



MAGYAR LUPUS EGYESÜLET

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2007 was very difficult and stressful for our group. We started 2007 without a Chairman, because the founder of Hungarian Lupus Society, named Gabriella Schopper, had died from lupus. She was the chairman of our group for 10 years. In the first months of 2007 our group had to re-organize and re-support, we had to elect a new chairman, named Zoltán Purgel and moved into a new office. It was difficult but we managed to save our association. We could make our non-profit activity only from our club fees, supports of our members and taxation (in Hungary an offer of 1% of tax to a non-profit association).

In 2007 we organized free lectures for lupus patients four times a year. We received the lecture-room named “Club Lucas” gratis from Prof. Dr. Gyula Poór in the National Institute of Rheumatology and Physiotherapy (abbrev. ORFI). The highest Hungarian doctors gave a course of lectures, totally free. Our first meeting was on March 27th. Prof. Dr. Peter Gergely gave a lecture at this time about lupus and its new medicines and research results. Informal talk followed this high-standard presentation, finally we kept our general assembly then, where we had to elect a new chairman and modify our club-laws. Our second meeting was on May 29th. We had to begin it with a general assembly again, because our group had some financial problems to solve. The director general of ORFI named Prof. Dr. Gyula Poór was our first lecturer, who talked about an establishing of a new department for lupus patients in ORFI (National Institute of Rheumatology and Physiotherapy, Department of Clinical Immunology and Rheumatology) in Budapest. It was great news, because the lupus patients in this area were looking forward to opening it. It is a really big help for us. On this date our second lecturer, Prof. Dr. Teréz Pozsonyi kept a presentation with a title of “Pregnancy and lupus”. A lot of questions had to be answered. During the lectures a film was shown and finally there was an informal talk between patients and doctors. Our third meeting was on September 29th. After a short general assembly Dr. Emese Kiss, associate professor and head of new autoimmune department in ORFI talked about lupus. She is an internationally acknowledged doctor. Our second presentation within the capacity of everybody was made by Prof. Dr. János Kádár, who analysed what organic damages can cause lupus and what are the opportunities for some special medicinal treatments here in Hungary. He answered our questions after his high-standard lecture. Our fourth meeting was on December 1st. Prof. Dr. Pál Géher came from a hospital of Sisters of Charity in Budapest to us. He gave a presentation with a title of “Lupus and rheumatoid arthritis”. Our second lecturer was Dr. Emese Kiss again and she gave a projector presentation with a title of “Lupus and cardiac troubles and haemal complications”. Finally we made an end-of-year party with some lupus patients and its doctors.

We could make DVD's about the third and fourth group meeting, in order to send these to the lupus patients who are not able to leave their home. We managed to post 600 DVD's, and we could also publish these DVD on Internet websites of our group (www.lupusz.hu, www.sle.hu, www.autoimmun.hu), where there was approx. 62000-77000 registered site downloading monthly. We have a forum on our website where lupus patients and surrounders can chat. However the amount of calls at our office has decreased as people are now using our website for information, leaders and delegates of Hungarian Lupus Society had to answer more e-mails and letters daily. They tried to help more than a thousand autoimmune patients and its surrounders to find a clinic, a doctor and/or medicines, to give information, etc. To coordinate these activities, we accomplished regional representations in more of Hungary's regions in 2007. Neither our leaders nor delegates got money for their work, we made it altruistically. Most of them have lupus; therefore they know what it means to get a helping hand. We nominated Krisztina Hevér for international contact. We would like to extend our contact with domestic and foreign patient-organisations. In 2007 we could not make newspapers, leaflets and information booklet with many updated articles for health professionals and patients in the deficiency of a material source but next year we try to find support to do this. We would like to send these to lupus patients and to put these out in clinics. 2007 has been a successful year but there is much more to be done in many areas and we will continue to do so for years to come.