

# PREFACE

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## **FORTHCOMING EVENTS**

***18<sup>th</sup> Convention of ELEF***

*12th September – 16th September 2007*

*Mainz / Germany*

**PLEASE ADVISE RUDOLF HOCKS (ABOVE) OF ANY CHANGES TO THE REGISTER**

## **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 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 ELEF Register and the “Caring and Sharing” newsletter are both published at the beginning of every year and the “Broadsheet” is published in April and September each year.

The members of ELEF are the national and other properly-accredited Lupus Groups in Europe. At this moment there are 20 countries with 22 organisations and about 35,000 patients represented:

<i>Belgium</i>	<i>Italy</i>
<i>Cyprus</i>	<i>Malta</i>
<i>Denmark</i>	<i>The Netherlands</i>
<i>Finland</i>	<i>Norway</i>
<i>France</i>	<i>Portugal</i>
<i>Germany</i>	<i>Spain</i>
<i>Hungary</i>	<i>Sweden</i>
<i>Iceland</i>	<i>Switzerland</i>
<i>Ireland</i>	<i>United Kingdom</i>
<i>Israel</i>	<i>Slovenia -interim member-</i>

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

In 1991 ELEF 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 ELEF.

The Trustees of ELEF 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.

ELEF has worked ongoingly to encourage Lupus Groups internationally to recognise October as Lupus Awareness Month every year.

There are contacts worldwide with other Lupus Organisations.

## **ELEF CONVENTIONS**

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

## **AIMS OF ELEF**

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.*

**EUROPEAN LUPUS ERYTHEMATOSUS FEDERATION  
(ELEF)**

**Federation established in 1989**

**UK Charity Commission: registered charity No. 803768**

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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.**

*CIB-Liga vzw*

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*Belgium*

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*E-Mail: [nele@reumanet.be](mailto:nele@reumanet.be)*

### **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

**Chairperson**

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E-Mail: [maria.toledo@swing.be](mailto:maria.toledo@swing.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.

Support medical research.

Organize lectures and meetings between patients and doctors

**Name of Magazine & Frequency of Publication**

" L.E. LIEN " 4 times a year

**Activities of Group**

Three meetings a year.

Contact between members.

Publications in Dailies and Weeklies.

## CYPRUS

### **Name of Group**

*(in native Lang.)*

*Αντιρευματικός Σύνδεσμος Κύπρου*

### **Name of Group**

*(in English)*

*Cyprus League Against Rheumatism*

### **Chairperson**

*Mrs Foula Markidou*

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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.)*

*SLE-gruppen, Gigtforeningens diagnosenetwork for SLE / LED / Lupus*

### **Name of Group**

*(in English)*

*SLE-Group, The Danish Rheumatism Association*

### **Chairperson**

*Lene Witte*

### **Official Address & Tel. No.**

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### **Year Group established**

*1994*

### **Number of Members**

*240*

### **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 the SLE-Group edits and publishes a short newsletter for its members twice a year.*

### **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**

Marjatta Sykkö

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### **Year Group established**

1975

### **Number of Members**

659

### **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.

## **FRANCE –AFL+–**

### **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*

### **Chairperson**

*Marianne Rivière*

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### **Year Group established**

*1984*

### **Number of Members**

*930*

### **Population**

*61 000 000*

### **Aims of Group**

*Disclose information. Help exchanges about experiences nationally and internationally.*

*Help patients to defend their rights.*

### **Name of Magazine & Frequency of Publication**

*" Bulletin AFL+ " 4 times a year*

### **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.*

**Name of Group**

*(in native Lang.)*

LUPUS France

**Name of Group**

*(in English)*

LUPUS France

**Chairperson**

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E-Mail: [presidente@lupusfrance.fr](mailto:presidente@lupusfrance.fr)

URL: [www.lupusfrance.fr](http://www.lupusfrance.fr)

**International Contact**

Ginette Volf - Philippot

**Address of Contact & Tel. No.**

Rue de Rocroy 7

F-75010 Paris

France

Tel./ Fax: +33-1-45 26 33 27

E-Mail: [presidente@lupusfrance.fr](mailto:presidente@lupusfrance.fr)

**Year Group established**

1999

**Number of Members**

750

**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*

### **Chairperson**

*Borgi Winkler-Rohlfing*

### **Official Address & Tel. No.**

*Doeppersberg 20*

*D-42103 Wuppertal*

*Germany*

*Tel. : +49-202-496 87 97*

*Fax.: +49-202-496 87 98*

*E-Mail: [lupus@rheumanet.org](mailto:lupus@rheumanet.org)*

*URL: [www.lupus.rheumanet.org](http://www.lupus.rheumanet.org)*

### **International Contact**

*Rudolf Hocks*

### **Address of Contact &- Tel. No.**

*Hinterfeldstrasse 4*

*D-65520 Bad Camberg*

*Germany*

*Tel.: +49-6434-90 88 32*

*Fax.: +49-6434-90 88 33*

*E-Mail: [rhilupus@aol.com](mailto:rhilupus@aol.com)*

### **Year Group established**

*1986*

### **Number of Members**

*2800*

### **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 terme 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.*

## HUNGARY

**Name of Group**

*(in native Lang.)*

*Magyar Lupus Egyesület*

**Name of Group**

*(in English)*

*Hungarian Lupus Society*

**Chairperson**

*Details to be advised later*

**Official Address & Tel. No.**

*Details to be advised later*

**International Contact**

*Details to be advised later*

**Address of Contact & Tel. No.**

*See above*

**Year Group established**

*1993*

*February 1996 registered as a Non-Profit-Organisation*

**Number of Members**

*452 and 224 supporters*

**Population**

*10 300 000. Estimated SLE patients about 8,000-9,000 people*

**Aims of Group**

*Spread information, educate people about SLE and how to live with chronic illness, awareness, financial support, rehabilitation, establish and train in different areas where SLE patients can work with their changed health condition.*

**Name of Magazine & Frequency of Publication**

*Lupus Newsletter (3 - 4 times a year)*

*2nd edition of the Lupus info booklet*

**Activities of Group**

*Meeting 4 times a year, when doctors talk openly about SLE, cultural events, close contact with other self-help groups. Travelling and educating regional organisations. Talk about patients rights to all. We have our own web-site, and we can be found under the Hungarian Rheuma Organisation web-site also.*



## 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**

Laufey Karlsdóttir (Mrs) and Sigridur Gunnarsdóttir (Mrs)

### **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](http://www.gigt.is)

### **International Contacts**

\*Laufey Karlsdóttir and \*\*Sigridur Gunnarsdóttir

### **Address of Contact & Tel. No.**

\* Lindarsmara 57

IS-201 Kópavogur

Iceland

Tel.: +354-564-45 53

E-Mail: [laufey@gn.is](mailto:laufey@gn.is)

\*\* Hraunbaer 17

IS-110 Reykjavik

Iceland

Tel.: +354-567-23 11

E-Mail: [sigridgu@simnet.is](mailto:sigridgu@simnet.is)

### **Year Group established**

1994

### **Number of Members**

65

### **Population**

280 000

### **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](mailto:irishlupus@iol.ie)*

*URL: [www.lupus.ie](http://www.lupus.ie)*

### **International Contact**

*Mary Feehan*

### **Address of Contact & Tel. No.**

*See above*

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

*E-Mail [desfeehan@eircom.net](mailto:desfeehan@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](mailto:lupus@drc.co.il)*

*URL: [www.lupus.org.il](http://www.lupus.org.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](mailto: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 Publication 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**

*Giuseppina Politi*

### **Official Address & Tel. No.**

*Via Arbotori, 14*

*I-29100 Piacenza*

*Italy*

*Tel.: +39-0523-75 36 43*

*Fax: +39-0523-75 36 43*

*E-Mail: [info@lupus-italy.org](mailto:info@lupus-italy.org)*

*URL: [www.lupus-italy.org](http://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](mailto: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 bodies for social assistance about problems of disease.*

*Raise funds for research. Prepare informative material and organise meetings to study disease.*

### **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**

Ian C. Lochhead

### **Official Address & Tel. No.**

Lupus Support Group Malta

St Paul's Garden

IX-Xwieki

L/o Gharghur, NXR 09

Malta, GC

Tel.: +356-21 370 234

Fax: +356-21 377 402

E-Mail: [elizian@maltanet.net](mailto:elizian@maltanet.net)

### **International Contact**

Ian C. Lochhead

### **Address of Contact & Tel. No.**

See above

### **Year Group established**

1999

### **Number of Members**

50

### **Population**

400 000

### **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**

To be advised

### **Official Address & Tel. No.**

Bisonspoor 3004

NL-3605 LV Maarssen

The Netherlands

Tel.: +31-346-55 24 01

Fax.: +31-346-56 92 73

E-Mail: [info@nvle.org](mailto:info@nvle.org)

URL [www.nvle.org](http://www.nvle.org)

### **International Contacts**

Ineke Boomker

### **Address of Contacts & Tel. No.**

Niersstraat, 12

NL-5626 DW Eindhoven / Acht

The Netherlands

Tel : +31-40-262 35 09 private

E-Mail : [sj.boomker@hetnet.nl](mailto: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**

"N.V.L.E." 4 times a year

### **Activities of Group**

Bring patients together, housework meetings, meetings with doctors;  
trying to get publicity in newspapers, radio etc.

## **NORWAY**

### **Name of Group**

*(in native Lang.)*

*Lupus Foreningen 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.: +47-22-75 81 56*

*E-Mail: [flavoll@online.no](mailto:flavoll@online.no)*

### **International Contact**

*Fatima Maria Lavoll*

### **Address of Contact & Tel. No.**

*Bekkeveien 11*

*N-0667 Oslo*

*Norway*

*Tel.: +47-22-75 81 56 and +47-917-74 7 31*

*E-Mail: [flavoll@online.no](mailto: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**  
*Dr. Rita Andrea*

**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: [associacao.lupus@clix.pt](mailto:associacao.lupus@clix.pt)*  
*URL: [www.lupus.saudeglobal.com](http://www.lupus.saudeglobal.com)*

**International Contact**  
*Dr. Rita Andrea*

**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.*



## SPAIN

**Name of Group**

*(in native Lang.)*

Federación Española de Lupus

**Name of Group**

*(in English)*

Spanish Lupus Federation

**Chairperson**

Blanca Rubio Heméndez

**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](mailto:felupus@felupus.org)

URL: [www.felupus.org](http://www.felupus.org)

**International Contact**

Isabel Díaz

**Address of Contact & Tel. No.**

See above

**Year Group established**

1996

**Number of Members**

2057

(18 Associations)

**Population**

43 198 000

**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.)*

SLE/Sjögrenrådet - Reumatikerförbundet

### **Name of Group**

*(in English)*

The SLE-Sjögren-group

### **Chairperson**

Kerstin Källander

### **Official Address & Tel. No.**

Reumatikerförbundet

Box 128 51

119 98 Stockholm

Sweden

Tel.: +46-8505 805 12

E-Mail: [kerstin.kallander@reumatikerforbundet.org](mailto:kerstin.kallander@reumatikerforbundet.org)

URL: [www.reumatikerforbundet.org](http://www.reumatikerforbundet.org)

### **International Contact**

Kerstin Källander

### **Address of Contact & Tel. No.**

See above

### **Year Group established**

1986

### **Number of Members**

1200

### **Population**

88 837 500

### **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**

*SLE-Sjögrenrådets Infoblad 4 times a year to 250 contact persons*

### **Activities of Group**

*Local, regional and national support groups. Meetings, lectures, seminars and exhibitions.*

*Publishing articles, leaflets, etc. besides our periodical SLE-Bulletinen.*

## SWITZERLAND

### **Name of Group**

*(in native Lang.)*

Schweizerische Lupus Erythematoses Vereinigung (SLEV)

### **Name of Group**

*(in English)*

Swiss Lupus Erythematosus Association

### **Chairperson**

Erika Rosch

### **Official Address & Tel. No.**

Niesenstrasse 9

CH-3076 Worb

Switzerland

Tel.: +41-31-839 69 76

E-Mail: [me.rosch@gmx.ch](mailto:me.rosch@gmx.ch)

Url: [www.slev.ch](http://www.slev.ch)

### **International Contact**

Britta Krismer

### **Address of Contact & Tel. No.**

Bogenweg 15

CH-8620 Wetzikon

Switzerland

Tel.: +41-44-930 33 64

E-Mail: [b.r.y.krismer@bluewin.ch](mailto:b.r.y.krismer@bluewin.ch)

### **Year Group established**

1987

### **Number of Members**

500

### **Population**

6 968 000

### **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 :**

Katia Caravatti

Piazza da Sora

6997 Sessa

Tel.: +41-91-608 28 27

E-Mail: [katia.caravatti@freesurf.ch](mailto:katia.caravatti@freesurf.ch)

### **Contact for French speaking persons :**

Marie-Louise Hagen

Speerstrasse 5

CH-8305 Dietlikon

E-Mail: [malou.hagen@bluewin.ch](mailto:malou.hagen@bluewin.ch)

## UNITED KINGDOM

### **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](mailto:chris@lupusuk.org.uk)

URL : [www.lupusuk.org.uk](http://www.lupusuk.org.uk)

URL medical: [www.medical.lupusuk.org.uk](http://www.medical.lupusuk.org.uk)

### **International Contact**

Yvonne Norton

### **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](mailto:yvonne@wmlg.freemove.co.uk)

URL : [www.westmidlandslupus.co.uk](http://www.westmidlandslupus.co.uk)

### **Year Group established**

1978

### **Number of Members**

7500

### **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.*

**Slovenia -interim member-**

**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.: +386-1-436 22 80*

*Fax: +386-1-236 24 57*

*Mail: [drustvo@reumatiki.si](mailto:drustvo@reumatiki.si)*

*URL: [www.rematiki.si](http://www.rematiki.si)*

**International Contact**

*Marjan Hudomalj*

**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.*

## **OTHER CONTACT ADDRESSES**

### **POLAND**

#### **Polska Fundacja Toczni "Motyl"**

Chairperson : Agnieszka Plonkowska - Gronert

Ul. Kleczkowska 46/4

50-227 Wrocław

Poland

Tel./ Fax: +48-71-792 45 15

E-Mail : [biuro@fundacja.iweb.pl](mailto:biuro@fundacja.iweb.pl) or [a.gronert@interia.pl](mailto:a.gronert@interia.pl)

## **ELEF CONSTITUTION**

REVISED CONSTITUTION AGREED BY COUNCIL 12th SEPTEMBER 2003

### **1. NAME**

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

*EUROPEAN LUPUS ERYTHEMATOSUS FEDERATION (ELEF)*

### **2. OBJECTS**

2.1 *The objects of the Federation 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 the European Lupus Erythematosus Federation.*

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 the European Lupus Erythematosus Federation is open to all nationally registered Lupus 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.*

*The Federation shall also consider admission to nationally registered organisations bordering Europe.*

4.1.2 *Associate (non-voting) membership of the European Lupus Erythematosus Federation is open to additional regionally or nationally registered Lupus 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.*

*The Federation shall also consider admission to additional regionally or nationally registered organisations bordering Europe.*

4.1.3 *Following four years as Associate (non-voting) members of the European Lupus Erythematosus Federation, 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 shall be allowed one vote.*

4.5 *Each elected organisation shall be expected to offer full support to the Federation.*

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 the Federation 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 *Long-term Advisors co-opted by Trustees shall also serve on Council and shall carry one vote.*

5.4 *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.*

5.5 *Council shall set annual membership subscription rates for both full and associate member organisations.*

5.6 *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.*



## **6. TRUSTEES**

- 6.1 *The general administration of the Federation shall be undertaken by the Trustees.*
- 6.2 *The Trustees shall consist of the Chairperson, the Vice-Chairperson, the Secretary, the Treasurer and the Special Projects Officer. The Trustees may co-opt up to a maximum of three long-term Advisors at any time for special purposes. Other Advisors may be co-opted for a specific short-term project and, in this instance, shall be non-voting.*
- 6.3 *The Trustees shall be elected by Council, shall hold office for four years and shall be eligible for re-election.*
- 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 the Federation 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 the Federation 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 the Federation, the publication of accounts and the recommendation of Auditors to the Trustees.*

## **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 the Federation to cease to be a charity in law.*

## **9. DISSOLUTION**

- 9.1 *The Federation 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 the Federation, 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 the Federation but shall be given or transferred to such other charitable institution or institutions having objects similar to some or all of the objects of the Federation as the Federation 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 (LUPUS UK Representative to ELEF)  
Brian Hanner (Projects Advisor)*

*Agreed by ELEF Council, Belgium, 12<sup>th</sup> September 2003*

*Approved by Charity Commission 27<sup>th</sup> August 2004  
– recorded from 12<sup>th</sup> September 2003*