

EUROPEAN LUPUS ERYTHEMATOSUS FEDERATION



CARING & SHARING

THE NEWSLETTER OF ELEF - WINTER 2006

A MESSAGE FROM THE CHAIRMAN

Dear Friends,

After the elections of 2005, it is the first time that the Board of Trustees could show to the member countries the interesting work which they have been performing during the past 12 months.

But let me first of all express my gratitude to the Norwegian Lupus Foundation and the Norwegian Rheumatism Association. These two organizations were hosting the 17th Annual Convention in the splendid town of Bergen from the 06 – 10 September. All the delegates present at the Convention agree that we were in good hands and had time for business and time for leisure (the marvellous tour of the fjords). Many thanks to all concerned.

As you all have noticed, we have an excellent team now and a lot of good work has been done. This Board of Trustees has been preparing a structure for the future within ELEF and put in place guidelines for the years to come.

In a much more global environment, ELEF has to be able to act as the “service provider” for all Members Countries under its wings. It is very clear that we have to move into a well performing organisation. Internal communications with own

Members and external communication with the European Union has to be brought to a higher level. The only way to get there is by moving into a professional organisation. Without money, this objective cannot be achieved and the necessary steps are being implemented.

Our future is also the youth of today! The Board of Trustees is very happy to assist the younger members with their active participation. In this respect they prepare themselves to take over responsibilities and are getting themselves more involved in the daily operations of ELEF.

A newcomer to our Annual Convention was Cyprus. This member country has been voted as a Full Member of ELEF. Congratulations and thank you for being with us. I am convinced that we are approaching interesting times. Do not forget the Patients and Doctors Conference in Shanghai, in May next year.

Getting close to the end of the year, I wish all of you a Wonderful Christmas and a Very Prosperous 2007.

Jean-Paul Sanders

UNITING PEOPLE WITH LUPUS ACROSS EUROPE

ST. JAMES HOUSE, EASTERN ROAD ROMFORD, ESSEX, RM1 3NH, UNITED KINGDOM
REGISTERED CHARITY NO. 803768

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

SECRETARY'S REPORT

Meetings of ELEF Trustees were held in September/October 2005 in Amsterdam, in January 2006 in Belgium and in June 2006 in Düsseldorf. Two further meetings were held in Bergen before and after the Convention 2006.

During the first meeting, the Annual Convention held in Bergen was discussed whilst the Convention 2007, being held in Mainz, Germany was confirmed.

The last issue of CARING AND SHARING was printed and distributed by the Dutch Lupus Group at no cost to ELEF. This generous gesture was greatly appreciated.

An exhaustive Agenda was set for the January 2006 meeting in Belgium. The Trustees had a thorough look at ELEF's finances, membership, publications, website, World Lupus Day, formation of new Groups, Convention guidelines and the creation of a Management Manual and a Development Plan. These were initiated last year and discussed in detail this year. The June meeting in Germany continued to elaborate on the January meeting, particularly on the most pressing subject, i.e. ELEF's finances.

The London Marathon provides the bulk of much needed funds necessary for our continued existence. Members' subscriptions, although very much appreciated, adds very little to our fund.

The Fundraising project expected to start soon should give a boost to our financial balances.

By now, all Presidents and National Groups have received a letter asking for contributions towards funds. This is a "one-time" contribution and I am sure that all Groups will contribute according to their financial resources.

Four new members have applied to join ELEF. These are Cyprus, Romania, Poland and Slovenia. Cyprus was formally admitted as a full member, with Slovenia and Poland as "interim members".

ANNUAL CONVENTION 2006

Bergen, Norway

The 17th Annual Convention of ELEF was held at the Scandic Bergen Airport Hotel, two kilometres away from Bergen airport in Norway. Our hosts, The Norwegian Rheumatism Association (NRF) in conjunction with the Norwegian Lupus Group, made everybody feel at home from the very first day of our Convention.

A sightseeing tour of the famous city of Bergen was organised. After a short walk around the city, we took a cable car to Mount Fløyen where we were guests of the Bergen Municipality. The Vice Mayor greeted us and during a lavish reception he delivered a short speech of welcome, to which our Chairman replied. On our way back to the hotel, we stopped at a beautiful village to experience going under a magnificent waterfall.

The Convention was attended by 24 delegates from 12 different countries and various items of interest were discussed. Full Convention Minutes have been sent to all concerned.

Three physicians addressed the Medical session of the Convention.

Dr. Roald Omdal MD spoke on "What does Lupus do to the Brain", whilst Dr Johan Brun MD delivered a lecture on "SLE and Cardiovascular Disease".

A highly interesting and demonstrative lecture by Dr. Audun Myskja MD entitled "Can music heal? A cultural expression becomes part of medicine" closed the session.

We say thank you to our Norwegian hosts and look forward to our next meeting in Mainz, Germany, next September.

Our website will be reviewed in June 2007.

The Management Manual is in its final stages of completion and should be available by the end of this year. Tangible results should be visible by the first half of next year.

Anthony M Bonello

BORN BEFORE 1986?

According to today’s regulators and bureaucrats, those of us who were kids in the 60’s, 70’s or early 80’s, probably should not have survived...because:

- Our baby cots were covered with brightly coloured lead-based paint which was promptly chewed and licked;
- We had no childproof lids on medicine bottles, or latches on doors or cabinets and it was fine to play with pans;
- When we rode our bikes, we wore no helmets, just sandals and fluorescent “spokey dokeys” on our wheels;
- We would ride in cars with no seat belts or airbags and riding in the passenger seat was a treat;
- We drank water from the garden hose and not from bottles and it tasted the same;
- We ate chips, bread and butter pudding and drank soda stream with sugar in it, but we were never overweight because we were always outside playing;
- We shared one drink with four friends from one bottle or can and no one actually died from this;
- We would spend hours building go-carts out of scraps and then went top speed down the hill, only to find out we forgot the brakes;
- After running into stinging nettles a few times, we learned to solve the problem;
- We would leave home in the morning and could play all day, as long as we

were back before it got dark. No-one was able to reach us and no-one minded;

- We did not have Play stations, no video games, no ninety nine channels on TV , no mobile phones, no DVDs, no personal computers and of course no internet chat rooms. We had friends and went outside and found them;
- We fell out of trees, cut ourselves, broke bones but there were no law suits;
- We walked to friends’ homes and believe it or not, we also walked to school, we did not rely on Mum or Dad to drive us to school;
- We made up games with sticks and tennis balls. We rode bikes in packs of 7 and wore our coats by only the hood;
- The idea of a parent bailing us out if we broke the law was unheard of.....they actually sided with the law;
- This generation has produced some of the best risk-takers and problem solvers and inventors ever;
- The past fifty years have been an explosion of innovation and new ideas;
- We had freedom, failure, success and responsibility, and we learned how to deal with it all and YOU are one of them...

CONGRATULATIONS!

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WHEN THE SUN SHINES

A warm morning sun always ushers in a certain kind of awe. It ignited zeal and energy within “Odapus” (person living with Lupus) volunteers and friends on the morning of May 9th and 10th when they roamed the main streets of Bandung, Indonesia to distribute stickers that invite care and share information about Lupus. Concurrently a talk-show rally was broadcast on various local radio and TV stations. It was quite exhausting days for an Odapus friend.

No one could fathom where the energy came from, but everyone knew for sure that those in action were determined to voice the heart contents and echo the message of care. Sincere will and determination were infused into the efforts, as was obvious in the memorial service on World Lupus Day, with the families of Odapus who had passed away. The remembrance of life with them and their departures fanned the fires to continue walking the line. Nothing is more powerful than a realization that life is such a precious opportunity given by the Almighty. Life is the chance to gather what truly matters in eternity. This realisation inspired a volunteer to share a song during “Odapus Friend in Memoriam:

No Time Wasted

*It was still a long road
For you to journey on
All the way, downhill and uphill
You don't need to fret upon*

*The time left was not wasted
As long as you know for sure
Where His signs have directed*

*Every breath is grace
Worthy beyond the values of this world
That's the breath you embrace*

*The Almighty One
The Most Sovereign One
keeps the promise
of this life to rise*

A string of extraordinary actions happened again at the peak of WLD 2006 at Bandung Institute of Technology's West Hall. There were two major events on campus that day. At the same time as the modest World Lupus Day commemoration, a glamorous Journée Français (The French Day) was run hosted by a top public relations firm featuring a full band, cabaret and, of course, croissant. However, a Lupus volunteer of French nationality made time instead to translate the information on Lupus in French. This was what WLD was all about, sincere desire to share feelings, experiences and knowledge.

Ultimately, the intent was to share love born from empathy, sympathy and care. If not by this intent, why would the volunteers and all who were involved work so hard together without expecting any returns for themselves?. They are not Lupus patients, nor have family members who live with Lupus – but they were willing to do good to help others. Have a look at pro-bono consultation booths run by various specialist doctors who care about Lupus. There were thirteen of such, clearly saying that Lupus needs an integrated management.

One can only imagine the extent of treatment a Lupus patient needs when his/her Lupus has become systemic. The integrated consultation model displayed in WLD 2006 began in 2004 and hopefully the approach will be adopted by various hospitals, starting with Hasan Sadikin Hospital which would pilot the model in June 2006

Everything done on the day started with a dream, not wishful thinking but one forged with zeal and hard work. An architecture student who created a design for Lupus Hospital as her final year project may have her dream come true someday.

The initiative to open channels for cheaper medicine also began with simply collecting 1,500 signatures from supporters across many areas in West Java, Jakarta and

Lampung, representing the hopes of Odapus friends around Indonesia.

The plan was to send a small Care for Lupus – Syamsi Dhuha team of Odapus representatives, doctors and volunteers for an audience with the Indonesian Minister of Health to follow up this initiative. May the interviews open a channel for Odapus friends who have been squashed and pinched by high costs of medicines. Listen to the plea from an Odapus friend, "Ema". "Sister, I want to take medication but I cannot afford it". It is easy to understand why. The medication to manage her illness cost around \$3.00 each and she has to take 3 to 4 tablets a day. Another friend "Siti" had to rush to hospital as her condition deteriorated because she could not afford medicine for two months. She only takes medicine when she has money to buy it. When a Care for Lupus volunteer designed the poster "Open Your Eyes for Lupus" he was beckoning others to care.

Is this where initiatives stop? Certainly not! A research growth has been facilitated as well. The number of theses on Lupus may be less than ten to-day but the number has grown compared to two years ago when Care For Lupus - SDF began in Bandung. In fact, one of the recent theses received a recognition in a national science forum. More and more people attend the annual event at West Hall ITB, rising from 250 to 400 people in the past two years. The Lupus consultation stands grow from 6 to 11. Last but not least is the signing of a care charter by representatives from the hospitals to show their intent in improving health services and from the pathology clinics and pharmacies that provide special discounts for Lupus patients.

At the climax of WLD 2006 celebrations, 3 volunteers presented a butterfly dance in colourful costumes. The delightful eye-catching dance invited all to see the pretty side of a butterfly instead of the "butterfly rash", an unwelcome mark that typically appears on the face of an Odapus friend at the onset of the illness. The dancers graciously carried forward a souvenir to an

Odapus friend sitting on his wheelchair and to the representative of doctors who care about Lupus. Their gentle movements whispered "Thanks, Doc. Your caring saves lives." The psychiatry session "Serene Souls Make Lupus Fly Away" enlightened a group of medicine students who rode a long way from Lampung on their motorcycles. We salute their strong will to continue learning and attain knowledge from the Supreme Scholar. Hopefully one day we would no longer hear a plea from an Odapus friend from the tips of Sumatera and Kalimantan for the right treatment by a doctor who cares about Lupus.

The butterfly icon was also manifest in bright colours on canvas by a volunteer. The choice of colours was deliberate, an attempt to inject zeal in Odapus friends and all who care to never give up despite the problems that have to be overcome not only medically but also socially and economically. A rock solid motivation to continue fighting Lupus is crucial, from the time, "the butterfly lands" until "the butterfly departs", or, if it does not go away, how to live with it.

This is another dream, that one day we will know what causes Lupus so that we can prevent and heal it. No more endless medication, no more continuous side effects and long-term complications. Odapus friends want healing not treatments. As small as the possibility may be for this dream to come true, the seed of care has been sown. One does not know when it will bear fruit or when a harvest can be gathered. What matters now is to continue making initiatives and being a value of kindness to those that champion the cause. Does the Almighty and the All Loving treasure the journey?

Editor's Note:

The writer of this article is *Dian Syarief*, Chairperson of CARE FOR LUPUS – SDF, Bandung Indonesia. She lost her eyesight some years ago and everything she wants to write has to be dictated to someone else.

OUR MEDICAL ADVISOR WRITES...

Management of Systemic Lupus Erythematosus (SLE)*First Evidence-based guidelines*

The Lupus community is expecting that some new drugs will become licenced for indications in Lupus in the next few years. Those drugs will hopefully offer new options especially for patients who do not respond to the currently-used drugs or who react with side effects. In current clinical trials, the new drugs are mostly tested for the indications of lupus nephritis and major flares. This strategy may limit the future indications of these substances, but from the pharmaceutical company side there is a need for these focussed indications because only a clear aim will hopefully bring up the benefits of the new substances.

However, does this strategy lead to new options for the patients who urgently need alternatives? Is this the greatest need for Lupus patients with nephritis? To answer these questions, it is necessary to analyse what is proven in the management of SLE and where the needs are. The European League against Rheumatism (EULAR) therefore set up, in 2005, a task force of 19 Lupologists that reviewed more than 8,000 papers relating to Lupus and its management to come up with evidence-based recommendations for SLE.

It is well known that in SLE the variations in management are enormous. This is mostly explained by the rarity of SLE, by its heterogeneous expression and by the very limited number of so-called randomised controlled trials, studies with the highest quality. The evidence-based medicine (EBM) approach is to categorise clinical trials and so help to separate what is really proven and what we only believe. EBM thereby supports decision making in daily practice and improves the quality of management.

The EULAR lupologists identified 12 most important questions in the management of Lupus and answered them on the basis of the existing literature. These answers will

be published soon in the annals of rheumatic diseases. As the 19 lupologists represent 12 European countries we hope that this important positive information will soon find its way to the European SLE self-help groups and to the GPs. The task force also identified grey areas during the process of developing the recommendations where there is an urgent need for more information. What are these areas? How can we improve an earlier diagnosis of Lupus? Is it possible to screen for people who are at high risk and to prevent SLE completely before manifestation? There is an obvious need for more sensitive and scientific diagnostic criteria.

One important field is environmental factors. It is well accepted that UV radiations may induce exacerbations of Lupus, but are there other environmental factors that may contribute to the development and activation of Lupus? We recommend some protection, but how important is it to stop smoking for the course of Lupus? There is no doubt that smoking carries the risk of lung cancer and supports the development of arteriosclerosis, but there is also clear evidence that smoking facilitates Lupus. There is less evidence to recommend a specific diet, but diets are not carefully analysed in Lupus.

Concerning treatment, we especially need options for resistant organ involvement and also for resistant mild disease, for example rashes. Surrogate markers for active disease will help to find more precise indications for starting and, at least similarly important, for stopping therapies. What are the best strategies to prevent so-called co-morbidities, which are in SLE especially based on accelerated arteriosclerosis, for example stroke for heart attack?

Most of these unsolved questions and problems are not in the scope of pharmaceutical companies. Therefore we cannot expect that they will sponsor clinical trials in these areas. We need more

investigator-driven trials that address these questions and because high numbers of patients are needed for such studies, an international approach is necessary which means high costs.

How can the patients and their self-help groups in Europe support the initiation of international small budget trials that help answer their urgent questions?

One option may be to start a process to identify one question they would all go for. Is there one problem, in the view of the patients, that has the highest priority in all countries so that all are willing to start a unified campaign for it? The process should start from the base-point, from the local support groups in every country. Can

you imagine the power and strength of the consensus process already, and much more of the one identified target that all will aspire to in their regions and countries and will address to the authorities up to the European Parliament?

All European Lupus patients, with their relatives and friends will then speak with one voice and everyone will hear the challenging message. This is a proper task and challenge for the ELEF organisation and its member groups from the European countries.

Prof. Dr. med. Matthias Schneider
University of Düsseldorf



Human Genome Sciences advances
Belimumab into Phase 3 clinical trials for
Systemic Lupus Erythematosus

Human Genome Sciences (HGS) and GlaxoSmithKline (GSK) are initiating two large Phase 3 clinical trials of Belimumab in Systemic Lupus Erythematosus (SLE) in late 2006. Belimumab is a human monoclonal antibody that specifically recognizes and inhibits the biologic activity of B-Lymphocyte stimulator, or BLYS™.

The Phase 3 trials were designed in collaboration between HGS and GSK, together with leading international experts, and aim to enroll more than 1600 patients with active SLE. To our knowledge this is the largest clinical trial program undertaken to date researching a new drug in this disease.

Human Genome Sciences has met with both the European Agency for the Evaluation of Medicinal Products (EMA) and the U.S. Food and Drug Administration (FDA), and has received agreement on the major components of the Phase 3 program including the primary efficacy endpoint, target patient population, and dose selection.

Human Genome Sciences is a biopharmaceutical company with a mission to discover, develop, manufacture and market innovative drugs that serve patients with unmet medical needs.

Early clinical and preclinical results to-date has demonstrated the potential safety and efficacy of Belimumab enabling progress to the Phase 3 program.

This Phase 3 development program will include two double-blind, placebo controlled, multi-center Phase 3 superiority trials, BLISS-52 and BLISS-76, which will evaluate the efficacy and safety of Belimumab plus standard of care, versus placebo plus standard of care, in the treatment of patients with active SLE. Approximately 1600 patients will be enrolled through 2007.

If you would like to learn more about the BLISS studies, visit www.clinicaltrials.gov or call Human Genome Sciences at 001 (866) 447 – 9749.

SPOTLIGHT ON.....the Lupus Erythematodes Self-Help Community – Germany



History

The founder of the LE-SHG e.V. (Lupus Erythematodes Selfhelp Community e. V.) was Karin Hilmer, a woman who suffered from Lupus. There were about 40 Lupus Patients who she gathered in the area of Dortmund (Ruhr-District) in monthly meetings to have medical talks by helpful doctors on Lupus but also to help each other cope with their dreadful disease.

In October 1986 the LE-SHG e.V. was founded. Her basic idea in founding this group was that she was convinced that help for self-help would be the proper way for lupus patients to cope with their disease. There are 8 persons on the board including 2 medical advisers and all of them work voluntarily.

What did we achieve in 20 years?

First we started to form regional groups across Germany and we are very proud to have now 3,000 members in 83 regional groups and another 5 will be initiated this year. Those regional groups are organised within the LE-SHG and are led by lupus patients. They are the cells where lupus patients are really looked after and where they get help in medical, social and legal ways. In their regular meetings they get new information about lupus, they exchange their experiences etc.

In 1998 Karin Clement, the wife of a German politician became our patron. She is not only a wonderful lady but her engagement for the LE-SHG is tremendous. It has to be said that since she has been our patron the donations for our organisation have made a jump in the right direction. This allowed us to establish in the following year our head-office where 3 ladies are working part-time. Right from the beginning of our group we produced a magazine with the name “Der

Schmetterling” (Butterfly). At the beginning it was a four page A4 simply-made newsletter. Today it is an A5 booklet with 68 pages full of medical, psychological and legal information. There are also events (workshops, meetings) announced and one can read about experiences of lupus patients. Our magazine is also valued by many doctors. It is published 4 times a year.

There are about 10 workshops and 5 seminars each year on offer for our members. We also give medical, legal and social advice to our members and in case of emergency we can arrange an appointment with a lupus specialist or name the nearest hospital which has experience with lupus.

There is a program called “Training the Patient”. It was developed by the German Association for Rheumatologists, Merck AG (pharmaceutical company) and the LE-SHG. It is a seminar consisting of 6 Modules; they are diagnostic, similar diseases like lupus, pregnancy and hormone therapy, therapy of lupus, coping with lupus, avoiding stress etc. The seminar takes place on 4 evenings. The doctors and psychologists who are training patients are also trained before they are allowed to do the training.

Since May this year we have a new layout of our website (www.lupus.rheumanet.org). There are 2,000 – 3,000 daily calls to this website. Once a month there is a chat with experts. A chat-room is also available where the members can chat with each other 24 hours a day. A discussion forum can also be used by our members.

Every 2 years the LE-SHG announces the Award for Lupus Research. This is very important for our group to stimulate the research of lupus. Therefore we started in 2001 the Lupus-Longtime-Study at the University of Duesseldorf. It is a study

about the progress of lupus with patients for 10 years and includes not only medical but also psychological, legal and political questions. It is solely financed by our group. More than 800 Lupus patients take part in this study. There were already 3 projects being funded by our group before this one. For our 20th anniversary which we celebrated in May 2006 our group made itself a very nice and helpful present. The LUPUS FOUNDATION GERMANY was set up. The task of this foundation is the support of scientific research on Lupus. Now we do hope to get many big donations and legacies.

The Future

There are some new projects in the pipeline like the ICF-Score, a study about Inception Cohort, Lupus passport, etc. The ICF-Score study is recognised by the University of Vienna and the LE-SHG; their members were asked to participate in this study which is financed by the WHO. Its aim is the knowledge of the restrictions and limitations of lupus patients in their normal way of life. The participants receive 4 times a questionnaire by mail and after answering this questionnaire have to send it back by mail. The participants received a code by our head-office and only they know the names of the participants, so the anonymity of the patients is guaranteed.

Network Lupus

Right from the beginning we became a member of the LFA (Lupus Foundation of

America) and when ELEF was established we belonged to the founding body. The relationship between a lupus patient and her/his doctor is of the utmost importance.

Therefore we established a sound relationship between our group and doctors and we are members of the German Association of Rheumatologists, EULAR and Net of Competence of Rheuma.

We are also member of the German Rheumaligue. There are two other big organisations for other chronic diseases with whom we are working closely together. In 2005 the ACHSE (Alliance of Chronic Rare Diseases) was founded. We are one of the founding members. Although our main focus is on the well-being of lupus patients we noticed lately that it is very important for our group and our work to focus on politics.

Our chairwoman is a member of some working groups where NGOs, organisations of doctors, officials of Ministries are discussing the preparation of new legal laws. For us it is very important and helpful to fight there for the rights of lupus patients.

In Conclusion

The story that you have been reading started over twenty years ago and now our Group must achieve double the amount of work in the next 20 years – wish us well !

Rudolf Hocks

THE ELEF ANNUAL CONVENTION 2007

The 18th ELEF ANNUAL CONVENTION will be held in the German town of Mainz between the 12th and 16th September 2007.

The Trustees and Members of ELEF extend their thanks to our German hosts.

ARE YOU DRINKING ENOUGH WATER?

.....*Your health could depend on it*

Next to air, water is the element most necessary for survival. A normal adult is 60% to 70% water – we can go without food for almost two months but without water for only a few days. Yet most people have no idea how much water they should drink. In fact some run the risk of living a dehydrated state, especially older people who ‘never feel thirsty’.

Without water we would be poisoned to death with our own waste products. When the kidneys remove uric acid and urea these must be dissolved in water. If there isn't enough water, wastes are not removed as effectively and may build up as kidney stones. Water is vital also for chemical reactions in digestion and the body may not metabolise fat adequately. Retaining more fluid also helps keep the weight up.

The minimum daily water intake for healthy people should be around eight to ten 220 millilitre glasses each day and we need more if we exercise or live in a hot climate. Those who are overweight should drink an extra glass for every 4 kilos by which they exceed their ideal weight. We should consult our own doctors for their recommendations.

If you convert to drinking the above quantities, you may wonder if you'll spend lots of time in the bathroom. The answer is ‘yes’ initially but after a few weeks your bladder tends to adjust and you urinate less

frequently but in larger amounts. Your water intake should be spread evenly throughout the day and evening and by drinking this volume of water you could be on the way to a healthier and leaner body. Water carries nutrients and oxygen to the cells through the blood and helps to cool the body through perspiration. Water also helps to lubricate the joints.

We need water to breathe – our lungs must be moist to take in oxygen and let out carbon dioxide. It is possible to lose half a litre of water each day just through inhaling.

If we do not drink enough water we might impair every aspect of our physiology. By not drinking enough water many people incur poor muscle tone and size, and suffer decrease of digestive efficiency and organ function. Also possible are increased toxicity in the body, joint and muscle soreness and water retention.

If we do not drink enough water our bodies may retain water to compensate. It's a paradox that fluid retention can be eliminated by drinking more water not less and proper water intake is suggested as one of the keys to weight loss.

Do we have any choice? Drink more water!!!

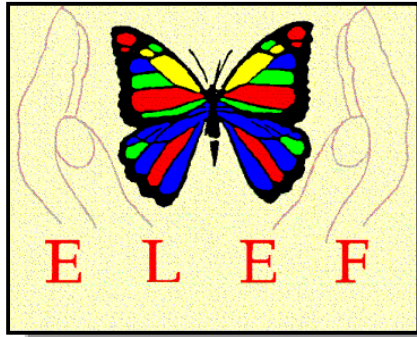
Brian Hanner

6th SPANISH NATIONAL LUPUS CONGRESS 2007

The Spanish Lupus Federation is co-organising its 6th National Lupus Congress with the Association of Galicia. It is being held on the 11th and 12th May, 2007 at the Auditorium of Galicia, Santiago de Compostela.

During those days there will be conferences about Stress, Psychological resources, Pregnancy, Cardiovascular risks, new treatments and Prognosis of Lupus. Besides, we are also preparing a complementary programme which includes Pilgrim Mass in Santiago Cathedral and sightseeing in the City.

For further information and to attend the Congress, please contact FELUPUS by e-mail : felupus@felupus.org or visit our website: www.felupus.org



PICTORIAL
SUPPLEMENT



17th Annual ELEF Convention
6th September – 10th September 2006

SCANDIC BERGEN AIRPORT HOTEL
BERGEN, NORWAY

All Photographs courtesy of Rudolf Hocks

Beautiful Bergen – City tour



At the Mayor's Reception



CONVENTION MEETINGS



Medical Session – Can music heal?

A cultural expression becomes part of medicine.





**DELEGATES ATTENDING THE 17TH ELEF CONVENTION
IN BERGEN, NORWAY
6TH SEPTEMBER – 10TH SEPTEMBER, 2006**

Berland Norvald, *Norway*
 Buijsrogge Hans, *The Netherlands*
 Bonello Anthony, *Malta*
 Bonello Yvonne, *Malta*
 Boomker Ineke, *The Netherlands*
 Caeyers Nele, *Belgium*
 Canzona Augusta, *Italy*
 Eide Anna-Britta, *Norway*
 Feehan Mary, *Ireland*
 Hamon Andrée, *France*
 Hanner Brian, *United Kingdom*
 Honne Karin, *Norway*

Hocks Rudolf, *Germany*
 Iosif-Stylianou Iosefina, *Cyprus*
 Krismer Britta, *Switzerland*
 Lavoll Fatima, *Norway*
 Lerstrom Kirsten, *Denmark*
 Marchiori Francesca, *Italy*
 Norton Peter, *United Kingdom*
 Norton Yvonne, *United Kingdom*
 Rasmussen Hanne, *Denmark*
 Riviere Marianne, *France*
 Sanders Jean-Paul, *Belgium*
 Verwerft Frie, *Belgium*

Number of delegates: 24 Number of Countries: 12

Members not present: Finland, Hungary, Iceland, Israel, Portugal, Spain and Sweden

TOTAL NUMBER OF ELEF COUNTRIES: 19

NATIONAL REPORTS 2006

BELGIUM (Flemish)

This year we are celebrating our 25th Anniversary. The League which was founded by a few patients in 1981, has now grown into a 700 member strong Group.

During this year we organized special events such as Vasculitis Day and Sjogren's Day, where members obtained specific information on these illnesses. A large celebration was held on the 16th September, where national and international doctors spoke on developments in the medical world, focussing on the role of the patient in the treatment programme. This was followed by a Reception, Dinner and Cabaret.

Also this year, together with four other Flemish Groups, we started Reumanet (similar to CLAIR in the French-speaking part of Belgium) where we talked about joint projects. Reumanet was also present during the EULAR Conference held in Amsterdam.

Our quarterly magazine had a special 25th Anniversary issue where we paid special attention to the history of the League and the medical developments in the field of CTD over the years.

A new brochure, containing specific information on our six pathologies, is being printed.

Nele Caeyers

CYPRUS

The Cyprus League against Rheumatism was founded on 12 December, 1984 and at present has around 1800 members. It is governed by a 21-member Board and is a voluntary, non-profitable organisation with offices in Nicosia. Among its main goals, one finds the provision of free medicines, action to found scientific centres for the need of sufferers, scheduling lectures and publishing of information to enlighten patients, the development of activities and co-operation with government and other bodies both locally and abroad for the promotion of these goals.

It organises several programmes such as recreation and support, information and training, physiological, social and moral support, physiotherapy and self-help, educational and staff training for volunteers.

Provision of "at home" care, companionship, escort to the doctor and shopping assistance are services provided by the League.

It keeps in contact with various government ministries, organises seminars, an Annual week for patients, social and recreational events such as lunches with journalists, an annual cruise for members, Christmas tea party and other social and fund-raising activities.

This year we joined ELEF as FULL MEMBERS.

Iosifina Iosif-Stylianou

DENMARK

We have been members of ELEF for a year and the good ideas and inspiration from last year's Convention have already been integrated into our activities.

Awareness is very important as Lupus is still unknown both by the general public and the medical profession. A recently produced butterfly pin has been distributed in our community. World Lupus Day was celebrated for the first time and more than one hundred participated including patients, delegates from Norway and Sweden, relatives and professionals. The event was quite successful and plans for next year are already in place.

Our website www.sle.dk has been renewed – among other things an improved interface for the forum facility together with an English presentation. This site is both popular and useful. A new Group has been established - SLE South, under close collaboration with our core Group. We also keep a close contact with our sister organizations in Scandinavia and the SLE Group in Iceland.

Kirsten Lerstrom

FINLAND

The Finnish SLE group was founded in 1975. The activities were started by a newspaper announcement calling all SLE patients to attend an inaugural meeting.

In August last year the Group arranged a week end long celebration at the Rehabilitation Centre to celebrate its 30th Anniversary.

In honour of this occasion two awards were granted by the SLE research fund. One of the recipients Dr. H. Julkunen gave a lecture with the theme “Lupus in the past and today”. A poster exhibition on SLE activities was also organized. Approximately 60 people took part. This included representatives from the Finnish and Estonian Rheumatism Associations.

The Group has continued to publish the newsletter twice a year, with a Special edition published for our anniversary.

We updated the SLE information package and continued the telephone support service as in the past.

On World Lupus Day, both local and regional newspapers published information on Lupus.

Jaana Hirvonen

FRANCE AFL+

This year we have organized many doctors/patients meetings both at national and regional level. We held regular meetings and always manned the office to help patients and also to put them in contact with competent doctors. We participated in regular meetings organized by the Rare Disease Alliance, EURORDIS, Inserm and the Ministry of Health. We also form part of the official commissions, and through our association with the Rare Disease Alliance we can put forward the problems of Lupus sufferers.

A quarterly bulletin is published and this is highly appreciated. We also distribute information and publicity material on Lupus. We also have a register of other auto-immune diseases and we support research through annual donations and assist Lupus sufferers who find themselves in difficulties.

For World Lupus Day we have reproduced a butterfly carrying the world on its wings, organized talks by doctors, organized displays and held a Press Conference in Strasbourg. We held an open air manifestation, permitting the general public to come in contact with our Association.

We had a varied year with our first objective being the support of Lupus patients, and the amelioration of the quality of life of persons with auto-immune diseases.

Marianne Riviere

FRANCE Lupus

With its ever increasing membership, currently standing at 850, we are an active presence in all areas of the health system where change is underway.

These changes, part of the legal framework in public health, affect all patients.

The battle is being fought on two fronts, the National reference centre for Lupus and the Rare Disease Platform involving over one million sufferers.

Our main effort is nonetheless focussed on running the Association. This year we changed the Statute and established a Charter which stipulates mandatory training for all our administrators.

This policy and a long term educational agenda, coupled with great care in choosing our active members are the best investment of our association.

The legislation concerning disease-related associations, which we have campaigned for so long has finally been passed and will provide additional protection.

Ginette Volf-Philippot

GERMANY

During this year's Annual Meeting it was decided to found the Lupus Foundation of Germany. The primary task of this foundation is to support the research for lupus within Germany.

On World Lupus Day we celebrated our 20th Anniversary with a press conference in the parliament of the German state North-Rhine Westphalia.

During the festivity, Ms Karin Clement and Ms Borgi Winkler-Rohlfing, patron and chairperson of LE-SHG respectively, were awarded the “Silver Butterfly” whilst Prof. Matthias Schneider and Rudolf Hocks, Medical Adviser and Vice-Chairman of ELEF respectively, were presented with the “Golden Butterfly” for co-founding the LE-SHG and their 20 year outstanding service to the organization.

The reform of the health system still gives us some headache. Fortunately, being members of a governmental committee, we are able to influence some decisions.

During the year we have organized 8 workshops, 4 seminars and took part in 4 medical conferences. We held 625 meetings at regional groups with an attendance of more than 6800 patients. We had an increase in membership now totalling 2835.

Financially we are quite good as donations have increased remarkably during the last year. Our homepage has been re-designed and we are proud that this is now barrier-free. With an average of 7750 visitors daily, the monthly chat with lupus specialist is much appreciated.

Rudolf Hocks

ITALY



During this year we have been very busy. Our regional groups have promoted conferences, conventions and regular doctor-patient meetings to keep patients up-to-date and to increase awareness and understanding of the illness.

In Rome we run Art Therapy groups and self help groups for patients and relatives. We run a free-phone where patients can call for psychological and medical support. We celebrated National Lupus Awareness month in October, this being advertised on television.

Posters were placed on buses and leaflets handed out to GPs and pharmacies, as well as a press and radio conference.

The same programme was followed on World Lupus Day.

Our public relations include the publication of our magazine “Icaro”, published three

times a year, a national website, two internet fora, books, posters leaflets and bookmarks.

We also participate in all public volunteer events to collect funds as our financial reserves have now been used.

Recently, a law has been passed allowing taxpayers to donate 0.05% of their taxes to non-profit organizations, and we are on this list, hopefully to benefit from these donations.

Since our last report our membership has increased to about 3700.

Augusta Canzona

MALTA



This has been a relatively uneventful year.

We gave up the idea of organizing large functions and concentrated on smaller events.

Our fundraising has made it possible to send a contribution to the Middlesex Hospital in London, pay our dues and also donate one thousand euros to ELEF towards its fundraising project.

This year we have planned to repeat our very successful Lupus Awareness Month campaign through the use of billboards on the main thoroughfares.

We continue to hold our monthly meetings for our members and medical professionals have been kind enough to talk to us on a regular basis.

We have been heartened to receive News and Views from Lupus UK and also the American version Lupus Now, both of which are extremely helpful.

Ian Lochhead

IRELAND



This year were sad to say good-bye to our past president Barbara O'Neill whose departure was marked by a presentation of art work in recognition of her long outstanding work on our behalf. Two young members joined us on the board of directors.

Various outreach support meetings were held in different venues around the country

with a very positive response from all who attended.

As usual World Lupus Day was the focus of awareness with activities and interviews arranged on both local and national radio. A feature on Lupus was printed in the Irish Times (our most prestigious paper) and one of our members was profiled in Woman's Way (a very popular woman's magazine).

Our proudest achievement last year was the launching of our website and we are now in the process of establishing links to other sites.

Financially we were successful in securing two donations in the form of grants from "Dublin Bus", Health Services Executives, a one-off corporate donation and managed to raise ten thousand euros from the Mini-Marathon.

We are grateful to our members, their families and friends for their fundraising, such as coffee mornings, head-shaves, mountain climbs and the women's mini-marathon, without whose support we could not continue to function.

Mary Feehan

THE NETHERLANDS



On being elected Chairman, it was decided to have a thorough look at our Association and the Board came up with some conclusions. Our volunteers have to become more active and for this we organized a weekend seminar where we had a look at what we are doing and how we can do a better job.

We receive a subsidy from the Dutch Rheumatism Fund and to continue receiving funds we will have to integrate and get subsidy specifically for lupus patients. To get government subsidy we will have to merge with the other Lupus Group. This looks quite natural as we will get a government subsidy as one strong group instead of two small ones.

We have to modernise our Association by renting a shared office and a secretary together with other patient groups to cut down on expenses and our monthly magazine will now be published quarterly. Finding volunteers to run the Association is

quite hard and we have been talking to a number of members trying to persuade them to be more active.

Meetings between regional groups, with guest speakers are organised.

A National Congress was held where ideas on integration, organization and government assistance were discussed.

There are lots of possibilities for improvement and another National Congress is planned for later on this year.

Hans Buijsrogge

NORWAY



Our Annual Conference has elected a new Board and decided to have two other Conferences inviting medical speakers. The ELEF Annual Conference in Bergen was the most important. The Board travelled to Denmark this summer to attend World Lupus Day there. All Nordic Groups were invited to spend a day together.

Our magazine "Lupus News" was given a new look and through a handsome donation we were able to print and distribute 650 copies to all our members registered under the NRF.

At the same time we asked our members to contribute NOK 100 to receive four issues of the magazine. This was very well received. A CD and a book, with information about Lupus were produced and sold to patients and the medical profession. We also sell Lupus wristbands and all these leave a handsome profit to our organization.

A lupus helpline was established all over Norway. We improved our internet site where we reproduce our Lupus News and also include a Nordic discussion forum.

A brochure "What is Lupus" produced last year was distributed to general practitioners all over the country.

Fatima Maria Lavoll

SPAIN



The Federation was founded in 1996 and has twenty association members all over the country. It is the website administrator of the Registry of Spanish Patients with SLE and

Anti-phospholipid Syndrome performed via the internet (www.rewgisterolesaf.com).

We have also been co-ordinating the participation of 73 physicians and 19 associations in the project since May 2003. In all there are 3,382 patients.

On May 12 and 13, we celebrated World Lupus Day by organizing our 5th National Lupus Congress in Seville where we gave information about the psychological, social, sexual and health problems of people with lupus and their families.

We showed the antecedents of this Day and read the international Proclamation.

The audience numbered more than three hundred and many local and foreign physicians spoke at the Congress. This was broadcast by internet on our website.

We have published two issues of our magazine, one contained a monograph on rehabilitation and the other was completely dedicated to our National Congress.

We have a national, free telephone help-line for people with Lupus. This line is manned by 20 of our members. Through it, people can obtain the information about the necessary resources to improve their situation as well as how to make contact with the nearest Lupus association.

Isabel Diaz

SWITZERLAND



The first eight months of this year were busy and successful. We held three Board meetings, two regional group leaders meetings and nine regional group meetings all over the country. All members showed very active participation. Two patient workshops and two medical presentations were also held. A third one is being held in November.

We publish a quarterly magazine informing patients and interested people about the latest news on Lupus. Our website which includes a forum and a chat-room to bring patients together is well visited.

We work very closely with the Swiss Rheumaliga and this organization supports us in many ways, including training courses and financial support. We also had the opportunity to publish some articles in their

newspaper and to explain more about Lupus. On World Lupus Day we were present at one of our co-operative hospitals in Lucerne to share information about Lupus and its implications.

Next year we celebrate our 20th Anniversary and for this occasion we are planning some special events. Many members all over the country will support this manifestation with ideas and manpower.

Britta Krismer

UNITED KINGDOM



We have as usual had a very busy year and have continued to work to promote and raise general awareness of Lupus as well as reaching out to help Lupus patients.

Meetings were arranged with the All Party Parliamentary Group for Lupus and the Scottish Cross-Party Group for Lupus.

We continue to raise funds for research projects and Specialist Lupus Nurses.

Lupus Clinics are being established in hospitals throughout the country

During medical conferences, national conferences and AGMs a large amount of literature is given out to delegates, and in particular, the GP Guide and Nurses Guide are much in demand.

Our website remains the main source of publicity, but we have recently acquired the services of a PR agency with a view to placing Lupus articles in the press, radio and possibly TV.

Our membership remains around 7000, although there is still an annual drop-off. This is slowing down due to the use of the Direct Debit (payment through the bank) system. Lupus Awareness Month and World Lupus Day have seen the production of new posters, envelope stickers, leaflets and bookmarks.

A lot remains to be done to reach patients needing support. Doctors still need educating about treatment of Lupus patients, care services need improvement and the general public needs to be informed. LUPUS UK will continue to work in these areas.

Yvonne Norton

SHANGHAI CONFERENCE AND WORLD LUPUS DAY 2007

The Conference

This is being held from the 23rd to the 27th May, 2007. The programme of the scientific part of the Conference is not yet finalised as this depends on the funds being raised. The revised version of the Patient Programme Outline, as received from the LFA is published below. At lunchtime there will be “Lunch with the Experts” where presentations will be made. It should be quite interesting to hear the views of Lupus experts. Twice each day there is a “model medical fitness programme.” On the 23rd May there will be the Lupus Leadership Forum. This provides the structure for leaders of lupus organisations to develop the best lupus leadership and growth in each representative’s country and for the whole lupus patient community.

World Lupus Day 2007

It is planned to move World Lupus Day 2007 from 10th to the 25th May just for 2007.

The LFA has proposed a World Walks for Lupus event in the early morning of May 25th. The walk, about 2 to 3 km long, takes place near the Congress Centre.

All attendees and the Chinese Lupus patients and their families are invited to take part in this event. The rationale reason for the change of date next year is:

- The international press coverage is a priority for the 2007 International SLE Congress and
- China increasingly attracts worldwide attention. As a result, international professional meetings in China have a greater chance of receiving global media coverage. This is virtually assured with a singular, focussed media campaign.

The Lupus community worldwide will celebrate WLD 2008 on the 10th May.

Rudolf Hocks

PROGRAMME	Wed 23 rd May	Thurs 24 th May	Fri 25 th May	Sat 26 th May
07:00 – 08:00	International Lupus Leaders Conference (ILLC): Worldwide Lupus Patient Groups (10:00 – 17:00)		Walk / Run for LUPUS 2007 World Lupus Day	
08:00 – 09:00		Opening ceremony		
09:00 – 09:30		<i>Tea</i>		
09:30 – 11:00		Breakthroughs in Understanding of Lupus – New Approaches to Treatment	Prevention of Heart and Blood Vessel Disease in Lupus: New Knowledge; Skin Disease in Lupus – Treatment and Protection	The Prevention and Treatment of Antiphospholipid Syndrome: State-of-the-Art Approaches
11:00 – 12:00		A Model of Medical Fitness Programme (Mind, Body, Spirit)		
12:00 – 13:30		<i>Lunch with the Experts – Panel Presentation</i>		
13:30 – 14:30		Kidney disease and Lupus (Detection, treatment, prevention and safety)	Lupus and Pregnancy	The Mental Connection – Fatigue, Depression and Difficulties in Thinking: Cause and Effect – A Panel Presentation
14:30 – 15:30		A Model of Medical Fitness Programme (Mind, Body, Spirit)		
15:30 – 16:00		<i>Tea</i>		
16:00 – 17:00		New Approaches to Lupus – Industry Panel Presentations	Lupus Treatments: Current and Future – Physician Panel – Audience Q&A	<u>Closing Lecture</u> <i>Looking into the future: What improvements in prevention and treatment can we realistically expect in 2010?</i>

IN A LIGHTER VEIN.....

Dictionary Updates by Oxford

Atom Bomb: An invention to end all inventions.

Board meetings: Keeping minutes and losing hours

Boss: Someone who is early when you are late and late when you are early.

Cigarette: A pinch of tobacco rolled in paper with fire at one end and a fool on the other.

Classic: Books that people praise but do not read.

Committee: Individuals who can do nothing individually and sit to decide that nothing can be done together

Conference: The confusion of one man, multiplied by the number present.

Conference Room: A place where everybody talks, nobody listens and everybody disagrees later on.

Compromise: The art of dividing a cake in such a way that everybody believes he got the biggest piece

Criminal: A guy no different from the rest....except that he got caught.

Diplomat: A person who tells you to go to hell in such a way that you actually look forward to the trip.

Divorce: The future tense of Marriage.

Doctor: A person who kills your ills with pills and kills you with his bills.

Etc: A sign intended to make others believe that you know more than you actually do.

Experience: The name men give to their mistakes.

Father: A banker provided by nature.

Lecture: Art of transferring information from the notes of the lecturer to the notes of the student without passing through the minds of either.

Miser: A person who lives poor so that he can die rich.

Office: A place where you can relax after your strenuous home life.

Opportunist: A person who starts taking a bath if he accidentally falls into a river.

Optimist: A person, who while falling from the Eiffel Tower says in midway "See, I am not injured yet".

Smile: A curve that can set a lot of things straight.

Tears: The hydraulic force by which masculine will-power is defeated by feminine water power.

Yawn: The only time some married men ever get to open their mouth.

How do you recruit the right person for the right job?

Put about 100 bricks in no particular order in a closed room with an open window. Then, send 2 or 3 candidates in the room and close the door. Leave them alone and come back after 6 hours:

If they are counting the bricks put them in the **Accounts** Department.

If they are recounting them, put them in **Auditing**.

If they have messed up the whole place with bricks put them in **Engineering**.

If they are arranging the bricks in some strange way put them in **Planning**.

If they are throwing bricks at each other put them in **Operations**.

If they are sleeping put them in **Reception**.

If they are sitting idle put them in **Human Resources**.

If they have broken all the bricks put them in **Information Technology**.

If they have tried different combinations and did not move a brick put them in **Sales**.

If they have already left for the day put them in **Marketing**.

If they are staring out of the window, put them in **Strategic Planning**.

If they are talking to each other and not a single brick has been moved:

Congratulate them and put them in **Top Management**.



YOU'RE ANOTHER YEAR OLDER.....

Remember when you were under 10 and 21 seemed a lifetime away. When just three more months elevated you to 10 and a quarter. Were you ever 36 and a half? Never! And do you recall getting to Four – would you get to Five in this lifetime?

You are now a teenager. Proudly thirteen – and still 21 is over the hills and far away. Eventually you make 16, and you need to live a third of your life again to get to the elusive 21. Suddenly you are 29 – yes, that happens. You've had the 21st Birthday Party and now 30 looms. You turn 30.

.....SO PLAN TO STAY YOUNGER

Numbers: Throw out the non-essentials – let the doctors worry about age, weight, height. That's why you pay them....

Friends: Keep only the cheerful ones - the grouchers will pull you down.

Learning: Never let the brain be idle, on any account.

The Simple Things: Enjoy them - the sunsets, soft rain, happy children....

Laugh: Often, long and loud. Laugh until you gasp for breath.

Tears: Let them come, as they must. Endure, grieve, move on. The only person with you all your life is you! Be alive while you are alive.

What you love: Surround yourself with pets, keepsakes, music, plants, hobbies,

Turn – like milk going bad. Watch out now, you are pushing 40, reach 50 and make 60 – wow, it really must be a struggle.

Maybe you hit 70 – hit. Now happenings are daily, reaching Wednesday, getting to the weekend, surviving holidays, enduring Christmas, then crawling into your 80s. Now it is permitted to say “You know, I am 84....” . Then “ I am in my 90's, although I bet you don't think so!” Finally, get to the Big 100 and you are allowed to start all over again with the fractions – “ I am 100 and a half now”.

whatever. Your home is very much your refuge.

Health: Cherish it – if it's good, work to preserve it. If it's unstable, improve it. If it's beyond what you can improve, get help.

Guilt Trips: Don't take them, emotionally or physically. Do a shopping trip or a sporting event, go to the next county , to a foreign country but do not go to where the guilt is or was...

Who You Love: Tell those you love of how you feel, at every proper opportunity.

Finally: Remember, life is not measured by the number of breaths we take but by moments that take our breath away.

HAVE A WONDERFUL DAY.....



The **ELEF BOARD OF TRUSTEES** would like to extend **SEASON'S GREETINGS** to the Chairpersons, delegates, members, families & friends of all National Groups and wishes them a Holy & Happy **CHRISTMAS** and a Prosperous **NEW YEAR**



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<p style="text-align: center;">CARING & SHARING</p> <p>“Caring & Sharing” is the newsletter of ELEF, published in December each year. Articles are to be in English only and sent to the editor by the 15th October. Articles appearing in the newsletter do not necessarily reflect the opinions of ELEF, its officers or members. The editor’s decision regarding publication is final and the right is reserved to edit or shorten articles.</p> <p>Anyone submitting original papers for publication and wishing to reserve copyright, should ensure that their full name and the year of publication, together with the © sign is added to the end of the article.</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td>Editor: Anthony M Bonello (ambonello@hotmail.com)</td> </tr> <tr> <td>Deputy Editor: Brian Hanner (brian@hanner.org.uk)</td> </tr> </table>		Editor: Anthony M Bonello (ambonello@hotmail.com)	Deputy Editor: Brian Hanner (brian@hanner.org.uk)
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