INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

National Lymphoedema Framework
Annual Reports June 2019 – November 2021

Contents

Our Mission: To improve the management of lymphedema and related disorders in the United States while contributing to global international advancement. This mission is being achieved by defining best practices of lymphedema management and developing a minimum data set to improve lymphedema outcomes. The ALFP is establishing a leadership role in lymphedema risk reduction, treatment, education, health policy, and research. These outcomes are achieved through a partnership among all lymphedema stakeholders, including patients, healthcare professionals, researchers, industry representatives, and third-party payers.

Dr. Kathleen Francis and Dr. Electra Paskett are representing the ALFP at the framework pre-conference day and presenting at the November 2021 ILF conference with a keynote, a panel presentation, and 2 research posters on behalf of the ALFP team.

The ALFP has collaborated with the ILF and other national frameworks in the dissemination of survey links to potential participants in the U.S. We have participated in the recruitment, data collection and analysis, and dissemination of the ILF-COM study findings. We presented a poster in Chicago at ILF, will present a panel paper at the ILF in Copenhagen, and have a manuscript in press at *Journal of Lymphedema*.

Three original ALFP steering committee members are now ex officio (Dr. Janice Cormier, Dr. Bob Stewart, and Ms. Bonnie Lasinski). Sadly, we lost Ms. Kim Andrews to pancreatic cancer in 2020.

In 2021, the ALFP awarded a postdoctoral fellowship to Elizabeth Anderson, PhD, MSN(Ed), RN, CLT, who has studied return-to-work and lymphedema self-management among Latina/Hispanic U.S. women treated for breast cancer. The post-doctoral position at University of Missouri Sinclair School of Nursing (mentored by Dr. Jane Armer) will continue for 1 year, after which Elizabeth will transition to a full-time faculty position.

ALFP steering committee members led (Armer) and participated (Fu, Beck, Lasinski) in the published 2020 Oncology Nursing Society guideline development for cancer-related lymphedema (*ONF* and *CJON*).

Among the lymphedema/lymphology organizations, the ALFP (alfp.com) has uniquely partnered with Sosido, an online knowledge exchange network for professional healthcare associations, creating community around research and practice knowledge (sosido.com). Using selected search terms specific to our field, more than 1000 peer-reviewed articles have been retrieved for weekly email digests curated for clinicians, educators, and researchers in the lymphedema field who are ALFP-Sosido members and followers. Since the ALFP-Sosido partnership launched on October 21, 2015, this weekly digest has posted 337 publications (co)authored by ALFP steering committee members; 1,233 publications authored by ALFP members (including Steering Committee member publications); 1,532 new publications on the topic of lymphedema pulled from across all journals indexed on PubMed (the "ALFP Scan"); and 547 publications from lymphedema-specific journals (*Lymphatic Research and Biology*, *Lymphology*, and the *Journal of Lymphoedema*). Interested persons may join to receive the curated publication list by completing the form at: (1) the Sosido signup form on the ALFP site: https://www.alfp.org/sosido/ or (2) going through the Sosido signup form: http://blog.sosido.com/join-sosido/ (in the form, one will be asked which group on Sosido s/he is interested in joining - ALFP is one of the options). The Sosido partnership is now fully supported by ALFP. Opportunity for financial partnership with ILF and the other national frameworks is open for discussion.

sosido

www.alfp.org

Respectfully submitted,

Jane M Armer

Jane M. Armer, PhD, RN, CLT, FAAN, ALFP Founding Director, and ALFP Steering Committee 11/17/2021

The **Belgian Lymphoedema Framework**, or **BeLymph**, is a sub-organization under the recognized International Lymphoedema Framework with its own legal status signed with a notarial deed. BeLymph is nationally acknowledged by the Health Organization (INAMI – RIZIV) and has been involved in discussions around the criteria to achieve in the centers of expertise.

The purpose of BeLymph is to educate patients with lymphoedema and their health care providers about the optimal treatment of lymphoedema. This information is based on most recent scientific, clinical and technical knowledge in the domain of lymphology.

It speaks for itself that safety, health and quality of life of the patients are central.

Organigram of BeLymph

BeLymph consists of the Board of Directors and four Advisory Boards and has two types of members, i.e. full members and supporting members.

The Board of Directors consists of a president, vice-president, treasurer, secretary and the presidents of the four Advisory Boards. They meet at least six times a year.

The four advisory Boards are the patient board, scientific board, clinical board and technical board. The patient, scientific and clinical board consists each of a president, vice-president, secretary and a maximum of four members. The technical board consists of a president, vice-president, a secretary and a non-limited number of members. They meet at least four times a year.

The full members have an executive function in the Board of Directors and/ or in one of the four Advisory Boards. The supporting members of BeLymph are patients, medical doctors, physical therapists, nurses and other health professionals or persons / parties interested in lymphology. Supporting members do not have an executive function in BeLymph. They receive information about diagnosis, evaluation, prevention and treatment of lymphoedema. All persons with interest in the goals of BeLymph and which have paid their contribution may become supporting member.

The General Assembly consists of all full and supporting members and meets at least once a year.

BeLymph has currently more than 500 members among patients, researchers or medical professionals.

On March 25, 2017 the first BeLymph symposium took place in Brussels. In the morning, it was given the floor to clinicians, stakeholders and researchers; the afternoon was devoted to patients.

On October 29, 2017, BeLymph hosted the first National Patient Day for people with lymphoedema.

Others Patient Days were organized locally.

During the aforementioned events, BeLymph benefited from the support of companies in their organization.

BOARD OF DIRECTORS

Dr. Liesbeth Vandermeeren
President of BeLymph

Prof. Dr. Nele Devoogdt
Vice-president of BeLymph

Mrs. Sophie Vankerckhove
Treasurer of BeLymph

Dr. An De Groef
Executive Secretary of BeLymph

Mrs. Mary Coronel

Dr. Sarah Thomis

Mr. Jean-Paul Belgrado

Dr. Jean-Baptiste Valsamis

PATIENTS BOARD

Mrs. Mary Coronel
President Patients Board

CLINICAL BOARD

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President Clinical Board

Dr. Dina Hertens
Vice-president Clinical Board

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Vice-president Scientific Board

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Treasurer of BeLymph

Dra. Hanne Verbelen

Dr. Dina Hertens

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Dr. Jean-Baptiste Valsamis
President Technical Board

Signature

Pr. Jean-Paul Belgrado, PhD

CLF PCL
CANADIAN LYMPHEDEMA FRAMEWORK
PARTENARIAT CANADIEN DU LYMPHOEDÈME

Canadian Lymphedema Framework Report: Summer 2019 – Fall 2021

(Submitted Nov 17 by David Keast (Co-chair) and Anna Kennedy (Board Advisor)

New initiatives

In the midst of uncertain times, the CLF took on two bold **knowledge translation initiatives** (moving research into practice). Partnering with the University of Alberta, the CLF successfully secured a MITACS Accelerate Grant to support hiring a postdoctoral fellow to support two key projects. The first project involved developing an online course titled: *Lymphedema and Chronic Enema Management*. This six-week course follows the trajectory of lymphedema across the lifespan, and includes expert lectures on topics ranging from emerging research to clinical practice. Launched in Spring 2021, over 50 healthcare professionals have so far taken the course.

The second MITACS project involves a national initiative to update the *2002 Canadian Clinical Practice Guidelines* relative to the Diagnosis, Assessment and Management of Breast Cancer Related Lymphedema. The protocol has been accepted for publication in the Canadian Medical Association Journal (CMAJ Open), with work on the guideline update now in process.

Developed surgery position statement for publication thru the *Pathways* magazine.

Produced Physicians Card for distribution to 70,000 physicians and surgeons across Canada through the Canadian Medical Association Journal.

Developed new reciprocal partnerships with Wounds Canada, Journal of Lymphoedema, Australasian Lymphology Association, British Lymphoedema Society and Lymphedema Education & Research Network

Implemented new communication strategy (Social Media, Linked In, Instagram, Twitter) and YouTube videos

Recurring and ongoing projects

Pathways: The magazine continues to be a success with the CLF receiving an Aid to Publishers Grant from the Canadian government to help grow the marketing and distribution of the magazine. New partnerships were established with organizations for reciprocal content and distribution.
HP Toolkit – liaised with other frameworks for reciprocal resource sharing of tools to support clinical practice
Delivered a successful 2019 conference in Toronto, Canada
The 2021 conference is scheduled for Dec 3-4, 2021 as a virtual event and in collaboration with Wounds Canada. We will have 45 speakers representative from the international lymphedema community. Academy Actress Kathy Bates is our Keynote address on Saturday.

Financial sustainability

Strengthened and redesigned industry partnerships for a more all-inclusive and sustainable sponsorship package
Successfully secured several grant opportunities to fund initiatives

- MITACS and University of Alberta joint funding
- Canada Summer Jobs federal program funding for marketing coordinator
- Heritage Grant – Aid to Publishers and Translation grants
- Government subsidy to support operations due to declines in revenue during COVID.

Redesigned affiliate model with provincial associations and subsequent pricing of Pathways and other resources we provide them.

Governance and operations

Transitioned from an Executive Director (Anna Kennedy officially retired) to a more engaged board
Adapted administrative processes to virtual environment (online banking, signature approvals etc.)
Updated CLF goals and missions document during annual planning meeting

DANSK NETVÆRK FOR LYMFØDEM (DNL)
DANISH LYMPHOEDEMA FRAMEWORK (DLF)

Activities in DLF (Danish lymphoedema framework) since 2019.

Planning of the 10th ILF conference in collaboration with the Danish wound healing society.

A national research project- A national prevalence of children and young (0-30 years) CHILD-LIMPRINT. Running over the next 3 years

Planning of the first one day meeting in 2022 for children and their families.

The VASCERN co-Chair of ePAG pediatric & primary Lymphedema elected to the board of the Danish patient support group DALYFO.

Running of the ILF International outcome measure project ILF-COM.

Partenariat Français
du Lymphoedème

Partenariat Français du Lymphoedème (PFL)

Since the last meeting we have created an integrated pathway for the management of primary and secondary lymphoedema.

This pathway will be experimented in the area of Occitanie and includes patients managed in hospital and followed at the community level. The project is funded by the DGOS - Direction Générale de l'Organisation des Soins according to the article 51 of the french social and healthcare law.

It takes into account the difficulties to access to treatment that the PFL identified during the prospective economic survey Lymphorac (Mercier G et al. PLOS 2018).

If the experiment shows a benefit in the access to treatment and the quality of care, it will be implemented in the whole country.

Best regards,

Isabelle Quéré

Greece Framework update

Dear friends and Framework partners,

This is a brief report from Greece from our team in the University General Hospital Larissa. It is going to be indeed brief because unfortunately not a lot of projects were accomplished during the pandemic.

Our main focus was to find ways to get in contact with patients and health professionals who did not want to visit the hospital. Early in the first months of the pandemic we realized that we stopped receiving new appointment requests and our patients refused to visit for their 6 month check. Most of the patients and especially those struggling with cancer or surviving cancer were afraid of Covid and getting infected while visiting the hospital.

Our first project was “online consulting”. It is divided in three categories a personal chat for patients, a group chat for patients and a personal chat for “lymphoedema prevention in breast cancer” . Patient friendly measuring charts with instructions were sent to each patient so that they can keep a file of their situation and report back to us. Leaflets and booklets were partially changed and distributed on line. We made a video of self bandaging and self management (these were instructions that we used to give face to face).

Our second project was to change the out-patient management protocol. The lymphedema management in the hospital (according to the hospital and goverment guidelines) had to change. The time for each out-patient was to be maximum 15 minutes. And each patient had to be alone in one room. So we introduced all materials that are time saving. And all other components of the management that we could not fit in a “15 minutes session” went on line, video instructions and charts were patients could record what they had been doing.

Our third project was the cooperation with more patient organizations. This became our priority because patients were not afraid of the meetings there. All materials were distributed to more patient organizations. We organized sessions of small number of people in the premises of the patients organizations to inform but also to check for lymphedema patients. We trained as much as possible from volunteers to be our “link partner” for patients in these organizations that showed first signs of lymphoedema.

Our forth project was “open air meetings”. To avoid people coming in the hospital we organized day meetings at the main squares of cities nearby where people can meet with professional get a first impression and be guided in self management or other kind of managements. Other ‘open air meetings” were held in the hospital garden.

Our fifth project was diminish of management cost for the patients. Covid pandemic has left many people with no jobs or with minimum paycheck of 400 euro. More and more patients cannot afford buying the bandaging and stocking materials. The government is not funding any of the materials. So we focused on putting pressure to the government (that what we always do with no result) and on donations. Having some donations of non used or slightly used garments from the “Nij Smellinghe team” in Drachten, Holland we thought about expanding this to a donation campaign for materials that are not needed any more, stockings that were misfit and bandaging materials that someone can buy and send to us for use in patients that are need of treatment but cannot afford one.

All in all these were our project, mostly as University Hospital Larissa Lymphoedema team, less than Greek Framework but the ultimate goal was the same: e-management, open air meetings and donations.

We are really sorry we could not make it to the Framework meeting. Unfortunately due to pandemic measures in our hospital since September all leaves are cancelled and we are not allow to get any days off work.

We will miss you much. Enjoy the time together and keep the good effort.

We would be glad if we could read reports about other countries. That would certainly give us a boost and a new perspective.

Kind regards to all,

On behalf of the Greek Framework Team

Christina Papadopoulou

Lymphoedema Framework National NLF Ireland

NLFI activity June 2019 to date and future plans

2019

October : 9 children with lymphoedema and 34 adults with lymphoedema attended NLFI education day. Together with family members, carers, some health care professionals there was a total number of around 80 participants on the day. The day was financially supported and attended by our partners in industry.

The formal feedback was very positive with participants reporting they were "very satisfied", rates of 92% to 96 % , with all the elements of the day.

November : NLFI supported the ILF Genital Oedema project by circulating the GO questionnaire to the appropriate stakeholders in Ireland.

2020

February : NLFI presentation to Chartered physiotherapists in Oncology and Palliative Care on the structure of ILF and the national frameworks and the work being done by NLFI, nationally and internationally to educate, promote awareness and improve management of Lymphoedema

May : NLFI collaboration with HSE, ISCP, LI, MLDIreland on two documents to support patients during the Covid-19 pandemic :

1. Covid-19 Guidelines for people living with lymphoedema and Lipoedema in Ireland

2. Self-Management Advice for people with pre-existing Lymphoedema during Covid-19 pandemic

July : Childrens QoL Questionnaire circulated by NLFI to appropriate stakeholders to support ILF research on this topic.

2021

January : NLFI meeting with Christine Moffatt to discuss current and future plans.

February : NLFI involvement is Italian Phlebo-Lymphology web congress, with presentations on the Irish perspective of surgical, social, educational and Limprint study findings on this subject.

March : NLFI video to support World Lymphoedema Awareness Day, available for viewing on NLFI and ILF websites and NLFI facebook page

March : NLFI developed Risk Reduction Guidelines, endorsed by Christine Moffatt and Melanie Thomas (copy on display at NLFI desk, ILF Conference 2021)

September : Finalization of the article for publication with Lymphatic Research and Biology - A Snapshot of Lymphoedema in Ireland – Results from LimprintSeptember : Review and comprehensive NLFI feedback of HSE/LNNI produced Risk Reduction guidelines

2022

April : NLFI Symposium/Webinar

2023

International Childrens Camp

ITALIAN
LYMPHOEDEMA
FRAMEWORK

Short summary of ITALF Activities from June 2019 to November 2021

2019

- 18-19 October ITALF National Congress in Naples with over 500 participants
- 11 November Patronage and organization of hearing of experts in Geneva at the WHO for the promotion of research and nosological classification of Lipedema

2020

- 6 March 2020 Message Association to members for World Lymphoedema day
- June Information to members and sympathizers on the management of COVID19
- July 2020 Participation and Patronage on Campus for patients with Lymphedema and Lipedema Viggianello (Basilicata)
- September 2020 Participation and Patronage on Campus for patients with primary Lymphedema and family in Candia Canavese (Piedmont)

2021

- March transformation of the Association Statute
- May Website restructuring with double Italian and English version
- June Fund raising for the Lipedema Project (Anatomical, immunohistochemical, genetic and metabolomic study) lasting three years (25,000 euros / year)
- July Participation with patronage in the Village for patients with lymphedema and lipedema in Viggianello (Basilicata)
- July Parliamentary questioning in collaboration with FAVO (Federation of Voluntary Associations in Oncology) for the homogenization of the services provided to patients throughout the Country by the National Health System
- August signing of an agreement with the University of Ancona and the Magi Genetics Laboratory (Trentino) for the ratification of a three-year study in patients with Lipedema, subsidized by ITALF and Lipedema Italia Onlus (association of patients) at 50% (150,000 euros overall over three years)
- September Participation and Patronage on Campus for patients with primary Lymphedema and family in Candia Canavese (Piemonte)
- 23 September Inclusion by the Italian Ministry of Health of the ITALF Association of scientific societies officially recognized as interlocutors with the Ministry itself
- October Sending first samples of the Lipedema study to the Laboratories
- November Copenhagen Congress and Joint Symposium at the National Congress SIAPAV (Italian Society of Vascular Pathology) between ITALF and SIAPAV on rehabilitation

Continuous organization’s work for the next ITALF national congress in Assisi June 2022

国際リンパ浮腫フレームワーク・ジャパン研究協議会
International Lymphoedema Framework JAPAN

Report from International Lymphoedema Framework Japan

International Lymphoedema Framework Japan celebrated its 10th anniversary in 2020. As a branch of the ILF, we have been participated in important international collaborative projects, developed as an academic organization for chronic edema/lymphoedema in Japan, and fostered young researchers. In the future, we would like to support the creation and implementation of evidence for edema management, the international development of our journal "Lymphoedema Research and Practice", and the international success of young researchers.
We would like to express our sincere gratitude to every one of the ILF!

ILFJ holds an annual academic conference. The academic conferences were held in 2019 (Professor Aya Sato, Fukui Prefecture) and 2021 (Dr. Akitatsu Hayashi, hybrid). In each conference, 100 participants including clinical practitioners and researchers discussed edema management.

The ILFJ Journal "Lymphedema Research and Practice" was published online every year. Among them, as the Best Paper Award, Professor Toyoko Yoshizawa (Japanese Version of the Quality-of-Life Measurement for Limb Lymphoedema: its Reliability and validity. 5: 1-8. , 2017) in 2020, Dr. Misako Dai (Validity of pocket ultrasound device to measure thickness of subcutaneous tissue for improving upper limb lymphoedema assessment. 6: 10-20, 2018) in 2021 were awarded. To commemorate the 10th anniversary of ILFJ, we also published the 10th anniversary special issue. Furthermore, the 10th anniversary award to the ILFJ directors were presented.

As for the International project, two articles of LIMPRINT study were published in Lymphatic Research and Biology (2019, 2021). ILF-COM presented at the International and domestic conferences, then we are currently preparing for publication. The genital lymphoedema project and children's project are proceeding by ILFJ researchers' teams.

Regarding the future plans of ILFJ, we are planning an academic conference in 2022 (Dr. Ayumi Naito) and 2023 (Dr. Misako Dai).

Furthermore, we are also looking for submissions to our journal from overseas!

NLNet
Nederlands Netwerk voor
Lymfoedeem & Lipoedeem

11-11-2021,

As so many events were cancelled due to Covid-19 our NLNet conference was postponed towards 2022.

Instead we focused on:

1. **Information provision**, through webinars (industry), website (information on Covid-19 for lymphoedema patients). We published 4 lymfologica's (NLNet magazine)

2. **Patient advocacy**
   Participating in research projects regarding lymph nodal transplant and LVA shunting (supporting patients' rights, ethical decision making and legal issues)
   Taskforce compression, NLNet was initiator of this initiative regarding the indications and reimbursement of compression materials (compression devices and stockings). This compression module was approved by 'de Zorginstituut Nederland (ZiN)'. This Module will be implemented in 2022 and will be part of the reimbursement strategic vision and planning of all Dutch healthcare insurance companies by 2023

3. **Peer support**
   online virtual meetings (lipoedema, men living with lymphoedema)

We would like to know if any type of research regarding social-economic costs of having lymphoedema as well as lipoedema could be supported and initiated by ILF, using the ICF coding system internationally (core-sets) and describe the outcomes in Quality-adjusted life years (QALYs) and Disability-adjusted life years (DALYs).

Kind regards,

Wouter Hoelen, board member NLNet

Dutch Lymphoedema Framework and Lipoedema Network

LAOSA
Lymphoedema Association
of South Africa

Status Report : South African Framework LAOSA

- **New executive committee** voted in August of 2020; officially took over the reigns in May 2021. The change over highlighted shortcomings in the association and we have been working hard to improve communication with members and grow membership.

- **LAOSA AGM 2021 – Virtual Congress**
  We hosted our first full day annual meeting virtually, after postponing it twice. We had various speakers; surgeons, therapists and patients throughout the day address various lymphoedema topics.

- **LIMPRINT South Africa**
  Our biggest stumbling blocks in getting the study off the ground, are the lack of continuity in the executive committee and ethical clearance. We are hoping to conduct the study in various centers across the country; this means ethical clearance in each province. We seem to have found a solution and are hoping to start collecting data by mid 2022.

- **Patient Advocacy**
  As a NPO we partner with other NPO's particularly in the Breast Cancer and secondary lymphoedema space. We often exhibit at walks, open days and talks to spread the word about lymphoedema. Our association partners with other NPOs to increase awareness of the organization and condition. COVID has put stop to this.

Swiss Lymphoedema Framework

The difficult health situation has further disrupted the development of our association. Very busy with COVID, journalists contacted to promote World Lymphedema Day on March 6, 2020 did not respond more than the WHO.

Regarding this day, we made the choice, at the last minute on March 3, 2020 to reasonably cancel the congress set up on the 6 at the Universitary Hospital Lausanne on this occasion. We made the decision when the start of the first lockdown was set for March 9.
Despite the "paralysis" of all sectors, reorganizations and tension in all areas and especially in health following the pandemic, some projects discussed at our last meeting on November 13, 2019 were nevertheless able to be carried out. I am thinking of our site which has been updated with various new texts on the themes of lymphedema and lipedema and enriched by the brochure on lymphedema from the Swiss Cancer League which has also been put online.

SLF activities 2021 – 2022

We have to try to get the membership of the Swiss Societies of Pediatrics Gynecology and Plastic surgery.

Because March 6, World Lymphedema Day is a Sunday we decided to make Saturday March 5, 2022 a live congress afternoon (2 p.m. --> 5 p.m.) simultaneously at the Winterthur Hospital and at the Universitary Hospital in Lausanne. Dedicated to patients and therapists, with the theme lymphedema given World Lymphedema Day the next day in Lausanne and lymphofluoroscopy in Winterthur.

Didier Tomson
President

LENFÖDEM
DERNEĞİ

ILF-Turkish Lymphedema Framework Activities since June 2019 and Planned Schedule for 2022

Anatolian Lymphedema Association-ALA (Turkish Lymphedema Association)

Since 2019 June, majority of the planned activities of ALA has to be postponed due to the COVID-19 pandemic started in 2019 March.

The Activities Performed between June 2019 - November 2021 are as follows:

1. Just before the pandemic lock-down, ALA executive committee members organized lower extremity lymphedema rehabilitation course, in winter Meeting of Turkish Society of PMR, in Bursa between
2. The members of ALA have been encouraged to attend web-based study about pediatric lymphedema using official web-site [Title of Study: Exploring the Quality of life of children and young people with Lymphedema].
3. A half day Educational Meeting for patients and their families was also conducted in 6th of March 2020, World Lymphedema Awareness Day, by the sponsorhip of Medicana International Ankara Hospital. (before the pandemic lock down in Turkey). General information on skin care, treatment approaches, self-management techniques were undertaken. The questions and expectations of the patients were discussed together with the guidance of lymphedema specialists and other health professionals. Lymphedema exercises has been performed by participants under the guidance of speaker at the end of the meeting. Healthy lymphedema lunch plates and refreshments were served by hospital management and face-to-face communication of patient – physician - physical therapist were provided by ALA. Purple lymphedema bracelets were also given to the patients as a gift and reminder of the “World Lymphedema Day”.
4. The members of ALA have been attended as faculty and/or speaker to web-based conferences of breast surgery, cardiovascular surgery and plastic surgery with topics of lymphedema/phleboedema/ lipedema, during the pandemic.
5. In 2021 6th of March; a web-based meeting for ‘Lymphedema Awareness Day’ was conducted for health professionals and patients. A special program was implemented by ALA.
6. Television program and broadcast announcements were carried out by the president of ALA-Professor Borman on the week of 6th March 2021.

7. The Nigerian patient with lymphedema has been successfully treated in Medicana International Ankara Hospitals and broadcast announcements were carried out by the co-chair of ALA-Professor Ayhan in 13.07.2021. https://www.haberturk.com/fil-hastaligina-yakalanan-nijeryali-kadin-turkiyede-sagligina-kavustu-3132385
8. 4th Annual Symposium of ALA was held face to face in 23 October 2021 in the Campus of Kahramanmaraş Sütçü İmam University with the 120 participants from neighborhood environment (South-east Turkey). Cancer rehabilitation, Lymphedema, Phleboedema, Lipedema were discussed under the headings of lymphatic anatomy and physiology, differential diagnosis, diagnosis, pediatric lymphedema, genital lymphedema, all aspects of treatment including complex decongestive treatment, were all covered in the sessions of this meeting. Local media has announced and published this meeting in their news which helped for the awareness of lymphedema in this area. https://www.ksu.edu.tr/depo/duyuru_belge/Lenfodem_Sempozyumu_ve_Ust_Ekstremite_Lenfodem_Rehabilitasyon_Kursu__2_2110211519365018.pdf, https://www.aksutvhaber.net/kahramanmaras/ksu-lenfodem-sempozyumuna-ev-sahipligi-yapti-h70094.html
9. We supported and donated the bandaging materials and compression garments of poor and needy 6 patients from the budget of ALA in 2020 and 2021.
10. The first textbook about 'Cancer Rehabilitation in Turkey was written and edited by ALA members (in press).

Planned Schedule for 2022

1. The arrangements of the 2nd Lymphedema Congress (16th-18th September 2022, Istanbul) with multidisciplinary and International Participation have begun. Warm-ups are going ahead.
2. We planned to organize a hands-on course for lower extremity in National PRM Meeting which will be held between 9-12 December 2022, in Antalya.
3. For 2022 6th of March; a scientific meeting and a patient conference of "lymphedema awareness day" are planned to be held in Ankara City Hospital, Physical Therapy and Rehabilitation hospital which will be hosted by ALA.
4. A multidisciplinary symposium was planned in lipedema awareness month-June (date will be determined later) which will be hosted by ALA.
5. An agreement study was planned and Turkish translation was made with permission of corresponding author, and website access was provided for dissemination following consensus: European best practice consensus on lipoedema 2020, JWC International Consensus Document, Lipoedema: a paradigm shift and consensus. Journal of Wound Care Consensus Document VOL2; 11, Nov 2020. Delphi round is going ahead and planned to be ended in the first months of 2022.
6. The Pediatric Lymphedema Camp which has been planned for 2020 Spring to 15 children and families, but have to be postponed due to pandemic may again be planned according to the pandemic situations and permissions.
7. An formal application of Erasmus plus project about pediatric lymphedema submitted to The Center for European Union Education and Youth Program (Turkish National Agency) with support of our 5 different partners from EU countries including Denmark, France, Italy, Poland, and UK. Form ID KA220-

ADU-272AB877 Deadline (Brussels Time) 20 May 2021 12:00:00. The results and acceptance are eagerly waiting.

LYMPHOEDEMA NETWORK WALES

Annual Report 2020/2021

GIG CYMRU NHS WALES

Rhwydwaith Lymffoedema Cymru
Lymphoedema Network Wales

WHAT WE STAND FOR

Purpose

Together, improve wellbeing & healthcare for all

Ambition

Better health, better care, better lives

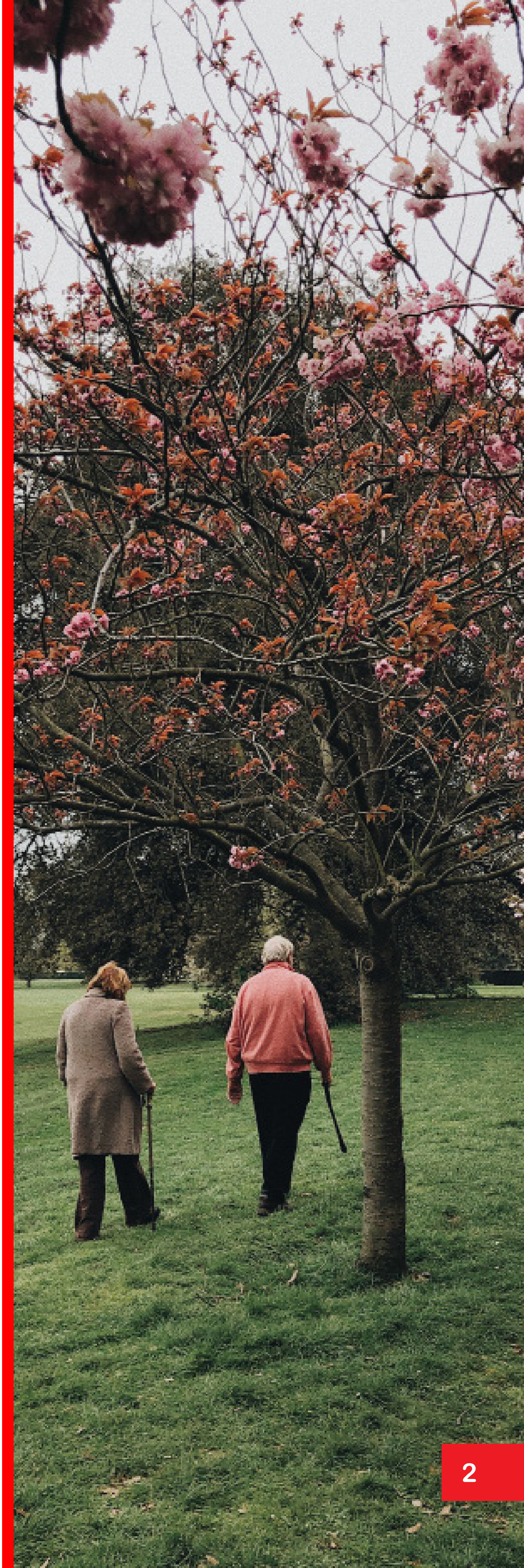
Stragetic Aims

Support **better health** and wellbeing by activly promoting and empowering people to live well in resilient communities.

Deliver **better care** through excellent health and care services with competent and confident Lymphoedema staff.

Helping people to be informed and achieve the outcomes that matter most to people with Lymphoedema to lead **better lives.**

Rhwydwaith Lymffoedema
Cymru
Lymphoedema Network
Wales



EXECUTIVE COMMENTARY

This year has been like no other, but when the pandemic hit Lymphoedema Network Wales staff led by example and were deployed where they needed to be. Some staff went to Intensive Care, Covid-19 wards, Testing, on the community and even supported Mass Fatalities and Bereavement Services. Nevertheless, they also ensured that every person with Lymphoedema had access to the care and support that they needed. In some ways there were positives, as the pandemic accelerated our virtual appointment plans with 'Attend Anywhere' ensuring that only those with the greatest need were seen face to face. Activity for 20-21 was 36,187 contacts which is very similar to last year's 36,759. However, referrals to the national service was 41% less from 7,687 to 4,571 yet discharges remained static from 6,323 to 6,010.

The research agenda continued and we have actually published several articles with a further four articles accepted and due for print in April/ May. The National Team have also presented virtually locally, nationally and internationally. Education continued albeit virtually with 292 people attending Lymphoedema courses.

Positively even in the midst of the pandemic new programmes of work have commenced like the Cellulitis Improvement Programme which is already making great strides in Value-Based Healthcare. Project B is now up scaled throughout Wales and patients can now access their compression garments in a timely and cost efficient way. Lastly, On the Ground Clinical Education (OGEP) which is phase two of the Value Based Business Case is now being prioritised in three Health Boards and again benefits are being realised. 21-22 will continue on these programmes of care.

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Read the full annual report from Lymphoedema Network Wales here: https://www.lympho.org/wp-content/uploads/2022/02/LNW-Annual-Report-V9.pdf