

ISRAELI LYMPHEDEMA ASSOCIATION

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In November 2004, as a result of meetings and discussions held over 10 years, the Israeli Lymphedema Association (ILA) was established by the Tel Aviv Lymphedema Patients' Support Group, and registered in Israel. The ILA is a non-profit organisation that promotes knowledge and increases awareness about lymphoedema among patients and healthcare professionals in Israel. The ILA members work on a voluntary basis and include lymphoedema patients, their families, lymphoedema physiotherapists and other healthcare professionals and interested parties.

Key words

Lymphoedema support group
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In November 2004, the Israeli Lymphedema Association (ILA) was established and registered in Israel. The ILA is a non-profit making organisation that promotes knowledge and increases awareness about lymphoedema among patients and healthcare professionals in Israel.

The ILA operates on a voluntary basis. Its members include people with lymphoedema, their families, lymphoedema physiotherapists and other healthcare professionals and interested parties.

Reasons for establishing the ILA

The ILA was established:

- ▶▶ To represent lymphoedema patients
- ▶▶ To provide patients with an organisation to which they can turn for consultation and support regarding lymphoedema issues

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- ▶▶ To promote knowledge and awareness about lymphoedema in the medical and paramedical professions
- ▶▶ To promote awareness about the demands of coping with lymphoedema.

The origins of the ILA

In 1996 a group of physiotherapists, who completed the first combined decongestive physiotherapy (CDPT) course held in Israel, formed the Lymphedema Special Interest Group under the auspices of the Israeli Physiotherapy Society.

The group, consisting of 20 physiotherapists all of whom were certified in CDPT, met on a regular, six-weekly basis at the Tel Aviv Medical Center to share knowledge and experiences and to hear lectures by invited specialists in related fields (vascular surgery, micro-vascular surgery, wound care, plastic surgery). Issues discussed in depth were the standardisation of lymphoedema treatment, the patient's right to treatment recognised by the health management organisations (HMOs), reimbursement for treatment compression garments and bandages, and the means of dispersing information about lymphoedema and treatment availability in Israel.

During this period, the Physical Therapy Lymphedema Special Interest Group was the sole body in Israel dealing with patient and therapist queries on the subject of lymphoedema.

The group's goals were to:

- ▶▶ Increase awareness of lymphoedema
- ▶▶ Improve knowledge about lymphoedema prevention
- ▶▶ Ensure a high standard of lymphoedema treatment by physiotherapists trained in accordance with international standards
- ▶▶ Make treatment readily available in all areas of the country.

Also during 1996, the Tel Aviv Lymphedema Patients' Support Group was founded and headed by Ruthi Peleg, licensed physiotherapist and coordinator of lymphoedema treatment services at the Tel Aviv Medical Center.

It was the first lymphoedema support group for patients in Israel. The participants share personal lymphoedema stories and information, and are attentive to each other. The group is a source of strength and support in dealing with chronic lymphoedema.

The group continues to meet each month and in the past two years, after 10 years of meetings and discussions, has been changed by the participants into a self-managed peer support group.

The ILA's creation was triggered by a personal story. During a support group meeting, one of the participants reported a recent experience she had in a medical centre. In the past she had undergone a bilateral mastectomy and axillary lymph node dissection. Subsequently, her right arm developed lymphoedema.

Some time afterwards she needed surgery for cancer of the colon. She requested that no infusion be inserted into her arms, as she had lymphoedema in one arm and the other arm was at risk of developing the condition. She indicated to the lymphoedematous arm.

The surgeon had brushed her words aside and assured her that nothing would happen. Despite her objections, they put the infusion line into her non-lymphoedematous arm. She expressed anger at their lack of consideration towards her and frustration at her weakness, lack of control over her body and fate and at the doctor's ignorance. She felt resentment at the domination of the medical staff.

Her story caused great emotion among the members of the support group and a desire to 'do something'. The group concluded that there was a need for an organisation that would promote the interests of lymphoedema patients. A large organisation would have greater influence than individual activists. This was not a new idea to the group, however; this incident was the trigger which set them into action.

The idea was to combine the strengths of the two existing groups to create a large association which would include patients and healthcare professionals in the medical and paramedical fields.

An additional prompt was the visit to Israel of Rachel Pritzker, former Chair of the Lymphedema Association of Quebec, Canada (LAQ). The Tel Aviv Support Group and a few lymphoedema therapists organised a meeting with Ms Pritzker, to which patients and physiotherapists treating lymphoedema from all over the country were invited.

Ms Pritzker described how the LAQ had been created and talked about its activities. The outcome was the establishment of the Israeli Lymphedema Association (ILA) which was registered in Israel as a non-profit making organisation in November 2004.

ILA's aims and goals

- ▶▶ To distribute and explain information regarding lymphoedema and its treatment

- ▶▶ To increase awareness among lymphoedema patients and relevant medical personnel
- ▶▶ To assist and support lymphoedema patients
- ▶▶ To promote lymphoedema-related issues among decision-makers in the health, medical and nursing sectors including health funds, hospitals, tax authorities and social security (national insurance)
- ▶▶ To establish support groups in Israel
- ▶▶ To arrange meetings and seminars in Israel
- ▶▶ To exchange information and promote common goals with lymphoedema associations abroad
- ▶▶ To support research into lymphoedema.

Administration of the ILA

A chair and steering committee coordinate ILA activities. The committee membership is 80% patients and 20% healthcare professionals. The steering committee holds regular meetings to which ILA members are invited. By 2006, the ILA membership stood at 130, of which two-thirds are patients and the remainder healthcare professionals.

ILA activities

ILA website

The ILA helps to distribute information and has set up the ILA website for this purpose (www.ial.org.il; Figure 1).

The website provides information and updates regarding lymphoedema, methods of treatment, lists of therapists in Israel by geographical distribution and current information regarding meetings, updates and activities of the association. The logo of the Israeli Lymphedema Association is the Rudbeckia flower (Figure 2). The Rudbeckia (coneflower) is named after Olaf Rudbeck a 17th century botanist and scientist of Uppsala University in Sweden. He established the first botanical garden in Sweden and discovered the lymphatic system.

Translation of internet site into English

An English homepage of the internet website is linked to various websites, such as www.lymphnetzwerk.de, but recently the whole website was translated into English by Julie Levy, a member of the ILA's

steering committee. This is available online at: www.ial.org.il.

Other activities

Other activities of the ILA include: writing and distributing a newsletter and information booklet in Hebrew, Russian and English (an Arabic version is planned for the near future); annual conferences held at the Hebrew University campus at Rehovot; and running a lymphoedema forum (www.doctors.co.il). This website offers information about health issues and forums for different medical conditions, including the lymphoedema forum.

Three lymphoedema physiotherapists run the lymphoedema forum and offer advice regarding lymphoedema issues.

Influencing decision-making bodies

The association's goal is to establish an effective lobby to influence decision-making bodies at all levels of health administration services. The ILA aims to exert influence regarding lymphoedema issues on the decision-making bodies of the HMOs and National Insurance Institute – initially to persuade them to recognise lymphoedema as a chronic disorder, and second to achieve improved rights to suitable treatment and reimbursement.

Preliminary meetings have been held with the Israeli Cancer Association (ICA), National Insurance Institute (NII, social security) and National Health Insurance.

Israeli Cancer Association (ICA)

The Israeli Cancer Association has historically been supportive to lymphoedema therapist training courses and supports all educational activities organised by the Physical Therapy Lymphedema Special Interest Group.



Figure 1. ILA website.



Figure 2. Logo of the Israeli Lymphedema Association.

Reciprocally, lymphoedema physiotherapists have responded to invitations to participate in conferences organised by the ICA, in the form of frontal presentations and as members of expert panels. Pamphlets on lymphoedema treatment are written by lymphoedema physiotherapists and printed and distributed by the ICA, some in more than one language.

The ICA and ILA complement one another; in that the former distributes information regarding lymphoedema as a result of cancer treatments, and the latter reaches out to all lymphoedema patients.

National Insurance Institute (NII)

The National Insurance Institute recognises lymphoedema as a complication of cancer treatment, not as a disability. As a result, late development of lymphoedema as a result of cancer treatment or for other reasons does not give you eligibility for support from the NII. ILA members initiated meetings with NII representatives to broaden the institute's awareness and support for lymphoedema sufferers.

National Health Insurance

Lymphoedema treatment for cancer and vascular patients is included in the basket of health services stipulated by law and provided by the four health management organisations (HMO) (Clalit, Maccabi, Meuchedet and Leumi). Primary lymphoedema patients are not always granted eligibility for lymphoedema treatment and the ILA, as a body representing all lymphoedema patients, is aiming to achieve equal treatment rights for this group.

The HMOs differ in their interpretation of the various services available, which results in differences in the number

of treatments covered and extent of reimbursement for bandages and compression. Patients may be referred by the HMO to distant centres, even though closer centres offer treatment. The ILA would like to see all patients having a choice of treatment centres and good coverage for treatment, bandaging and garment costs

Raising awareness

Membership and funding have increased due to active recruitment. The ILA sends information leaflets to physiotherapists and lymphoedema therapists for distribution to the patient population. This has been an efficient way to increase patient awareness of the existence of the ILA. The ILA also sets up information booths at the annual Israeli Physical Therapy Conferences.

Patients themselves have been very active in passing on the information of the existence of the ILA to each other. The lymphoedema forum on the doctors.co.il website attracts many questions and has brought in new members.

Members of the ILA have been interviewed on radio programmes broadcast on Cancer Awareness Day. They have offered information about lymphoedema and the disability it causes, treatment, and how the ILA can help people with the condition. Lectures are also given at staff meetings for medical, nursing and paramedical staff in hospital and out-patient settings.

New associations are helped by a non-profit making organisation, 'Eitsa' (meaning advice), which helps and gives advice to new associations through management training and information on how to run support groups. The association's chairperson, Rachel Schwarz, underwent such a management training course.

Establishment of support groups

The Tel Aviv Support Group has been reorganised and the group coordinator (who has lymphoedema) participated in a course for support group management run by Eitsa. Preparations are also being made for the establishment of support groups outside the Tel Aviv area.

ILA's goals for the future

The association's future goals are varied

Key points

- ▶ In November 2004, the Israeli Lymphedema Association (ILA) was established to promote and increase knowledge regarding lymphoedema among patients and healthcare professionals in Israel.
- ▶ By 2006, the ILA membership stood at 130, of which two-thirds were patients, the rest being healthcare professionals.
- ▶ The ILA website (www.ial.org.il) was established to provide information and updates regarding lymphoedema, methods of treatment, lists of therapists in Israel and their geographical distribution.
- ▶ Cooperation between lymphoedema associations can benefit our common goals.

and extensive but are primarily to expand its areas of interest and to involve more activists. They include:

- ▶ Recruitment of activists to assist in attaining the goals
- ▶ Distribution of data through expansion of the website, increase in media exposure, annual conference
- ▶ Continued support group activity in Tel Aviv, establishment of additional support groups in other areas, as well as telephone assistance for patients
- ▶ Influencing decision-makers, including continued activity related to the NII (social security) and other institutions
- ▶ Recruitment of new members, as, more members = more power.

Summary

The ILA was launched in 2004 and the results have been encouraging. However, there is a great deal more work required. It has been much inspired and encouraged by the success of other organisations such as the National Lymphedema Network (NLN) and the Lymphedema Association of Quebec. Cooperation between lymphoedema associations can benefit our common goals. **IL**