



National Data Bank for Rheumatic Diseases

Thursday September 24, 2009

Dear LFA Member:

Most people with Lupus (SLE) receive their medical care from either their primary care physician or a rheumatologist in their community. Yet, most research about lupus is done in university centers where only a small minority of patients is treated. People treated outside of university centers may have a different kind of lupus, experience different types of problems, and have vastly different outcomes.

The National DataBank for Rheumatic Diseases (NDB) is an independent, non-profit, research organization (see below) committed to understanding lupus and other rheumatic diseases. The NDB is attempting to discover which treatments are most effective for most patients with SLE and to better understand their short-term and long-term side effects. It is also interested in costs of medical care, extent of disability caused by lupus, and the impact of lupus on quality of life. This research hopes to add a human touch to the important basic immunology work now being performed at university centers.

However, in order to improve the treatment of lupus, we need your help. It is only through research that the devastating disease can be overcome. NDB performs its research primarily by obtaining information directly from people with lupus. It does this by mailed questionnaires or secure online web forms. The information from thousands of patients with lupus from across the country is then combined to provide a powerful tool to better understand this complex disease.

Participation in this research may not help you directly. It may, however, expand knowledge of lupus which could one day lead to improved therapy. This may not happen soon. It could be decades away. But, it will happen. And, it will happen sooner with your help.

The National DataBank for the Rheumatic Diseases has been investigating various rheumatic diseases for more than 25 years. It has received funding from the National Institutes of Health, the Arthritis Foundation, and major pharmaceutical companies. Recently, it has begun a collaboration on a research grant from the Lupus Foundation of America.

Previously, the NDB has primarily studied rheumatoid and osteoarthritis. Its research has led to the publication of over 500 reports in some of the world's most influential medical journals. It is now focusing its efforts on lupus and believes it can make the same major impact on the treatment and outcomes of lupus as it did with rheumatoid arthritis.

NDB publishes a news letter that will be sent to you on a regular basis. It will also report to you the results of the research when it is published

Please help by signing up today, either on our secure website <https://www.arthritis-research.org>, or by calling us at 316-263-2125. We would also be pleased to answer any questions you may have.

Thank you.

Sincerely,

Fred Wolfe, MD

Founder and Director
National Databank for
Rheumatic Diseases

Michael Luggen, MD

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