



## THE BROADSHEET

April 2007

### **ELEF CONVENTION IN SEPTEMBER**

The ELEF Convention takes place in Mainz, Germany from Wednesday 12<sup>th</sup> to Sunday 16<sup>th</sup> September inclusive.

ELEF (Ineke Boomker, Trustee) will before end-May be sending out venue and booking information and all the member groups are warmly invited to send one or two delegates.

A full agenda is planned, and as usual those attending will have the chance to exchange ideas and details on lupus and other issues.

### **ELEF MEMBERSHIP UPDATE**

We were pleased to welcome Cyprus into membership at the 2006 Convention and hope their stay will be long and happy.

Poland and Slovenia are being encouraged to take up membership but the funding that they need to attend their first meeting is proving difficult. The Trustees of ELEF will be considering this issue in the hope that costs assistance is somehow possible.

### **WORLD LUPUS DAY ON MAY 10**

For the fourth successive year we can celebrate this national / international day in conjunction with lupus member groups across the world.

Did your group receive the publicity materials again kindly developed by the Lupus Foundation of America?

If not, mail Mary Worstell at the LFA ([worstell@lupus.org](mailto:worstell@lupus.org)) and she will soon have the excellent pack with you.

### **COMMUNICATION BY ELEF**

The Trustees are striving to find ways whereby ELEF can upgrade methods of communicating in a strong, lasting way. Member countries, Europe and other links are part of the target area for these two-way partnerships.

Jean-Paul Sanders, Chairman of ELEF, declared this intention in his article for 2006's edition of Caring & Sharing.

### **THE ELEF TRUSTEES**

Recommendations are in hand to hold the **elections of the Trustees** at every Annual Convention and thereby to elect individuals on a rotational yearly basis rather than all positions on every fourth year as at present.

**Extra posts** are in mind and younger colleagues are to be attracted in as Trustees to ensure continuity and progression with new ideas and fresh enthusiasms.

**The January meeting** of the Trustees was pleased to welcome observers from Spain, Denmark, Norway and Belgium (Flemish), all of whom took a full part in proceedings and were able to comment openly on established and future procedures. At end-June the Trustees and observers will meet again and consider the suggestions made above.

**Proposals will go forward to the Mainz Convention** where strong emphasis will be made on future developments and on recruitment of more people to strengthen ELEF.

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REGISTERED CHARITY No. 803768

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



### ELEF FUNDING I

In 2006 a small number of member groups were able to respond to an Appeal by the Trustees for one-off donations to help facilitate the fundraising project currently in hand. Some further groups may yet wish to help fund this vital project and they are invited to contact the ELEF Treasurer, Peter Norton ([peter@wmlg.freemove.co.uk](mailto:peter@wmlg.freemove.co.uk)) to know how best to make donations. Thanks are due to kind providers, also to any other groups who may be able to assist.

The fundraising project focuses on five major areas where ELEF wishes to increase knowledge about lupus and of support facilities already in place for patients or which it might be possible to develop.

The Trustees record with thanks a valued donation of 10,000 euros received in this Spring from a lady in Kent, UK who generously wishes to support our work. More donation funding is urgently needed in this way – please !

#### SHANGHAI CONFERENCES 2007

The three-yearly Clinical and Patient events take place between May 23 and 27 in the new location of Shanghai, China. Around 1,000 clinicians will attend to hear about the latest lupus research and drug development whilst some hundreds of patients expect to attend their separate informative sessions.

#### THE INTERNATIONAL PANEL

Some six colleagues from across the globe together with two senior LFA officers have worked together in the task of finalising World Lupus Day 2007 materials. Some will convene in China also to determine the possibility of creating a standing global body.

### ELEF FUNDING II

Following on from the above, it is much hoped to find funding for the translation and printing of leaflets and other materials, to help the existing member groups to extend facilities and to help other countries to establish support groups for the very first time. Funding for subsidised consultant visits to assist is sought together with other monies which will help to support and expand the ELEF Trustee function.

Full explanation of the wishes of the ELEF Trustees will be put in front of the ELEF Council in Mainz for deliberation and approval.

#### OTHER INFORMATION

**Butterfly Traveller** – another 23 copies of this publication are languishing in archives within ELEF..... If any member country is needing more copies kindly make contact with Brian Hanner on [brian@hanner.org.uk](mailto:brian@hanner.org.uk)

A second regional **Drop-In Clinic** for the Lupus patient has been established in the UK in Norfolk. These clinics give great opportunities for patients to mix without appointments with doctors and nurses.

#### ABOUT ELEF

The **Register** of ELEF is updated by the Vice-Chairman of ELEF, Rudi Hocks at [rhilupus@aol.com](mailto:rhilupus@aol.com). He can also advise if queries on the **ELEF website** at [elef.rheumanet.org](http://elef.rheumanet.org).

The Trustees endeavour to publish the **Caring & Sharing magazine** at each year-end, also the **ELEF Broadsheet** in April and October every year. Send in any information we might use !

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