



UNITING PEOPLE WITH LUPUS THROUGHOUT EUROPE

CARING & SHARING

The Newsletter of LUPUS EUROPE

WINTER 2008

A MESSAGE FROM OUR NEW CHAIRPERSON



Let me begin by introducing myself to readers of Caring & Sharing who do not already know me. My name is Yvonne Norton. I was diagnosed with Lupus during 1975 and, since then, most parts of

my body and organs have been affected to some degree.

I have been Chair of the West Midlands Lupus Group (almost in the centre of UK) since it was formed in 1978 and Vice-Chair and Trustee of LUPUS UK since it's formation in 1991.

Along with my husband, Peter, I attended the 1999 ELEF Convention in Brest, France, as the UK Representative and we have attended each Convention since then with Peter being elected Treasurer and Trustee in Switzerland during 2002. Following the 2007 Convention in Mainz, Germany, it was suggested that I should be nominated for the position of Chair when Jean-Paul Sanders stood down. I took quite a while to decide on this, being conscious of the major undertaking of the role.

I eventually agreed to be nominated and I was really shocked to be elected to the post during the September Convention in Palma de Mallorca as Kirsten Lerstrom from Denmark was also standing.

The first action I instigated as Chair was to invite Kirsten to become a Trustee and Tony Bonello (outgoing Secretary) to stay onboard in a co-opted position. I was pleased when Nele Caeyers (Belgium FI) was elected as Secretary and I know that, along with the other Trustees and co-opted advisors, we will form an excellent Team and all work together to the benefit of our charity.

I would like to thank Jean-Paul and Tony for their excellent work as Chair and Secretary of ELEF over the past six years.

A move which gave me great pleasure was that Council approved the motion to change the name of ELEF to LUPUS EUROPE – a much snappier name which 'says what it is' – there is no longer the need to explain the meaning of ELEF or European Lupus Erythematosus Federation – difficult to say, let alone explain!

So farewell ELEF...

...hello LUPUS EUROPE

There is much that LUPUS EUROPE can achieve – the Common Cause project can be advanced, the proposed changes to the EU light regulations can be challenged, pharmaceutical companies can be helped in their quest to develop better drugs to treat Lupus, the list is endless if we all pull together and work in union.

As Chair of LUPUS EUROPE it is my fervent hope that ALL Lupus patients throughout Europe will have access to doctors who 'know' the illness, that they will have the medication they need, that they will have the equipment they may need to live a comfortable life and that they will have the Support and Friendship that comes from being part of a united Lupus organisation.

I wish everyone involved with LUPUS EUROPE a Happy Christmas, a Peaceful New Year and a Healthy 2009.

Yvonne Norton

UK CHARITY COMMISSION REGISTERED ADDRESS:

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

OUTGOING SECRETARY'S REPORT



During this year, meetings of ELEF Trustees were held on the 20th January 2008 in Zandhoven, Belgium and on the 27th April 2008 in Birmingham UK. Two further meetings were held in Mallorca on the 10th and 13th September 2008 just before and after the Annual Convention. The Minutes of these meetings together with those of the Annual Convention were e-mailed to all National Groups.

The January meeting of Trustees was also attended by Yvonne Norton (UK), Nele Caeyers (Belgium Flemish), Kirsten Lerstrom (Denmark) and Blanca Rubio (Spain)

The meeting centered mainly on the Annual Convention where venue, dates, programme and Agenda details were fully discussed. It was decided to hold the Annual Convention in the Spanish capital Madrid, but should this not be possible, Palma de Mallorca was the second choice. The Annual Convention for 2009 in Strasbourg was confirmed as was that for 2011 in Denmark. Venue for 2010 has since been confirmed and will be held in Hungary. Cyprus has now offered to host the 2012 Convention.

The discussion on the ELEF website – a subject proposed at the Mainz Annual Convention, followed. Various types of websites were proposed and discussed. These would require a budget of around five thousand euro. It was hoped that ELEF would find the funds to make this dream come true.

The Birmingham meeting had a full Agenda. Most of the items introduced and discussed have been included in this year's Convention agenda. Among these, one finds, ELEF Common Cause, EULAR Recommendations on SLE Management, EU Light Regulations, Sponsorships, Membership and future Annual Conventions.

Of utmost importance this year were the amendments to the ELEF Constitution, including change of name and logo and the elections of Chairperson and Secretary.

Thanks to sponsorship funds initiated by our hard-working Vice Chairman Rudi Hocks, the long-awaited website should this year become a reality.

This is my last report as Secretary. I have been in this post for six years during which I have had the privilege of working with people who really have ELEF at heart. It was a pleasure recording Minutes, discussing, making important decisions and planning for the future, with people who are dedicated to this noble cause, that of improving the quality of life of lupus patients.

During these years I was also Editor of CARING AND SHARING, a magazine which I enjoy compiling and publishing. As Communications Advisor, this remains one of my responsibilities. Membership is another field I will be taking care of.

Finally, a sincere "Thank you" to all Trustees, Chairmen of National Groups, International Contacts and delegates whom I had met during the past six Conventions and from whom I have had the fullest support. Also, a warm welcome to the four National Groups which have joined us during these years. My wife, Yvonne, joins me in wishing you all the Very Best of Health.

Anthony M Bonello

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PROPOSED CHANGES IN EU LIGHT REGULATIONS

The 2007 edition of CARING & SHARING carried an article on the special Directive planned by the EU which would require all European countries to use recommended energy-saving light sources.

It had been discovered that the EU Project Team had not even thought about the effects that the changes to light-usage could have not only on lupus patients but also on others who are photo-sensitive – thought to be in excess of 3,000,000 people within Europe.

So, what has happened during the past year?

Within the UK a major Player in the fight to avert the proposed changes has been David Price, a Regional Chair within LUPUS UK and Co-ordinator of SPECTRUM - an umbrella organisation representing various charities whose members suffer from light sensitivity. David is causing a stir with the British Government and various agencies as he brings the argument of photo-sensitive people to their attention.

The Health Protection Agency has issued information sheets and a media release outlining the problems that energy-saving bulbs can cause people with photo-sensitivity. The All Party Parliamentary Group for Lupus has held Meetings with the APPG for Skin, dermatologists and representatives of the lighting industry. Janet Dean MP has presented an Early Day Motion to Parliament which mentions the problem. An on-line petition has appeared on the Prime Minister's website along with scientific papers, stories and quotes from patients.



The LUPUS UK Lupus Awareness Month media release highlighted the problems being caused by the proposed changes with the slogan 'DON'T LEAVE US IN THE DARK'. A supply of the various types of 'safe' light bulbs on the market are being tested by members of LUPUS UK.

There are people who are unable to go shopping because of fluorescent lighting and have to shop via mail order, over the internet or ask friends to shop for them. It is not just in the home or shopping malls that people are affected but also in the workplace. If you are affected in this way, you have the right to bring it to the attention of your employer and union representative. If you go into any public building, including hospital, it is most likely to have these lighting systems.

As wheelchair users have the right of access to all public buildings so people with light-sensitivity should also have the right to enter any building without fear of a flare-up of their condition.

In the not-too-distant future, it is hoped that, with co-operation between the medical profession and the lighting industry, volunteers can be tested under clinical conditions to find out which lighting systems are safe for them. This seems to be the only way forward to prove the levels of photo-sensitivity and the effect that energy-saving light bulbs can have on people.

A report update was presented at the Convention in Palma de Mallorca when several member countries requested further information on the proposed changes to EU light regulations with the intention of informing members of the risks they may face when energy-saving bulbs are used. If you would like more information please visit: www.eup4light.net www.lupusuk.org.uk or e-mail: yvonne@wmlg.freemove.co.uk



A very big thank-you to Brenda, a member of LUPUS UK who is severely light-sensitive, for allowing the use of her photo, both with and without the attire she needs to wear when out in public.

Yvonne Norton

Spotlight on... the Spanish Lupus Federation

Federación Española de Lupus

FELUPUS



It is always difficult to accept that one is sick. More so, when one is suffering from the disease that one has never heard of. This was the situation in Spain. The existing information on lupus

was limited to that provided by your physician (often with too little time) and some books, most of which were in English.

If significant was the lack of information, so too was the lack of psychological support and knowledge in the general society. It's due to fear of the unknown and rejection, that, often, the patient did not want to confess his/her ailment. Aware that this situation should change, not only in its medical aspect, but also socially and institutionally, we began to create the first support groups for people with lupus.

These groups were organised into local associations, operating in very specific areas such as medical, psychological, social and legal resources and conducting outreach and awareness days each year.

These first emerged in the early nineties in Andalusia. Due to the contacts between them and the necessity to unite and share resources, they formed the Spanish Federation of Lupus in 1996 with headquarters in the city of Malaga, where it is still today.

It was in 2001 when Isabel Diaz began working as secretary of the Federation, where she's still working and doing a very good job, promoting the creation and development of several associations that make up today's Federation.

Currently, the Federation brings together 22 associations in Spain. The board is composed of 7 people that also work in some of these groups. From the beginning, its goal has been that of improving the quality of life of patients with lupus.

To achieve this it initiated contacts with several medical professionals from different hospitals, to highlight its problems and shortcomings, and with the various local and state institutions, to qualify for public funds to enable it to carry out projects.

Amongst these projects are:

- Promoting the creation of new partnerships, providing support and assistance to its maintenance, acting as spokesman on domestic and international forums, events and organisations.
- Publishing a Journal for LUPUS SPAIN every six months, news bulletins and leaflets. Translation of articles and publications into Spanish, dissemination of related literature
- Organisation of an Annual Congress, in a different city each year - Assistance and support to the conference premises attendance to the functions of other organizations, to which we are invited.
- Direct assistance to the patients. Telephone line 900 e-lupus (900 358 787) Free and served directly by the Federation. (Co-financed by the Foundation of the bank LA CAIXA).
- Website www.felupus.org with information about the Institutions and the Government, the disease, about the different member associations, publication of the latest news on lupus, and forum for communication between those affected.
- Conducting campaigns on TV, radio and the internet (info on website). Web casting of the national congresses
- Press Releases
- Collaboration Network (At the National, European and International levels):
 - Member of COCEMFE (Confederation of people with disabilities). Working with the Spanish Society of Internal Medicine, Working with the Spanish Society of Rheumatology.
 - Member of LUPUS EUROPE. This year we successfully hosted the 19th Annual European Lupus Convention which was held on 10th to 14th September in Mallorca, Balearic Islands.
 - Contact with the Lupus Foundation of America. We are part of the organizing committee of the World Lupus Day since 2003. Sharing language "Lupus in Spanish" with different organizations in Latin America.

- Projects on the Internet – Creation and maintenance of the Register of Lupus Erythematosus Patients in Spain. (www.registrolesaf.com) in collaboration with member associations and hospitals. Conducting studies and surveys. A call for volunteers to perform home micro works and up-dating our website regularly.

Ongoing projects:

- Fostering autoimmune disease units in hospitals to co-ordinate the various medical specialties that we deal in. (There are now 7 in Spain).
- Consideration of sun creams or sunblocks as necessary medication for those who are suffering from lupus and therefore entitled to subsidy by the Social Security system
- For people with continuous activity of the disease, considering the degree of disability (compensation awarded to tax employers who hire people with this account)
- Promotion of lupus registry on the Internet (www.registrolesaf.es).
- Collaboration with Corporate Medical Societies

- Contact with the Spanish Society of Primary Care Physicians to improve its training and information on lupus (those who should diagnose the disease and refer patients to the appropriate specialist)
- Contacts with Universities of Medicine to promote the specialization in autoimmune diseases not only physicians, but also nurses, physiotherapists and the whole paramedical staff involved in the management of this disease.
- Contacts with Universities of Social Workers offering them personal contacts with people with lupus and proposing thesis about special circumstances in lupus.

All this would not have been possible without the help of the Social Issues Ministry (for maintenance grants), the Health Ministry and ONCE Foundation(for sponsoring our National Congresses) Foundation of Bank LA CAIXA (for our free telephone line) and AVENE Laboratories (for sponsoring our magazine).

I want to take this opportunity to thank all these organisations for their support.

Blanca Rubio



THE LUPUS EUROPE ANNUAL CONVENTION 2009

The 20th ANNUAL CONVENTION will be held in the French town of STRASBOURG between the 9th and 13th September 2009.

The Trustees and Members of LUPUS EUROPE extend their thanks to FRANCE AFL+

A WORD FROM OUR MEDICAL ADVISOR

Clinical trials in lupus are failing – the end of a successful story?



People want to be successful. This is obvious in sports but also true in medicine. Physicians want to be successful in treating diseases, in supporting patients and also in developing new therapeutic options for their patients. Overlooking a quarter of a century in supporting patients with lupus, I can honestly say that treating lupus is a success story. The 10-year survival data of lupus patients are an excellent indicator of our achievements: the survival rate has increased from about 50-60% in the 60s to over 90% today. Most physicians are aware of this complex systemic autoimmune disease, and antibodies which support the diagnosis are available everywhere. For most patients lupus has changed from a life threatening disease to a chronic disorder. The antiphospholipid syndrome was identified as a separate entity of the disease that that needs an appropriate therapeutic approach of its own. Sufficient standard therapeutic regimes are available for over 90% of patients, such as steroids, antimalarials and immunosuppressives. Several new therapeutic options are in the pipeline for the other group which are evaluated in the large international multi-centre trials.

And here the story of success seems to end: none of these studies meets the primary endpoint, i.e. the efficacy of the evaluated drugs for treating Lupus in severely ill patients. Interestingly, this is the same result with different kinds of intervention: immunomodulatory substances like LJP394, new immunosuppressives like mycophenolate, inhibitors of secondary signalling like abatacept or B lymphocyte targeting with Blyss or rituximab. The data are similar using different study designs: the primary endpoint showing the efficacy of the new drugs is missed, but in most cases patients treated with the new drug claimed an improved quality of life. Regarding daily life this is a clear success, but in clinical trials quality of life is not used as an endpoint because physicians and authorities believe more in laboratory analyses and in their own judgement of disease activity than in the patients' opinion about their quality of life. The following question arises: is it legitimate to base therapeutic decision and even a licencing of a new drug just on a patient's judgement? An excellent example for a positive answer is

ankylosing spondylitis, an inflammatory rheumatic disorder in which the disease response is mainly documented through a completely patient based activity instrument. Probably an approach that includes the evaluation of quality of life or other comparable outcomes parameters could be a chance in Lupus too. The existing large clinically randomised controlled trials could be evaluated in order to find new parameters that may show the benefits of the new therapeutic options. The trials would be, in my opinion, by no means a disaster because the trials formerly missed the primary endpoint.

First of all, it is a success that so many patients participate in those studies – thanks to all of you for supporting the treatment of lupus and taking the risks of clinical trials. Secondly, the lupus community is proud that several pharmaceutical companies detected lupus as a target disease for their research. Also, it is a success that, especially in lupus, no toxicity signals were identified in most trials. Our major problem with the results from these trials is that our expectations were not fulfilled. One consequence which is now an issue is that we have to challenge our expectations. The given explanations that lupus is a very heterogeneous disease with important racial differences and tremendous variation in disease expression are obviously not the explanation. Therefore it seems to be necessary that we expand our views to identify new study designs. Probably we have to take higher risks running those trials by including severely ill patients (for whom we need the new drugs) or by avoiding the rescue net with applying an initial steroid bolus. In my view, solving the actual blockade on the way back to success include a thorough analysis of the data from current clinical trials. Only analysing retrospectively what may have been a successful outcome parameter of a selected group of participants will be an insufficient step; the question to all trials is: which patients exhibit a clear response combining all these studies? Which parameter was generally useful? For such analyses it is necessary that all companies agree to provide their data.

In the meantime we all – patients and physicians – can continue to write the story of success in lupus. There is a lot of new knowledge available, especially concerning arteriosclerosis in lupus that needs to be further evaluated and transferred to daily practice to continuously improve life with lupus.

Prof. Dr. med Matthias Schneider

COMMON CAUSE

- During the Convention in Palma de Mallorca, a Workshop was held to discuss the responses of the countries taking part in the Common Cause project.
- 12 countries eventually took part and all were disappointed with the low response received to the leaflets/newsletter articles that went out to all members.
- I received the responses from all 12 countries and put them together in a PowerPoint presentation for the Workshop. From the responses it was obvious that the main issue, as seen by the majority of patients, is the need for improved education of the medical profession which should lead to earlier diagnosis.
- Other issues which were highlighted included:
 - Concern for long-term patients (i.e. what problems will patients having lupus for 30-40 years experience?)
 - Fatigue experienced by the majority of lupus patients
 - More research needed looking at the patient as a whole.
- The Common Cause Project Team will now be looking at the responses and working on a plan to, hopefully, solve them although the question of 'fatigue' is out of the Team's reach – medics please take note!
- The responses also brought to light issues within the various member countries which, with some thought and effort, can probably be solved. Contact will be made with the countries concerned to see what help the Team can give with this.
- Thanks go to all those who did take part in this project. Your comments, whether good or bad, are all being 'taken on board' and will enable the Common Cause to move forward.
- I would ask all members of LUPUS EUROPE to please take part in any future projects which include a questionnaire. These questionnaires are designed to help lupus patients and the details you give may just be the information needed to ensure the success of the project.

Yvonne Norton



The LUPUS EUROPE Board of Trustees extends **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**



The Interaction between BLYS™ and B-cells in SLE

Abstract of the presentation at the Convention 2008 of ELEF (LUPUS EUROPE) in Palma de Mallorca, Spain

Dr. Doug Hough

Executive Director,
Clinical Research
Human Genome Sciences, Inc.
Rockville, Maryland, USA

Dr. Christine Parker

Director,
Clinical Research
GSK R&D
Greenford, Middlesex, UK

Systemic Lupus erythematosus (SLE) is a multi-system, autoimmune disorder characterized by the generation of autoantibodies (directed against self) with abnormal activation of both B- and T-lymphocyte populations. Recent research indicates that the B-lymphocyte plays a major role in the development and persistence of abnormal immune responses leading to autoimmune disease. This B-cell dysfunction has been associated with an inflammatory cytokine (chemical signal between cells) known as B-lymphocyte stimulator (BLYS).

BLYS is a protein and member of the TNF family of cytokines, which plays a prominent role in B-lymphocyte development, growth and differentiation, survival, and B-cell population selection. Levels of available BLYS determine the threshold for the survival signals to B-cells. An auto-reactive B-cell would normally be identified and selected for elimination, in order to remove self-destructive cell lines. BLYS promotes the survival of auto-reactive cells and prevents the normal selection and programmed elimination with cell death. Thus autoreactive B-cells survive to create auto-antibodies which in turn leads to autoimmune disorders.

Activated B-cells may mature to become plasma cells that produce antibodies, may interact with T-cells to stimulate the immune system or to promote inflammation, or may become memory cells that will be programmed to react quickly to future encounters with a specific antigen (including self antigens). An antigen may be a protein, cell surface molecule, or DNA to which antibodies may develop. Autoantibodies may complex with self antigens and trigger local inflammation or the release of complement enzymes that cause an inflammatory cascade.

BLYS binds to three different receptors on the surface of B-cells. The BLYS binding surface receptors are expressed throughout most of the B-cell lifespan in the peripheral circulation, from naïve B-cells through to activated B-cells including plasma cells and memory B-cells. A new drug in development for the treatment of lupus has been directed at BLYS as a target. By binding free BLYS in the circulation, there will not be sufficient BLYS available to bind to the B-cell surface receptors and the autoreactive B-cells will undergo cell death and be eliminated.

This treatment could promote self tolerance and help control the B-cell abnormalities associated with SLE. This promising new drug, which is known as belimumab, is an antibody that binds to soluble BLYS that is available in the circulation. Belimumab is currently in late stage clinical development with two large international Phase 3 trials that completed enrollment this year with almost 1,700 SLE patients.

There are many recent advances in our knowledge about SLE and autoimmune diseases. Exciting new drugs are being developed that target B-cell mediated autoimmune diseases.

Further information about the clinical trials of Belimumab in SLE may be found at the following sites:

- www.clinicaltrials.gov
- www.BLISS-study.com
- Human Genome Sciences website: www.hgsi.com.

THE ROLE OF TRUSTEES



What is expected of someone who is appointed to act as a charity Trustee?

To be a Trustee requires time, understanding and effort. It is also a rewarding opportunity to serve the community and develop personal skills. This guidance answers some of the more common questions and sets out briefly the duties of Trustees.

Charity Trustees are the people who serve on the governing body of a charity. They may be known as Trustees, directors, board members, governors or committee members. Charity Trustees are responsible for the general control and management of the administration of a charity. The term board member should not be confused with that of an organisation where the Board controls policy making, which in terms of LUPUS EUROPE is the Member Countries

The great majority of Trustees serve as volunteers, and receive no payment for their work. Charity Trustees come from all walks of life, and are united by their wish to create positive change in society. Most people are eligible to serve as Trustees. The work of a Trustee should be rewarding and enjoyable, and an opportunity to serve the community while learning new skills.

Trustees and their responsibilities

- (1) Trustees have and must accept ultimate responsibility for directing the affairs of a charity, and ensuring that it is solvent, well-run, and delivering the charitable outcomes for the benefit of the public for which it has been set up.

Compliance – Trustees must:

- (2) Ensure that the charity complies with charity law, and with the requirements of the Charity Commission as regulator; in particular ensure that the charity prepares reports on what it has

achieved and Annual Returns and Accounts as required by law.

- (3) Ensure that the charity does not breach any of the requirements or rules set out in its governing document and that it remains true to the charitable purpose and objects set out there.
- (4) Comply with the requirements of other legislation and other regulators (if any) which govern the activities of the charity.
- (5) Act with integrity, and avoid any personal conflicts of interest or misuse of charity funds or assets.

Duty of prudence – Trustees must:

- (6) Ensure that the charity is and will remain solvent.
- (7) Use charitable funds and assets reasonably, and only in furtherance of the charity's objects.
- (8) Avoid undertaking activities that might place the charity's endowment, funds, assets or reputation at undue risk.
- (9) Take special care when investing the funds of the charity, or borrowing funds for the charity to use.

Duty of care – Trustees must:

- (10) Use reasonable care and skill in their work as Trustees, using their personal skills and experience as needed to ensure that the charity is well-run and efficient.
- (11) Consider having external professional advice on all matters where there may be material risk to the charity, or where the Trustees may be in breach of their duties

Remember, if you are a Trustee, you are giving your time, enthusiasm, skills and commitment to something that you think is worthwhile – and you are giving them for free.

Peter Norton

ROCHE SUPPORTS LUPUS EUROPE



Amsterdam is perhaps best known for its canals and its bicycles. But, the Roche exhibition stand at the 7th European Lupus Meeting in Amsterdam on May 7-10 2008, featured a bicycle with a difference – an exercise bike that delegates could ride to raise money for LUPUS EUROPE (see photo). Roche made a financial donation for every 100m cycled, and, over the four-day meeting, the energetic delegates raised a welcome total of €10,000 for Federation funds. Cycling challenge participants received a certificate acknowledging their efforts.

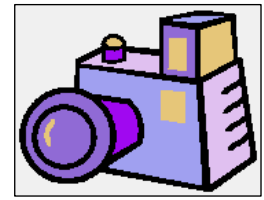


THANK YOU!

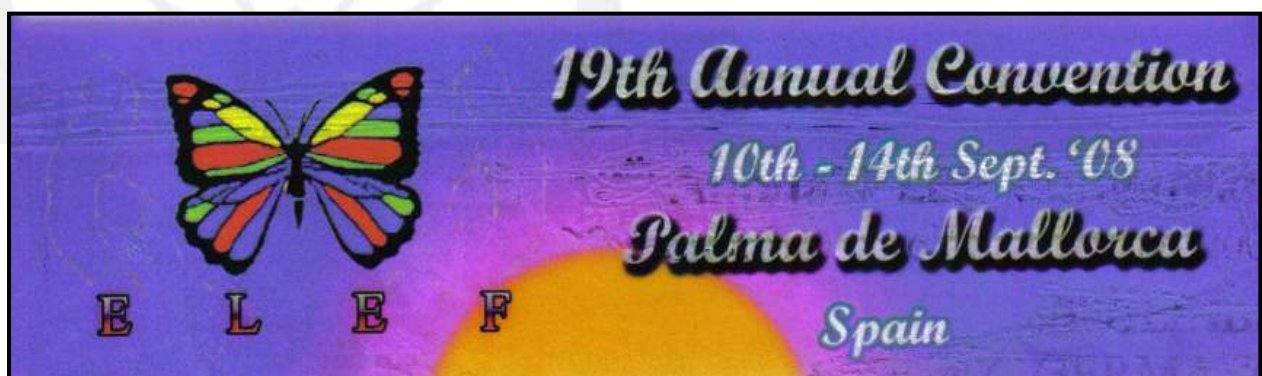
The Trustees and member countries are extremely grateful to Roche for instigating this novel event which raised valuable funding for LUPUS EUROPE.

It is hoped that the existing relationship will continue and that the ongoing support of Roche will help pave the way for future development of LUPUS EUROPE.

**Yvonne Norton MBE
Chair of LUPUS EUROPE**



THE ANNUAL CONVENTION IN PICTURES



All Photographs courtesy of Rudolf Hocks



Convention in session



↑ Medical session



→ A new hat for our new Chairperson



↑ Outgoing Chairperson delivering his final speech

Sightseeing in Valdemossa





Guided Tour around Palma de Mallorca



Final Night Venue

Showtime





**DELEGATES ATTENDING THE 19TH ELEF CONVENTION
IN PALMA DE MALLORCA, SPAIN
10TH SEPTEMBER – 14TH SEPTEMBER, 2008**

Bonello Yvonne, *Malta*
 Caeyers Nele, *Belgium (Flemish)*
 Cassoe Tove, *Denmark*
 Canzone Augusta, *Italy*
 Diaz Isabel, *Spain*
 Feehan Mary, *Ireland*
 Feehan Des, *Ireland*
 Hamon Andrée, *France*
 Hever Krisztina, *Hungary*
 Janovski Agnes, *Hungary*
 Krismer Britta, *Switzerland*
 Lavoll Fatima, *Norway*
 Lerstrøm Kirsten, *Denmark*
 Martaseki Ferenc, *Hungary*
 Muller-Prentis Simone, *Germany*
 Naversnik Dominika, *Slovenia*

Osborne Marcelle, *France*
 Purgel Zoltan, *Hungary*
 Rubio Blanca, *Spain*
 Stylianou Josefina, *Cyprus*
 Stylianou Petros, *Cyprus*
 Verwerft Frei, *Belgium*
 Volf-Philipot Ginette, *France*

Trustees

Bonello Anthony, *Malta*
 Boomker Ineke, *The Netherlands*
 Hanner Brian, *United Kingdom*
 Hocks Rudolf, *Germany*
 Norton Peter, *United Kingdom*
 Norton Yvonne MBE, *United Kingdom*
 Sanders Jean-Paul, *Belgium*
 Riviere Marianne, *France*

Number of delegates: 31

Number of Countries: 15

Countries not represented: Finland, Iceland, Israel, Portugal and Sweden

TOTAL NUMBER OF LUPUS EUROPE MEMBER COUNTRIES: 20

NATIONAL REPORTS 2008

BELGIUM (Flemish)



Unlike most other support groups, we continue to work with other connective tissue diseases such as Scleroderma, Sjogren's Syndrome, Vasculitis, Myositis and MCTD. This co-operation gives us the opportunity to work with larger patient's groups who have equal needs and prevents duplication.

This has been another full year organizing local activities, information sessions and social gatherings. The Passport for people with rheumatic condition was launched in March. Reumanet developed the booklet together with CLAIR and PARE, the doctors and patients groups in Belgium. Special highlight for lupus patients was World Lupus Day. We put up a special tent on the beach giving out information about lupus and other connective tissue diseases. Specially designed WLD umbrellas (as protection from the sun) drew a lot of attention. National TV had a special news item using the story of a patient to spread awareness for lupus.

In June, during the EULAR meeting in Paris we had the opportunity to talk with people from Lupus Federation of America. Hopefully these discussions will continue for further opportunities in the future.

NELE CAEYERS

BELGIUM (French)



We continued our activities of information and organization of medical conferences followed by questions and answers sessions between doctors and patients. We also took part in the organization of events with CLEAR, the confederation for the fight against rheumatic inflammatory affections.

In May, besides World Lupus Day celebrated in Ostende, we participated in the 20 km race to Brussels and the biking event Brussels-Paris in June.

The Association is very active in several studies carried out by the government on healthcare policy, adoption of plan for chronic diseases and financing patients associations. Our funds still come from members' subscriptions of 10 euro per year. We have 800 members. All the work in the Association is done by a small group of volunteers, all Lupus patients.

MARIA TOLEDO

CYPRUS



The Cyprus Lupus Group forms part of the Cyprus League Against Rheumatism and we participate in practically all its functions.

We celebrated World Arthritis Day by presenting a report on research we had conducted based on the message "Small Things Matter". Seminars were organized with a Gynaecologist, a Cardiologist and a Rheumatologist taking part in each Seminar.

On World Lupus Day we met at a restaurant where we discussed with a Psychiatrist how we can use Positive Thinking in our lives. This also served as a good social function. Another social function was the Annual Theatrical Play, where we met, talked and really had a very pleasant evening.

Our Newsletter "Poreia Zois" (Way of Life) includes all kind of information and also included the launching of our new logo – the Blue Butterfly. The League is also building a new web-page which will be easier to run with much more space, information and additional space allotted to each Group.

The aim of the Group is to establish a co-ordinative team of people who will be responsible for the different projects. Like an informative book about Lupus, a Newsletter, gatherings and social functions together with a DVD that will inform patients and the public about Lupus.

JOSEFINA STYLIANOU

DENMARK

The past year has strengthened our network between the five SLE groups in the country through a closer working relationship. We have tried all kinds of initiatives to attract new members and engage some of our followers to get more involved.

We want to have SLE treatments and follow-up organized better. During the past few years we have established closer ties with our specialists in SLE at the three University Hospitals and initiated our joint project of organizing centres for SLE. The Danish Rheumatic Association has financed this part of the project. We aim to be able to organize a "Lupus Environment" providing a pivot for all treatment, research and specialised education

Our Common Cause survey has proven worthwhile and shown several new steps, creating activities and keeping up our ties with the medical community.

We were invited for the first time to give a presentation on being a lupus patient to a group of researchers and scientists at Novo Nordisk, who will now focus on finding better treatments for Lupus.

KIRSTEN LERSTROM

FRANCE AFL+

This year things have moved quickly and we moved into refurbished new premises in Metz and engaged an Administrative Secretary. A communications firm gives us large support and helps our development.

Our collaboration with the medical and social teams increases every day and we participate in congresses on Rheumatology and Internal Medicine and in training sessions for personnel. We work in close collaboration with researchers and laboratories as well as with different Ministries and various government authorities.

Our Chairperson is Vice Chair of Arthritis Foundation Courtin. She is also founder member of Espace-RIC in Paris, - established in October this year - which will be receiving the sick and their families and providing answers and advice on social security benefits. She also participated in the publication of a book on Lupus written by specialists of the Reference Centre. This book is intended for Lupus patients and their families.

We have started our preparatory work for the LUPUS EUROPE Annual Convention which will be held in Strasbourg between the 09 and 13 September 2009. Various functions are being planned.

We look forward to welcoming you in Strasbourg to celebrate our Twentieth Anniversary

MARIANNE RIVIERE

FRANCE LUPUS

Since its foundation in 1999, LUPUS FRANCE continued to develop with membership of over a thousand. The trust of both doctors and patients, the quality of information given, the recognition within large organizations and the active participation on several boards, together with sustained relationships and the committed effectiveness of those elected have been our strength throughout the year.

Our main weakness is the fact that we spend a lot of energy raising funds to meet running costs and set up new projects. Notwithstanding, we continue to fulfil our mission and aims as set out in our statute and policy orientation.

We organize meetings from region to region, collaborate with doctors and patients, write and distribute documents and leaflets. We participate in large scale research at European level and take part in various actions of solidarity aimed at improving or defending the health service. Along with the National French Society of Internal Medicine, we finance and participate in research on the French validation of Scales for Health related Quality of Life and Activity in Lupus (FRESH QOLA). We are also planning a Forum on systemic auto-immune disease to be held in Paris in 2009 and completing the revision of "Lupus in 100 Questions" written by doctors of four referral centres,

GINETTE VOLF PHILIPPOT

GERMANY

The German Lupus Association, founded in 1986 is a non-profit and independent organisation with approximately three thousand members and around eighty regional groups throughout Germany, led by lupus-affected volunteers.

It gives regular support to lupus patients, their families and professionals by means of the 68-page magazine, published every quarter, organizing workshops for lupus patients, their families and professionals with the help of lupus specialists, hospitals and others and providing training for volunteers.

We are affiliated to the Lupus Foundation of Germany and are partners with LUPUS EUROPE, Lupus Foundation of America, German League against Rheumatism, Alliance against Chronic Diseases, Federal Association of Self- help and Children network, amongst others.

A long term study LuLa, is performed in co-operation with the Department of Rheumatology at Heinrich-Heine University and financed by our association. In 2006 WHO chose Lupus to specify an international classification of functional abilities (ICF) and we succeeded in getting patients involved in this process that is normally reserved for physicians. A Lupus prevention passport has been designed as a common project with the Department of Rheumatology Heinrich Heine University Düsseldorf, and thanks to public funding by the Federal Ministry of Health, this will be available this year.

Events throughout Germany promoting the First European Day of Chronic Rare Disease as a long term school project on rare diseases in an elementary school in Berlin, information desks with other organizations etc. The presentation was made on 29 Sept 08.

A directive regarding serious rheumatic diseases has been adopted by the German Ministry of Health whereby It is now possible to have a special lupus ambulance throughout Germany

SIMONE MULLER-PRETIS

HUNGARY

2007 was a very stressful and difficult year for our Group. We started the year without a Chairman as our founder Ms. Gabriella Schopper had died from lupus. She had been Chairman for 10 years and this post is now filled by Zoltan Purgel. The Group was kept going through membership fees, support from members and grants from taxation. In Hungary, the government distributes 1% of tax collected to non-profitable organizations.

Throughout this year we organized free lectures for patients in the lecture room of the National Institute of Rheumatology and Physiotherapy where Hungarian doctors lectured on subjects such as “pregnancy in Lupus”, “Lupus and rheumatoid arthritis” and “Lupus and cardiac troubles and haemal complications” At the end of these lectures we threw an end-of-year party for lupus patients and doctors.

We produced 600 DVDs to be sent to patients who could not attend these lectures. Besides we also put these lectures on our website where we registered around seventy-seven thousand downloads. We have a forum on the website resulting in less calls at our office as people are now getting the information they need from the internet. To co-ordinate these activities we established regional representations in more regions throughout the country.

We plan to be able to produce a newspaper, information leaflets and a booklet with articles for patients and health professionals as soon as we can find a sponsor for this project.

KRISZTINA HEVER

IRELAND

There was a health programme on national television about how people cope with long term illnesses. By reviewing and changing their diet and exercise regimes, people are helped to lead a healthier life. A person with severe Lupus was the subject of one of these programmes. This message of hope produced an increase in phone calls to our office in the aftermath of the programme.

A member of our Group has written an article on APS and Pregnancy and with her consent we are using her article to provide information by publishing it in booklet form. This is our first publication on the subject of which we are very proud.

We have written to the Authorities on the forthcoming withdrawal of incandescent bulbs and the effect this will have on people with photosensitivity to CF bulbs in the Lupus Group. A reply is still awaited.

Our Branches keep going from strength to strength with growth in membership. They host formal and informal meetings and information evenings. Most of our members find that their medical consultants are too busy to answer their questions on coping with the daily trials of living with Lupus and we try to fill this gap. Currently there is a study being undertaken in Trinity College, Dublin on "Fatigue in Lupus" in which we have been asked to participate. Twelve members are taking part, the findings of which will be published next year.

MARY FEEHAN

ITALY

We celebrated our 20th Anniversary on the 28th October 2007 in Parma and had our Annual Members' Meeting and elections to the Board of Governors on the same day. We are going through a period of great change and reorganization. We had changes in our Constitution, change in our official address which is now in Genova and new Chairman and Vice-Chairman in Maria Teresa Tuccio and myself respectively.

We continue to work hard to investigate problems related to our illness by organizing doctor-patient meetings and training on up-to-date therapies. Our regional sections have grown to 12 and we also have a national help-line

Two regular features on our calendar are World Lupus Day and the Month of October. On both occasions we distribute leaflets, raise public awareness about Lupus through information posters in pharmacies and public busses and distributing African violets in main cities. We organize medical conferences in major hospitals and publish short articles in the local press.

We keep pressuring our Public Health System trying to get the lawful rights we have as chronic sufferers and being exempt from payment of health care charges.

Our sources of information remain our magazine ICARO (published 3 times a year), a website, two internet fora, posters, bookmarks, leaflets and a publication "Guide for Patients and Nurses."

AUGUSTA CANZONE

MALTA

During Lupus Awareness Month we normally hire a huge billboard strategically placed on a major arterial road reminding one and all of our cause. This was unavailable this year so we concentrated our efforts on the national press, radio and television.

We printed and distributed five thousand leaflets to all major clinics and hospitals, held a public seminar on "The Auto-Immune System" and continued to keep our members informed by holding monthly meetings on a variety of subjects of interest to lupus sufferers and organizing social/ fundraising functions.

We had a Butterfly Buffet, which raised almost enough money to cover all our running expenses and sold the traditional "figolla" (an Easter delicacy) which also netted a good sum.

IAN LOCHHEAD

THE NETHERLANDS

Our highlights of the year included a new cover and layout of our quarterly magazine, World Lupus Day and the EULAR European Lupus meeting in Amsterdam, the NVLE award to rheumatologist Dr. Irene Bultink and the enlargement of our Medical Board from 9 to 13 members which includes specialists from eight University hospitals in the Netherlands.

Besides these important events we would also like to mention the activities of our youth group and their successful meeting in January, the first meeting with members of the National board of Sjogren patients organization with which we share an office and the September meeting of the National Board,

In April this year we said goodbye to our Secretary of the National Board for many years, Ineke Boomker. She did an excellent job and we still keep in touch not only because she is a member of the Board of LUPUS EUROPE but also as she is always willing to help with her expertise and interest in lupus.

Our secretary also resigned but we have since moved into a new office sharing the space and secretaries with the NSVP.

We have a new glossy magazine, published four times a year, a new logo, new editorial staff and also a new Chairperson Marja Kruihof. We have also renewed our website and included a special page for the younger generation. Our Board also has two new members and in April 2008 we will also have a new Secretary Janneke van den Heuvel.

MARJA KRUIHOF AND INEKE BOOMKER

NORWAY

The Norwegian Lupus Group within NRF has 750 members in 17 regional groups. It is administered by a national board of three ladies and meet regularly to arrange meetings and organize courses throughout Norway.

The NRF National helpline was inaugurated in Autumn 2006 and our group contributes by helping out with lupus patients. We publish a quarterly magazine "Lupus News" consisting of interesting articles written by specialists. A CD, lupus information booklet and printed articles are sold to professionals and patients. Our website www.sle.no is updated regularly and has a very active forum.

This year we seem to be more visible as a diagnosis group and this is reflected in a larger number of enquiries from different working groups. We are also very active in WHO Patients for Patient Safety network.

FATIMA MARIA LAVOLL

SPAIN

The Foundation was founded in 1996 and has 22 associated members all over the country. It has been the administrator of the Internet-based Spanish Patients Registry with SLE and Primary Anti-Phospholipid Syndrome. We have been co-ordinating the participation of 72 physicians and 19 associations in the project since May 2003. There are 3458 patients including 3180 with lupus and 278 with Hughes Syndrome.

We celebrated WLD by organizing our 7th National Congress in Barcelona during which we gave information about psychological, social and health problems of people with lupus and their families. A booklet entitled "Autoimmune Diseases: The Inside Enemy" was distributed during the meeting.

We published two issues of our magazine and joined the World Lupus Day Steering Committee to celebrate World Lupus Day 2008. We have actualized our website, receiving more than 20,000 visits per month. It contains information about FELUPUS, members' news, articles on lupus and its manifestations, guide for patients, forum, chat, dictionary lupus terms, events organized in our country and interesting links. We continue with our national free- phone help- line where people obtain information about resources, nearest lupus contact and how to improve their situation. This year we also hosted the 19th ELEF Annual Convention in Palma de Mallorca.

ISABEL DIAZ

SWITZERLAND

Our Association works closely with Swiss Rheumaliga and this organization supports us in many ways. Together we are running selected projects on a national basis. Together we are running selected projects on a national basis. We have regional groups all over the country with members totalling 507. This is the same level we had last year.

In 2008 we organized two medical presentations which took place in hospitals at different places. We did not have enough interested people to run it this last year but we could run it again very successfully next year as we received a lot of very good feedback.

We publish a magazine four times a year. This is distributed to all our members and informs them about the latest news and facts. The magazine is published in German and French.

World Lupus Day has increased our activities. Regional groups visited hospitals and distributed printed material Newspapers informed readers about lupus and we also gave interviews on radio and television.

For the upcoming months we intend to continue on our way, increasing information about Lupus all over the country and further improve our organizing capabilities. One of the challenges is to maintain the number of regional groups and increase the number of members.

BRITTA KRISMER

UNITED KINGDOM

During the past year we continued to work to promote and raise general awareness of Lupus to both the medical profession and the public as well as reaching out to help patients. To comply with various law changes LUPUS UK has now been entered into the Scottish Charity Register and the UK Fundraising Standards Board and is applying to become a recognised National Institute of Health Research Partner Organisation. Jane Dunnage, Chair, has played an active part and her fresh ideas are bringing changes that will, hopefully, bring more involvement of members and give more support to Regional Groups.

The All Party Parliamentary Group held a Reception at the House of Commons which was attended by the Health Minister, several MPs and Peers, National and Regional Patrons and Chairs. A joint meeting of APPG for Lupus and APPG for Skin was held with medical consultants and Managers of the Lighting Association to discuss the issue surrounding the withdrawal of incandescent light bulbs.

The two Lupus Centres of Excellence continue to give high standards of care to Lupus patients and it is hoped that other hospitals will soon feel able to fulfil the strict criteria and will apply for this status.

The Conference "Medicine and Me: Lupus" was organised by the Royal Society of Medicine in association with LUPUS UK and was held in London. Prof. Graham Hughes and Dr. Ian Bruce were among the speakers.

We have around 6500 paid up members, One third now pay their subscription by direct debit (payment via banks) and more new members are joining via our websites. A mini-website – Eclipse, the Light Sensitivity Support Group – is now 'live'. This website carries details of the light bulb campaign and light sensitive products.

This year's London Marathon had 20 runners in the LUPUS UK team, 12 in the West Midlands Group and 4 runners for ELEF. Many members also took part in the "Go That Extra Mile" and Lunch4Lupus. The Butterfly Ball was held in Birmingham with the ELEF Trustees as guests. Lupus Awareness Month, World Lupus Day and Common Cause were well patronized.

This has been a very successful year for LUPUS UK but there is still much to be done to reach and help those who are either seeking diagnosis or are diagnosed and seeking support. There are still medics who need educating about Lupus and the treatment of patients, patient care services need improving in many areas and more information needs to be put into the public arena. LUPUS UK will continue to work in these areas.

YVONNE NORTON

ROCHE RESEARCHES POTENTIAL NEW TREATMENT FOR LUPUS

Research Programme



Roche, has a large research programme devoted to finding new innovative treatments for autoimmune diseases, including lupus. In addition to their exhibition stand, the company held a lunchtime symposium on May 8 to highlight a potential new approach to lupus treatment. B cell therapy has been successfully used in some autoimmune diseases and Roche is now investigating whether lupus sufferers will benefit from this therapeutic approach. Presentations on B cell therapy were made by leading lupus researchers and the symposium was well-received by the 400-strong audience. The meeting was also broadcast live via the Internet and can be viewed at the following site www.b-proactive.net

The new B cell therapy that Roche is investigating is called ocrelizumab – a humanised monoclonal antibody that acts against particular receptors called CD20 on the surface of the B cells of the immune system. The hope is that ocrelizumab will benefit lupus sufferers by dampening down the autoimmune response that causes illness in this condition.

Ongoing clinical trial in lupus nephritis

To evaluate the efficacy of ocrelizumab in lupus, Roche is conducting an international, multi-centre, phase III clinical trial. The “Belong” study will investigate the efficacy and safety of ocrelizumab in patients with lupus nephritis. Patient recruitment is currently ongoing and the patients studied will receive either ocrelizumab or placebo in addition to standard therapy.

The results achieved with B cell therapy in other autoimmune diseases gives grounds for hope that ocrelizumab may improve the lives of lupus sufferers.

**David Close, Clinical Science Leader,
Roche Products Ltd, Welwyn Garden
City, UK**

For more information about B cell therapy and the Belong study

The company has provided information for patients and healthcare professionals wishing to know more about ocrelizumab and the Belong study which is available through the LUPUS EUROPE website: www.lupus-europe.org

IN MEMORY OF RONNIE GOURLEY



We were saddened to hear of the death of Ronnie Gourley on 31st October when he passed away peacefully from kidney failure.

Ronnie was Chair of LUPUS UK from 1991-2006 when he stepped down due to ill health.

Ronnie was involved with the initial Talks which led to the formation of ELEF (forerunner to LUPUS EUROPE) and was always interested to know what happened at the Annual Convention and Trustee Meetings. It was with his support that LUPUS UK gave financial assistance to ELEF.

Ronnie was known to a number of LUPUS EUROPE members and will be remembered with great affection.

Rest in Peace Ronnie.

**When things in your life seem almost too much to handle...
When 24 hours in a day are not enough...
Remember the mayonnaise jar and the 2 glasses of wine theory...**

A professor stood before his philosophy class and had some items in front of him. When the class began, wordlessly, he picked up a very large and empty mayonnaise jar and proceeded to fill it with golf balls.

He then asked the students if the jar was full. They agreed that it was.

The professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles rolled into the open areas between the golf balls. He then asked the students again if the jar was full. They agreed it was.

The professor next picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. He asked once more if the jar was full. The students responded with a unanimous "yes."

The professor then produced two glasses of wine from under the table and the entire contents into the jar, effectively filling the empty space between the sand. The students laughed. poured

"Now," said the professor, as the laughter subsided, "I want you to recognize that this jar represents your life. The golf balls are the important things; your family, your children, your health, your friends, and your favourite passions; things that if everything else was lost and only they remained, your life would still be full.

The pebbles are the other things that matter like your job, your house, and car. The sand is everything else; the small stuff.

If you put the sand into the jar first, " he continued, "there is no room for the pebbles or the golf balls. The same goes for life. If you spend all your time and energy on the small stuff, you will never have room for the things that are important to you.

Pay attention to the things that are critical to your happiness. Play with your children. Take time to get medical checkups. Take your partner out to dinner. Play another 18.

There will always be time to clean the house and fix the disposal. Take care of the golf balls first; the things that really matter. Set your priorities. The rest is just sand."

One of the students raised her hand and inquired what the wine represented.

The professor smiled. "I'm glad you asked. It just goes to show you that no matter how full your life may seem, there's always room for a couple of glasses of wine with a friend."



TWO GLASSES OF WINE



LUPUS EUROPE

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CARING & SHARING


“Caring & Sharing” is the newsletter of LUPUS EUROPE, 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 LUPUS EUROPE, its officers or members. The editor’s decision regarding publication is final and the right is reserved to edit or shorten articles.

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.

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