professional relationships with key individuals

Income generation

RAISING FUNDS

The LSN receives no statutory funding; originally costs were small but grew as the charity did. Income was raised from subscriptions, donations and small grants from trusts. It was a constant challenge and most work had to be done on a shoestring. Needing funds as our work increased and diversified, the LSN began ambitious plans to apply for lottery funding but were twice turned down. Eventually, in 2004, with the help of a professional fundraiser we successfully obtained a substantial grant from the Big Lottery Fund.

Managing our finances is a constant balancing act and whilst we remain dependent on subscriptions and donations, we now also raise income from corporate sponsorship, the sale of our information to specialist services and merchandise sales. We fund special projects from grant making trusts or restricted donations but such applications can be time consuming.

The LSN does not hold large fundraising events, as a small national charity, we do not have the manpower to do so and our supporters are spread across the UK. We produce a fundraising information pack for those wishing to hold events for us and are increasing opportunities to donate to us through our own website and online giving schemes. Occasional income from legacies is an added bonus, but cannot be relied on and the LSN remains as dependent on the generosity and loyalty of our members as we were at our inception.

Fundraising

- Persevere
- Balance spending with your ability to raise income
- Respect donations of all sizes, every penny counts

“I think for the subscription we pay each year we certainly get good value for money.”



6. Conclusion

- **Persevere** – it has taken us nineteen years to this point and we still have a long way to go.
- **Be realistic** – set goals that can be achieved and then aim just a bit higher.
- **Get the team right** – you need a balance of pragmatists and dreamers, those with specific skills and those who have the time and energy to dedicate to the cause.
- **Get the name right** – it will be with your organisation for life and should reflect the purpose of your organisation.
- **Work with partners** – we cannot be experts in everything, so find others who are, and work with them.
- **Be professional** – treat others with the respect you would like to receive whether they be a professor, clinical nurse specialist, company chief executive, patient or member of the public.
- **Do the boring stuff** – keep accurate accounts, comply with charity law, write policies and procedures. If you fall down on these you will not be able to continue your work, no matter how important it is.
- **Keep a sense of perspective and your sense of humour** – you will not get it right all the time and will never be able to please everyone. Remember that you at least are doing something positive, learn from your mistakes, minimise the damage and move on. Take pride in your achievements and remember to share a laugh when you can.



“ Since 1912 **Juzo** has understood that helping is a life long task, this together with constant improvement fuelled by technological advances ensures that our patients remain at the centre of our work and can rely on us for high quality, constantly improving garments. We share the LSN’s passion for empowering patients and are delighted to work with them to achieve this. ”

“ **BSN medical** is a global leader in compression therapy and we are committed to the development of world class products that offer high quality solutions for those living with lymphoedema. Our relationship with the LSN allows us to ensure we are listening to our customers in the UK and continue to respond to their needs. ”

“ **Sigvaris** has 150 years of expertise producing medical compression garments and this longevity and our reputation have been achieved, in no small part, through long term reliable customer relationships and collaborative partnerships. We value our relationship with the LSN and its membership and there is no doubt that they have enabled us to understand the issues affecting people with Lymphoedema which in turn has helped us in our mission to be the first choice for lymphoedema patients in the UK. ”

“ **Haddenham Healthcare** prides itself on our central values of caring, sharing and learning, we are passionate about the markets we serve and are innovative and responsive. We aim to make a positive contribution to the lives of people living with lymphoedema and consider our relationship with the LSN an important part of doing that. We are pleased to support them and know that our continuing relationship will ensure that those living with lymphoedema will continue to be at the centre of our work. ”

“ **Activa Healthcare** places the needs of the patients and health care professionals as its number one priority. By responding to what they require Activa aims to provide the best possible treatment and comfort options. To achieve this constant communication with our customers is vital and our relationship with the LSN is one which ensures we stay in touch with our users whilst being able to support the valuable work of the LSN. ”

“ **Medi UK** prides itself on producing a wide range of top class products. To achieve this it is vital that we work with clinicians and patients to produce garments which combine maximum efficacy with comfort and optimal appearance. We very much value our relationship with the Lymphoedema Support Network which allows direct access to our customers through a trusted, respected and realistic organization. This partnership benefits patients living with lymphoedema and will continue to do so in the future. ”



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The ILF Objective :

To improve the management of lymphoedema and related disorders worldwide

- To increase **awareness** by raising the profile of lymphoedema.
- To increase **knowledge** about lymphoedema by initiating and/or contributing to **Research Programmes**.
- To **disseminate** this knowledge by implementing an **international, not-for-profit, publications strategy**.
- To increase **understanding** of lymphoedema and its management by creating and/or contributing to the development of **Education Programmes**.
- To provide a cross cultural networking platform through an **Annual International Event** where all stakeholders will have the opportunity to contribute and influence the ILF agenda.
- To promote and document Best Practice with the development of an **International Minimum Dataset**.
- To facilitate and/or contribute to better **access to treatment** for patients worldwide.
- To promote and **support initiatives** whose goals are to improve the national/regional/local management of lymphoedema anywhere in the world.
- To help the Healthcare Industry understand the **real needs** of patients and practitioners, and develop and evaluate improved diagnostic tools and treatments.

