



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

REGISTER

August 2011

Belgium, Cyprus, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Israel, Italy, Malta, The Netherlands, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, United Kingdom

PREFACE

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LUPUS EUROPE REGISTER

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FORTHCOMING EVENTS

***22nd Convention of LUPUS EUROPE
September 21 – 25, 2011
Denmark / Copenhagen***

WHAT IS LUPUS?

So few have heard of it, yet worldwide it's seen as more common than leukaemia, muscular dystrophy and multiple sclerosis. 90% of the patients who suffer from Lupus are female of childbearing age. Even young children can be affected by lupus.

Lupus is a condition whereby the body's defence mechanism goes into overdrive and starts to attack itself. The symptoms are many and varied, and the illness often seems to mimic other diseases. This gives rise to difficulty in diagnosis and the condition can be overlooked, sometimes for years, unless the Family Doctor or consultant is alert to the possibility of lupus.

LUPUS IS NOT CONTAGIOUS

Lupus can be triggered

- *at puberty*
- *during the menopause*
- *after childbirth*
- *after viral infection*
- *through sunlight*
- *as a result of trauma*
- *after a prolonged course of certain medications*

THE SYMPTOMS

These may include

- *extreme fatigue*
- *joint and muscle pain*
- *eye problems*
- *depression*
- *mouth ulcers*
- *facial or other rashes*
- *hair loss*
- *anaemia*
- *possible involvement of the kidneys, heart, lungs and brain*
- *miscarriage (especially regarding Hughes Syndrome)*

THERE IS NO CURE...

People diagnosed normally remain in medical care, with continuing medication. Many symptoms have less impact as a result, but side effects often occur.

Lupus adversely influences the lives of sufferers, the family and their friends.

SLE - systemic lupus erythematosus
....hard to say - harder to live with....

HISTORY OF LUPUS EUROPE (FORMERLY ELEF)

A meeting took place in London during April 1988 when delegates from eight European Lupus Groups attended. The countries represented were: Belgium, Finland, France, Germany, Ireland, the Netherlands, Switzerland, and United Kingdom.

The idea of this meeting was to get to know each other, to exchange experiences, and to learn from each other. Everybody present agreed to meet again the following year in Leuven/Belgium, and it was there in 1989 that it was decided to found the European Lupus Erythematosus Federation –ELEF-. The LUPUS EUROPE Register and the “Caring and Sharing” newsletter are both published at the beginning of every year and Newsflash every six weeks.

The members of LUPUS EUROPE are the national and other properly-accredited Lupus Groups in Europe. At this moment there are 21 countries with 22 organisations and about 35,000 patients represented:

Belgium	Malta
Cyprus	The Netherlands
Denmark	Norway
Finland	Portugal
France	Romania
Germany	Slovenia
Hungary	Spain
Iceland	Sweden
Ireland	Switzerland
Israel	United Kingdom
Italy	

The aims of the LUPUS EUROPE you may read on the following page. According to these aims LUPUS EUROPE in 1990 became one of the NGO's (non governmental organisation) who advise the European Union in the field of disability.

In 1991 LUPUS EUROPE made a Europeanwide survey on the disease of Lupus. The First International Lupus Patients Conference in 1992 which took place concurrently with the Third International Scientific Conference on SLE in London / UK was organised by LUPUS EUROPE.

The Trustees of LUPUS EUROPE were centrally involved in the promulgation of World Lupus Day on May 10, 2004 in New York and World Lupus Day is now celebrated annually on this date.

LUPUS EUROPE has worked ongoing to encourage Lupus Groups internationally to recognise October as Lupus Awareness Month every year.

There are contacts worldwide with other Lupus organisations.

After 19 years, the Council, the governing body of **ELEF**, has voted to change the name of the organisation to **LUPUS EUROPE**. This decision was taken at the 19th Convention of ELEF during the Council meeting on 11th September 2008 in Palma de Mallorca, Spain. All the delegates voted for this change as they had the feeling that the new name LUPUS EUROPE pronounces strongly that we are uniting and caring for lupus patients throughout Europe. Following agreement with the Charity Commissioner the new name came into effect at the closure of the 19th Convention on 13th September 2008.

LUPUS EUROPE CONVENTIONS

1989	<i>Leuven, Belgium</i>	2002	<i>Thun, Switzerland</i>
1990	<i>Paris, France</i>	2003	<i>Brussels, Belgium</i>
1991	<i>Bologna, Italy</i>	2005	<i>Amsterdam, The Netherlands</i>
1992	<i>Amsterdam, Netherlands</i>	2006	<i>Bergen, Norway</i>
1993	<i>Malahide, Ireland</i>	2007	<i>Mainz, Germany</i>
1994	<i>Muenster, Germany</i>	2008	<i>Palma de Mallorca, Spain</i>
1995	<i>Lisbon, Portugal</i>	2009	<i>Strasbourg, France</i>
1996	<i>Pisa, Italy</i>	2010	<i>Budapest, Hungary</i>
1997	<i>Helsinki, Finland</i>	2011	<i>Denmark</i>
1998	<i>Eton, UK</i>	2012	<i>Cyprus</i>
1999	<i>Brest, France</i>	2013	<i>Paris, France</i>
2000	<i>Dublin, Ireland</i>		
2001	<i>Sliema, Malta</i>		

AIMS OF LUPUS EUROPE

1. *To collect information on all aspects of Lupus, both in the medical and sociological areas of the disease.*
2. *To assist in improving the knowledge of the disease for people with Lupus and members of the health, welfare and medical professions.*
3. *To encourage and/or undertake surveys and research projects related to the disease, and the publication of the useful results of any such research.*
4. *To promote awareness of the disease throughout Europe and the Support Groups that are available for sufferers in each member country.*
5. *To sponsor and/or promote European symposia on all aspects of Lupus.*
6. *To gain representation on any European or international body whose interests could be of benefit to members of the European Lupus Erythematosus Federation.*
7. *To assist with the establishment of Groups in other European countries where at present they do not exist.*
8. *To do all such other lawful actions as are necessary for the attainment of the above objects.*

LUPUS EUROPE

Federation established in 1989 -with the name European Lupus Erythematosus Federation(ELEF)-

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BELGIUM
(Flemish language)

Name of Group

(in native Lang.)

CIB-liga vzw

Liga voor Chronische Inflammatoire Bindweefselziekten vzw

Name of Group

(in English)

League for Chronic Inflammatory Connective Tissue Diseases.

Chairperson

Godelieve de Faudeur

Official Address & Tel. No.

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Year Group established

1981

Numbers of Members

700

Population in Total

10 400 000

Population Flemish Part

6 500 000

Aims of Group

To provide honest and professional information about CTD to give publicity to these diseases. Work for the benefit of physical psychological and social well-being of the patients. To stimulate scientific research.

Name of Magazine & Frequency of Publication

" Liga voor Chronische Inflammatoire Bindweefselziekten vzw " every 3 months

Activities of Group

Yearly National Information Day for patients and interested people. Talk to groups in different regions. Participate in health meetings. Service for patients-members.

BELGIUM
(French language)

Name of Group

(in native Lang.)

Association Lupus Erythémateux

Name of Group

(in English)

Lupus Erythematosus Association

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Carola Maggiulli

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Katharine Wheeler (Convention 2010): k.wheeler@skynet.be

Year Group established

1991

Number of Members

800

Population in Total

10 400 000

Population French Part

3 500 000

Aims of Group

Provide information to patients, doctors, paramedicals.

Provide support to patients

Defend patients' interests vis-à-vis public authorities

Support medical research and raise awareness.

Organize lectures and meetings between patients and doctors.

Name of Magazine & Frequency of Publication

" L.E. LIEN " 4 times a year

Activities of Group

Contact between members.

Publications in Dailies and Weeklies.

Participation in international conferences and colloquia.

CYPRUS

Name of Group

(in native Lang.)

Αντιρευματικός Σύνδεσμος Κύπρου

Name of Group

(in English)

Cyprus League Against Rheumatism

Chairperson

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Year Group established

2005

Number of Members

105

Population

700.000

Aims of Group

Increasing exposure through media.

Workshops to educate and inform sufferers.

Information and Support for the immediate family and friends of the sufferer.

Promote procedures to find solutions for socio-economical problems of the sufferers.

Name of Magazine & Frequency of Publication

"Poreia Zois" 4 times a year.

Activities of Group

Bring patients together, Lectures, Workshops to inform and support the sufferers.

Workshops and programs for information and education.

DENMARK

Name of Group

(in native Lang.)

Lupus DK / Gigtforeningens diagnosenetværk for SLE

Name of Group

(in English) Lupus DK

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Managing Director

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Year Group established

1994

Number of Members

300

Population

5.210.000

Aims of Group

Enroll new members and supply correct information about lupus to patients, doctors, the health service and the general public.

Name of Magazine & Frequency of Publication

The Rheumatism Association announces meetings and events in the magazine "LEDsager", where news related to Lupus is brought occasionally.

LEDsager is published bimonthly. Furthermore Lupus DK edits and publishes a short newsletter for its members twice a year and manages our own web site www.sle.dk

Activities of Group

Member support, collection and dissemination of information, arranging informal as well as formal meetings and seminars, keeping contact to scientists and specialists working with Lupus.

FINLAND

Name of Group

(in native Lang.)

SLE-ryhmä

Name of Group

(in English)

Finnish SLE-Group co.

The Finnish Rheumatism Association

Chairperson

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Year Group established

1975

Number of Members

693

Population

5 255 580

Aims of Group

Monitor the situation of and activities for people suffering from SLE, take initiatives to improve the position of the group and increase awareness about SLE in Finland, promote and provide information about disease and its treatment to SLE sufferers and health professionals, facilitate sharing own experiences between SLE sufferers.

Name of Magazine & Frequency of Publication

Perhoset (Butterflies) twice a year

Activities of Group

Publishing leaflets and other material for instance the SLE information kit and SLE Guide, organize national and regional meetings and local support group meetings, telephone support.

Name of Group

(in native Lang.)

Association Française du Lupus et autres Maladies auto-immunes - AFL+

Name of Group

(in English)

The French Association of Lupus sufferers and autoimmune diseases

(Officially approved by the French Ministry of Health)

Chairperson

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Year Group established

1984

Number of Members

2600

Population

61 000 000

Aims of Group

Disclose information. Help exchanges about experiences nationally and internationally.

Help patients to defend their rights. Getting recognized by the authorities and in public.

Name of Magazine & Frequency of Publication

" Bulletin AFL+ " 4 times a year

Publications: Lupus in 100 Questions

Activities of Group

Help self-awareness of patients possibilities, sensitize families about the daily environment problems and create a "bridge" between members and medical and paramedical bodies, participation in medicine congresses, partnership with pharmaceutical companies.

Name of Group

(in native Lang.)

LUPUS France

Name of Group

(in English)

LUPUS France

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Year Group established

1999

Number of Members

1200

Population

61 000 000

Aims of Group

Inform sufferers about their disease, public of symptoms, bodies for social assistance about problems of disease. Raise funds for research. Prepare informative material and organise meetings.

Name of Magazine & Frequency of Publication

La Lettre de LUPUS FRANCE every 3 months

Activities of Group

Publishing newspaper articles. Providing sufferers information on Lupus through a scientific committee of doctors. Fundraising to spread information, meetings and conferences. Education of patients, families and physicians.

GERMANY

Name of Group

(in native Lang.)

Lupus Erythematodes Selbsthilfegemeinschaft e.V.

Name of Group

(in English)

Lupus Erythematosus Self-help Association

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Year Group established

1986

Number of Members

3000

Population

83 000 000

Aims of Goup

Exchange of information and experience. Registration of and advice for patients. Research into cause and treatment in Germany and abroad. PR for SLE and avoidance of isolation. Organization of individual and group care. Support of regional groups and fundraising.

Name of Magazine & Frequency of Publication

" Der Schmetterling " (" The Butterfly ") 4 times a year

Activities of Group

Meeting of lupus patients including lecturers by lupus specialists and psychologists

Organisation of Workshops for lupus patients (about 10 per year)

Support of Research, e. g. a long term study of lupus -10 years- is completely financed by our group.

General help in the social field. Member of a governmental commission to secure the payment of special medication for chronicle diseases. Recent project: LUPus Prevention Passport for raising awareness of the risk of arteriosclerosis – linked with a survey on lifestyle. Online evaluation to prove that the LUPP helps reducing arteriosclerosis risk factors with lupus patients.

HUNGARY

Name of Group

(in native Lang.)

Schopper Gabriella Magyar Lupus Egyesület

Name of Group

(in English)

Gabriella Schopper Hungarian Lupus Group

Chairperson

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Year Group established

1993

February 1996 registered as a Non-Profit-Organisation

Number of Members

452 and 224 supporters

Population

10 000 000, estimated SLE patients about 8,000 – 9,000 people.

Aims of Group

Spread of information; education of people about SLE and how to live with chronic illness, awareness, financial support, rehabilitation.

Name of Magazine & Frequency of Publication

"Lepke" (Mini Butterfly) magazine (4 times a year).

"Pillangó" (Butterfly) magazine (once a year)

Other publications like DVDs about medical lectures

Activities of Group

Meeting 3 times a year, when doctors talk openly about SLE, cultural events, close contact with other self-help groups. The performances are recorded on video tapes; they are archived and distributed to patients who cannot attend our meetings. Talk to everyone about patients' rights. We have our own web-site, and we can be found under the Hungarian Rheuma Organisation web-site as well. A special meeting once in a year is the Lupus Day. Media coverage (television), giving lectures to doctors who rehabilitate patients so that they can help patients to get back to life even with lupus, filling-in national application papers in order to get funds from the government.

ICELAND

Name of Group

(in native Lang.)

KJARNINN, áhugahópur um Lupus

Name of Group

(in English)

The Lupus Group of the Icelandic League against Rheumatism

Chairpersons

Guðbjörg Jóhanna Björnsdóttir

Official Address & Tel. No.

The Icelandic League against Rheumatism

Armuli 5

IS-108 Reykjavik

Iceland

Tel.: +354-530 36 00

Fax : +354-553 07 65

URL: www.gigt.is

International Contacts

Guðbjörg Jóhanna Björnsdóttir

Address of Contact & Tel. No.

Reynimelur 34, Reykjavik

Iceland

Tel.: +35 562 7349 - +35 697 7349

E-mail: guggab2009@gmail.com

Year Group established

1994

Number of Members

65

Population

307 000

Aims of Group

Distribute information on Lupus both to patients and the public.

Support scientific research. Increase awareness and create atmosphere for communications between Lupus patients.

Name of Magazine & Frequency of Publication

"Gigtin" 2 times a year

Activities of Group

Informative meetings, writing articles, centre for discussions, etc.

IRELAND

Name of Group

(in native Lang.)

Cumann Cabhrach Lupus na hEireann

Name of Group

(in English)

Irish Lupus Support Group Limited

Chairperson

Mary Feehan

Official Address & Tel. No.

Carmichael Centre

North Brunswick Street

Dublin 7

Ireland

Tel.: +353-1-872 45 18

Fax: +353-1-873 57 37

E-Mail irishlupus@iol.ie

URL: www.lupus.ie

International Contact

Mary Feehan

Caroline Daly

Address of Contact & Tel. No.

See above

Tel.: Mary: +353-1-493 19 88

Caroline: +353-1-842 46 70

E-Mail Mary: desfeehan@eircom.net

Caroline: Dalyclan3@eircom.net

Year Group Established

1981

Number of Members

500

Population

3 533 000

Aims of Group

The prime object of the Group is the support of those who suffer from Lupus Erythematosus. We also promote Education on Lupus and Public Awareness of the disease.

Name of Magazine & Frequency of Publication

" Newsletter " 3-4 times a year

Activities of Group

Information and support. Telephone support.

Quarterly Support Group Meetings, Educational and Training meetings.

Works in co-operation with Government

Departments and other Health Organisations.

Our Board meets approximately once a month.

ISRAEL

Name of Group

(in native Lang.)

Irgun Ha-lupus Be'Israel

Name of Group

(in English)

Israeli Lupus Association (ILA)

Chairperson

Irith Regev

Official Address & Tel. No.

P.O.Box 14103

Tel Aviv 61141

Israel

Tel.: +972-3-677-3346

Fax: +972-3-635-44 64

E-Mail: lupus@drc.co.il

International Contact

Geula Paz & Mazali Irit

Address of Contact & Tel. No.

P.O.Box 9009

Ramat – Efal

Israel

Tel.: +972-3-535 03 76

E-Mail: lupus@netvision.net.il

Year Group established

1985

Number of Members

900

Population

6 956 000

Aims of Group

- 1. To supply information about Lupus to patients, their families and professional people;*
- 2. To provide a social framework for Lupus patients.*
- 3. Help promulgate information on all aspects of Lupus with the general public and the medical profession.*

Name of Magazine & Frequency of Publication

" Parpron - News" every 2 month

Activities of Group

Lupus Hotline

Self aid groups - regional.

Meetings and lectures twice a year of all the members.

Library & SLE information centre: Hebrew / Translations Books, Articles, DVDs – Movies & Lector

Pubication by professionals & members.

Publicise the Group's existence.

Raise funds to enable practical help to be given to people with Lupus.

ITALY

Name of Group

(in native Lang.)

Gruppo Italiano per la lotta contro il lupus eritematoso sistemico

Name of Group

(in English)

Italian SLE Group

(Italian Group for the fight against the Systemic Lupus Erythematosus)

Chairperson

Maria Teresa Tuccio

Official Address & Tel. No.

Via dei Monti Tiburtini 558

I-00157 Roma

Italy

Tel.: +39-329-103 49 85

Fax: +39-010-42 06 92 46

E-Mail: mariateresa@lupus-italy.org

URL: www.lupus-italy.org

International Contact

Augusta Canzona

Address of Contact & Tel. No.

Via dei Monti Tiburtini 558

I-00157 Roma

Italy

Tel./ Fax : +39-06-451 53 40

Mobile : +39-339-236 77 46

E-Mail: lupusroma@virgilio.it

Year Group established

1987

Number of Members

3000

Population 57 121 000

Aims of Group

Inform sufferers from SLE about their disease. Inform public of SLE symptoms and treatment. Inform codies for social assistance about problems of disease. Raise funds for research. Prepare informative material and organise meetings to study disease. Finance training and qualification of young doctors, finance "Lupus Clinics".

Name of Magazine & Frequency of Publication

"Icaro " Every 4 months

Activities of Group

Publishing newspaper articles.

Providing sufferers information on SLE through publications and a scientific committee of physicians.

Organising scientific meetings and conferences.

Fundraising to spread information.

Education of physicians, including GPs.

MALTA

Name of Group

(in native Lang.)

Lupus Support Group Malta

Chairperson

Prof. Dr. Dion Buhagiar

Official Address & Tel. No.

Lupus Support Group Malta

29, Vincenza

G. Pesci Street,

Iklin IKL 1421

Malta

Tel. : +356-21-43 56 47

Fax : +356-21-41 80 08

Mobile + 356-9926 9495

E-Mail: dion.buhagiar@um.edu.mt

International Contact

Prof. Dr. Dion Buhagiar

Address of Contact & Tel. No.

See above

Year Group established

1999

Number of Members

20

Population

416 000

Aims of Group

1. To support its members through meetings and sharing experiences in a happy atmosphere
2. To disseminate information about Lupus to both sufferers and the general public
3. To raise funds in support of the above objectives and for Lupus research.

Name of Magazine & Frequency of Publication

None

Activities of Group

1. Regular monthly meetings
2. Collating and distributing informative leaflets/books about Lupus to members, the general public (through pharmacies, clinics and hospitals) and the medical profession
3. Organizing fund-raising functions (mainly social)
4. Media coverage (Press and Television) on Lupus, seminars, talks and interviews

THE NETHERLANDS

Name of Group

(in native Lang.)

Nationale Vereniging LE Patienten

Name of Group

(in English)

National Society LE Patients

Chairperson

Marja Kruithof, marja.kruithof@kpnmail.nl

Official Address & Tel. No.

Postbus 4

NL-Bunnik

The Netherlands

Tel.: +31-30-65 69 630

E-Mail: info@nvle.org

URL www.nvle.org

International Contact

Ineke Boomker

Address of Contact & Tel. No.

Niersstraat, 12

NL-5626 DW Eindhoven / Acht

The Netherlands

Tel : +31-40-262 35 09 private

E-Mail : sj.boomker@hetnet.nl

Year Group established

1980

Number of Members

2500

Population

16 000 000

Aims of Group

*Collect information on all aspects of Lupus, Scleroderma and M.C.T.D.
(mixed connective tissue disease).*

Improve knowledge of disease for sufferers and doctors.

Bring patients together and help them accept the disease.

Name of Magazine & Frequency of Publication

NVLE Venster (NVLE Window) 4 times a year

Activities of Group

Bring patients together, meetings with doctors;

trying to get publicity in newspapers, radio etc., yearly NVLE award

NORWAY

Name of Group

(in native Lang.)

LUPUSGRUPPEN I NRF

Name of Group

(in English)

Lupus Foundation within NRF

Chairperson

Fatima Maria Lavoll

Official Address & Tel. No.

Bekkeveien 11

N-0667 Oslo

Norway

Tel.: +47-233 490 81

E-Mail: flavoll@online.no

URL: www.sle.no

International Contact

Fatima Maria Lavoll

Address of Contact & Tel. No.

Bekkeveien 11

N-0667 Oslo

Norway

Tel.: +47-233 490 81 and +47-917-74 7 31

E-Mail: flavoll@online.no

Year Group established

1992

Number of Members

750

Population

4 310 000

Aims of Group

Member support, spread information, strive to get more money for research on Lupus.

Name of Magazine & Frequency of Publication

We have a column in the N.R.F.'s magazine called "Rheumatikeren".

It is published 8 times a year.

Activities of Group

Enroll new members and supply correct information about lupus to patients, doctors, the health service and the general public.

PORTUGAL

Name of Group (in native Lang.)

Associação de Doentes com Lupus

Name of Group

(in English)

Association of Patients with Lupus

Chairperson

Rosa Maria Gonçalves

Official Address & Tel. No.

Avenida Defensores de Chaves No. 27 4. Dtº

P-1000-110 Lisboa

Portugal

Tel.: +351-21-330 36 40

Fax: +351-21-314 62 16

E-Mail: rosacgoncalves@iol.pt

URL: www.lupus.saudeglobal.com (URL for sale)

International Contact

Rosa Maria Gonçalves

Address of Contact & Tel. No.

See above

Year Group established

December 1992

Number of Members

2500

Population

9 979 450

Aims of Group

Disclose information to patients, families, doctors and public.

Help patients to defend their rights and frame work with them.

Prepare informative material to teachers and other professions.

Stimulate scientific research and to collect numbers of patients in Portugal.

Name of Magazine & Frequency of Publication

" Impaciente " every 4 months

Activities of Group

Bring patients together; meetings with doctors; distribution of booklets; visits with support of patients and families who need it; courses for patients (for leisure and for learning works that can be done at home); 3 flats with rooms for patients and families (2 in Lisbon and 1 in Oporto); Christmas Bazaar; helping with a small enterprise of painting tiles of a lupus patient; graphic works (the revue is done all here except the printing) kitchen work, etc.

ROMANIA

Name of Group (in native Lang.)

ASOCIATIA LES ROMANIA

Name of Group

(in English)

Association LES ROMANIA

Chairperson

Alecsandra Onac

Official Address & Tel. No.

Str. Izvorul Muresului nr 3

Bl. D6, scara 3, etaj 1, ap. 24

sector 4, Bucuresti

Romania

Tel.: +40-744 304 893

E-mail: alecsandra.onac@gmail.com

International Contact

Alecsandra Onac

Sorana Dinvale (Convention 2010): Tel.: +40 725 11 221 (E-mail: soranatm@yahoo.com)

Address of Contact & Tel. No.

See above

Year Group established

2009

Number of Members

16

Population

21 680 974

Aims of Group

Information and material support of lupus patients

Name of Magazine & Frequency of Publication

[...]

Activities of Group

Meetings with lupus patients and doctors specialists in lupus. Editing a booklet on lupus for free distribution in hospitals. Information and stimulation of the public opinion about characteristics and problems of the lupus disease.

SLOVENIA

Name of Group

(in native Lang.)

Društvo revmatikov Slovenije

Name of Group

(in English)

Rheuma Society of Slovenia

Chairperson

Marjan Hudomalj

Official Address & Tel. No.

Parmova 53

Si-1000 Ljubljana

Slovenia

Tel.: +386-590 75 366

Fax: +386-1-236 24 57

Mail: drustvo@reumatiki.si

URL: www.reumatiki.si

International Contact

Dominika Naveršnik

Dominika.naversnik@gmail.com

Address of Contact &- Tel. No.

See above

Year Group established

1983

Number of Members

2200

Population

2.100.000

Aims of Goup

Education, rehabilitation, social and legal support, workshops, seminars for independent living life and self management etc.

Name of Magazine & Frequency of Publication

Vestnik 3 – 4 times a year

Activities of Group

Rehabilitation groups (exercise) 2 – 3 times a week; weekend seminars; publication of educational material; regional meetings with lecturers from around the world 1 – 2 time a year; Self management education center (own) with simulation of the home appliances runned by occupational therapists; Education of own physiotherapists (14 parttime empl.); education of new members; education of children with condition; cultural and sport activities; Hotline telephone; legal advisers and advocacy, educational excursions, spa facilities for members etc.

SPAIN

Name of Group

(in native Lang.)

Federación Española de Lupus

Name of Group

(in English)

Spanish Lupus Federation

Chairperson

Blanca Rubio

Official Address & Tel. No.

C/ Lagunillas, 25

Locales 3 y 4

E-29012 Málaga

Spain

Tel./Fax : +34-952-25 08 26

E-Mail: felupus@felupus.org

URL: www.felupus.org

International Contact

Blanca Rubio

presidencia@felupus.org, +34 677 048 246

Address of Contact & Tel. No.

See above

Year Group established

1996

Number of Members

2200

(22 Associations)

Population

46 000 000

Aims of Group

Coordinate the work of the member associations unifying criteria and actions between all of them in order to help improve patients and family conditions in the psychological, social and medical levels.

Name of Magazine & Frequency of Publication

Magazine "Lupus España " half-yearly

Activities of Group

Union and guidance between all its associations; inform and make aware the public opinion, administration and medical staff on characteristics and problems linked to the disease; promote the study of lupus in the frame of investigation; guide people or groups of people who wish to create their own association.

SWEDEN

Name of Group

(in native Lang.)

Rheumatikerförbundet, Systemiska Sjukdomar

Name of Group

(in English)

The Swedish Rheumatism Association
Systemic Diseases

Chairperson

Greta Thoren

Official Address & Tel. No.

Reumatikerförbundet

Box 128 51

119 98 Stockholm

Sweden

Tel.: +46-8505 805 00

Fax : +46-8505 805 20

E-Mail: info@reumatikerforbundet.org

URL: www.reumatikerforbundet.org

International Contact

Greta Thoren

Eida Steen

Address of Contact & Tel. No.

Fotbollsgatan 39

60237 Norrköping

Sweden

Mobil +46-70582 1884

greta.thoren@reumatikerforbundet.org

Eida.steen@telia.com

Year Group established

1986

Number of Members

3 269

Population

9 000 000

Aims of Group

Safe-guard the interests of lupus sufferers. Promote and provide information on all aspects of lupus to members, professionals and the public. Support exchange of experience between lupus sufferers and their families.

Support and stimulate SLE research.

Name of Magazine & Frequency of Publication

Bulletinen 4 times a year to 1 513 contact persons

Activities of Group

Local, regional and national support groups. Meetings, lectures, seminars and exhibitions. Publishing articles, leaflets, etc. besides our periodical Bulletinen.

SWITZERLAND

Name of Group

(in native Lang.)

Schweizerische Lupus Erythematodes Vereinigung (SLEV)

Name of Group

(in English)

Swiss Lupus Erythematosus Association

Chairperson

Max Hagen

Official Address & Tel. No.

Speerstraße 5

8305 Dietlikon

Switzerland

Tel.: 0041 44 833 09 97

E-Mail: max.hagen@greenmail.ch

Url: www.slev.ch

International Contact

Britta Krismer

Address of Contact & Tel. No.

Wydumstrasse 22

CH-8620 Wetzikon

Switzerland

Tel.: +41-44-930 33 64

E-Mail: b.r.y.krismer@bluewin.ch

Year Group established

1987

Number of Members

500

Population

7 508 000

Aims of Group

Help members to accept and understand their illness. Provide information about medical treatment, research and important rules of behaviour with the disease.

Information of public about SLE. Form regional groups for personal contacts.

Name of Magazine & Frequency of Publication

“ Rundbrief ” Information about meetings, addresses, medical articles, letters and contributions by patients, edited four times a year.

Activities of Group

National level: Meetings with doctors various times a year.

PR for SLE

Hotline for any kind of information about SLE.

International contacts with other Lupus Support Groups.

Regional level: Monthly meetings to provide effective support and prevent isolation.

Contact for Italian speaking persons:

Donatella Odun

via Pietane3

6854S.Pietro

Tel: 076 481 2198

E- Mail: donafarmacia@hotmail.com

Contact for French speaking persons:

Janine Roth

Rebhaldenweg 5

5423 Freienwil

Tel: 056 222 01 00

E-Mail: janine.roth@slev.ch

Name of Group

(in native Lang.)

LUPUS UK

Chairperson

Jane Dunnage

Director

Chris Maker

Official Address & Tel. No.

St James House
27 – 43, Eastern Road
Romford/Essex
RMI 3NH
UK

Tel.: +44-1708-73 12 51

Fax.: +44-1708-73 12 52

E-Mail : chris@lupusuk.org.uk

URL : www.lupusuk.org.uk

URL medical: www.medical.lupusuk.org.uk

International Contact

Yvonne Norton MBE

Address of Contact & Tel. No.

8, Legge Lane
Coseley/West Midlands
WV14 8RQ
UK

Tel./Fax: +44-1902 49 82 36

E-Mail: yvonne@wmlg.freemove.co.uk

URL : www.westmidlandslupus.co.uk

Year Group established

1978

Number of Members

6500

Population

57 918 000

Aims of Group

Aid communication between Lupus patients. Help promulgate information on all aspects of SLE with the general public and the medical profession on symptoms and problems of Lupus. Publicise the Group's existence. Raise funds to enable practical help to be given to people with Lupus and, principally, towards research.

Name of Magazine & Frequency of Publication

" News & Views " 3 times a year

Activities of Group

Organising Contacts and Regional Support Groups throughout the UK. Providing an educational and publicity programme for Lupus patients, general public and medical profession. Funding of research and patient services.

OTHER CONTACT ADDRESSES

AUSTRIA

LES Steiermark

Chairperson : *Eva-Maria Hübler*

Lazarettgasse 29

8020 Graz

Austria

E-Mail: LES_Steiermark@gmx.at

LUPUS EUROPE CONSTITUTION

REVISED ELEF CONSTITUTION AGREED BY COUNCIL 11th SEPTEMBER 2008

1. NAME

1.1. *The name of the Association shall be:*

LUPUS EUROPE

2. OBJECTS

2.1 *The objects of LUPUS EUROPE are the advancement of public education concerning all aspects of Lupus both in the medical and sociological areas of the disease.*

3. AIMS AND POWERS

3.1 *To collect information on all aspects of Lupus, both in the medical and sociological areas of the disease.*

3.2 *To assist in improving knowledge of the disease for people with Lupus and for members of the health, welfare and medical professions.*

3.3 *To encourage and/or undertake surveys and research projects related to the disease and the publication of the useful results of any such research.*

3.4 *To promote awareness of the disease throughout Europe and the Support Groups that are available for sufferers in each member country.*

3.5 *To sponsor and/or promote European symposia on all aspects of Lupus.*

3.6 *To gain representation on any European or international body whose interests could be of benefit to members of LUPUS EUROPE.*

3.7 *To assist with the establishment of Support Groups in other European countries where at present they do not exist.*

3.8 *To promote all such other lawful actions as are necessary for the attainment of the above objects.*

4. MEMBERSHIP

- 4.1.1 *Full (voting) membership of LUPUS EUROPE is open to all nationally registered self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid Lupus or Mixed Connective Tissue Disease. Election of full member organisations shall take place at meetings of Council.*
- 4.1.2 *Associate (non-voting) membership of LUPUS EUROPE is open to additional regionally or nationally registered self-help organisations in Europe providing support for people suffering from Systemic Lupus Erythematosus, Discoid Lupus or Mixed Connective Tissue Disease. Election of associate organisations shall take place at meetings of Council and Council may exercise the right to ask the applicant organisation to attend a first Convention as an observer.*
- 4.1.3 *Following four years as Associate (non-voting) members of LUPUS EUROPE, nationally registered organisations may apply to Council for full (voting) membership having been nominated and seconded by two other full (voting) member organisations. Associate regionally registered organisations shall remain non-voting.*
- 4.2 *Each organisation prior to election shall be required to satisfy the Trustees that they are correctly set up and accepted as bona-fide organisations within their own country.*
- 4.3 *Each elected organisation shall be entitled to send a delegation of two people to Conventions and other appropriate meetings.*
- 4.4 *At all meetings, each full membership nationally registered organisation, having paid the set annual subscription, shall be allowed one vote.*
- 4.5 *Each elected organisation shall be expected to offer full support to LUPUS EUROPE.*
- 4.6 *At all meetings, delegates must have full powers to make decisions on behalf of their own organisation Management Board/Trustees.*

5. COUNCIL

- 5.1 *The overall control of LUPUS EUROPE shall be administered by Council.*
- 5.2 *One nominated delegate from each full voting member organisation shall serve on Council and shall carry one vote. Each Trustee shall also serve on Council and shall carry one vote.*
- 5.3 *Council meetings shall occur at every Convention which shall take place at least once in every twenty-four months and for which the Secretary shall give notice of at least 56 days.*
- 5.4 *Council shall set annual membership subscription rates for both full and associate member organisations.*
- 5.5 *Decisions of Council shall be accepted on a majority of one except where voting takes place at Special Meetings, on Amendments to the Constitution, on Dissolution or on removal of a Trustee.*
- 5.6 *The quorum at meetings of Council shall be one half the voting membership and must include one elected officer.*

6. TRUSTEES

- 6.1 *The general administration of LUPUS EUROPE shall be undertaken by the Trustees.*
- 6.2 *The Trustees shall consist of the Chairperson, Vice-Chairperson, Secretary, Treasurer and two other Trustees elected from Council. The Trustees may co-opt Advisors for specific projects, these Advisors shall be non-voting.*
- 6.3 *The Trustees shall be elected by Council, shall hold office for three years and shall be eligible for re-election on a rotational (three-year) basis.*
- 6.4 *The Secretary shall circulate the names of all nominees to each full member organisation 28 days prior to the Elections.*
- 6.5 *If at any time after the election of the Trustees a vacancy should arise the remaining Trustee members shall, at their discretion, appoint a replacement member whose appointment shall be approved at the next meeting of Council.*
- 6.6 *A Trustee may be removed from office by 2/3rds majority vote of Council at any time for any reason that may be considered contrary to the aims or the operation of LUPUS EUROPE provided that the individual concerned shall have the right to be heard before a final decision is made.*
- 6.7 *A Trustee may resign at any time by giving written notice to LUPUS EUROPE through the Secretary.*
- 6.8 *The Chairperson, or in his/her absence the Vice-Chairperson, shall conduct meetings of both the Trustees and Council and shall be responsible for the taking of any urgent action between meetings of the Trustees or Council.*
- 6.9 *The Secretary shall be responsible for the minutes, the notification of such meetings that are called and the preparation of the Agenda in consultation with the Chairperson and all correspondence in connection with meetings of the Trustees and Council.*
- 6.10 *The Treasurer shall be responsible for the proper management of the central funds, for receiving dues and contributions on behalf of LUPUS EUROPE, the publication of accounts and the recommendation of Auditors to the Trustees.*
- 6.11 *The quorum at meetings of the Trustees shall be four of its members.*

7. SPECIAL MEETINGS

- 7.1 *A Special Meeting may be called by two or more Trustees and/or Council Members by writing to the Secretary.*
- 7.2 *The Secretary shall then call a Special Meeting by giving member organisations at least 28 days notice of the Meeting where the Agenda shall comprise only of the business item giving rise to the calling of the Meeting.*
- 7.3 *Voting at a Special Meeting shall require the agreement of 2/3rds of the total Trustees and members present and entitled to vote.*

8. AMENDMENT TO THE CONSTITUTION

- 8.1 *A Resolution of Amendment to the Constitution must be received by the Secretary at least 35 days before the Council or Special Meeting.*
- 8.2 *At least 28 days notice of the Meeting must be given by the Secretary to full member organisations and must include details of the alteration(s) proposed.*
- 8.3 *Alteration of the Constitution shall require the agreement of 2/3rds of the total Trustees and members present and entitled to vote.*
- 8.4 *Provided that no alteration shall be made to Clause 2 (Objects), Clause 9 (Dissolution) or this Clause until approval in writing of the United Kingdom Charity Commissioners or other authority having charitable jurisdiction shall have been obtained and no alteration shall be made which would have the effect of causing LUPUS EUROPE to cease to be a charity in law.*

9. DISSOLUTION

- 9.1 *LUPUS EUROPE may be dissolved by a Resolution passed by 2/3rds majority of those present and entitled to vote at a Council Meeting or Special Meeting convened for the purpose of which 28 days notice shall have been given by the Secretary to member organisations.*
- 9.2 *Such Resolution shall give instructions for the disposal of any assets held by or in the name of LUPUS EUROPE, provided that if any property remains after the satisfaction of all debts and liabilities such property shall not be paid to or distributed among the members of LUPUS EUROPE but shall be given or transferred to such other charitable institution or Institutions having objects similar to some or all of the objects of LUPUS EUROPE as LUPUS EUROPE may determine and if in so far as effect cannot be given to this provision then to some other charitable purpose.*

Amendments to ELEF Constitution made by:

Yvonne Norton MBE (LUPUS UK Representative to ELEF)

Agreed by ELEF Council, Palma de Mallorca, Spain, 11th September 2008

ELEF to be renamed LUPUS EUROPE with effect from the close of the Council Meeting 13th September, 2008

Approved by Charity Commission 21st October 2008