Welcome to the 2007 issue of the Lupus Outcomes Study (LOS) newsletter. Once again, we would like to start by expressing our gratitude for your participation in the study. We know you have many demands on your time, which makes us all the more appreciative of the priority that you give this study. Whether you have just recently joined us or have been here since the beginning, thank you for being part of the Lupus Outcomes Study.

We have just started our fifth round of interviews for the LOS. We have enrolled 1,023 participants, and have completed nearly 3,500 interviews. Over the next year and a half, we hope to enroll an additional 150 people with lupus.

Over the years, some of you have wondered why we ask the same questions year after year, why we collect the information we do, or why so many of our questions seem to be related to mental health. We think that this issue will provide some answers about how we use the LOS data in our research. In every follow-up study, it is important to ask the same questions each year, in order to track changes over time. In a lupus study, where the disease can change a great deal from one year to the next, it is even more important that we collect the same basic information each time we speak with you.

The LOS research team includes several UCSF faculty members. They study topics as varied as the genetic factors associated with lupus, how people with lupus cope with their disease, and what enables people with lupus to remain actively engaged in their lives. Other researchers in our group are interested in health policy issues: how well people with lupus are able to access the care they need.

Research Update

In general, body composition (the amount of fat and muscle in the body) is associated with functioning. People who have very little muscle often have problems with function, as do people with a great deal of fat. In studies of large groups of people, body composition is usually estimated with the “body mass index,” or BMI, which is calculated from height and weight. While BMI is a reasonable estimate of body composition, a much more exact measurement of the amount of fat and muscle in the body can be obtained with a radiographic procedure called a DEXA scan. (You may have had a DEXA scan to find out if you have osteoporosis or to measure your bone density.)

Body Composition & Functioning

Patricia Katz, PhD

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Body Composition & Functioning

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Among people with lupus, the relationship between body composition and functioning may be more complicated. Some markers in blood that reflect disease activity may reduce muscle mass; fat tissue can produce some of these blood markers. People with joint problems or other lupus symptoms may tend to be less physically active, which can also reduce muscle mass as well as increase body fat.

In a study we presented at the recent meeting of the American College of Rheumatology, we reported some preliminary findings on the relationship between BMI and problems in performing valued life activities. Around 5% of Lupus Outcomes Study (LOS) members were underweight (see insert below), and about 25% were classified as obese according to BMI. People who were obese reported more difficulty performing activities than who were normal weight or overweight. People who were underweight also had significant functional problems – the amount of difficulty they reported in performing activities was almost as great as the difficulty reported by those who were obese.

We will be starting a new study in 2007 to try to untangle the relationship between body composition, disease activity, and functioning in lupus. For this study, we will ask members of the UCSF LOS panel to come to UCSF Hospital. At these visits, we will measure body composition with a DEXA scan (a bone density measurement will also be made), muscle strength, and physical function; draw blood to measure disease activity; ask questions about physical activity; perform tests of memory and thinking; and ask some questions about mood and how people usually feel. Participants will be asked to return for the second visit two years later. We expect that the findings from this study will provide clues to help people with lupus avoid some functional problems. If you live in the San Francisco Bay Area, your interviewer will talk to you about this study at the end of your telephone interview. We hope that you will be interested in participating.

Patricia Katz, Professor of Medicine and Health Policy, has been at UCSF for 20 years. Her current research focuses on issues related to disability in chronic illness.

Calculating your body mass index (BMI)
Using your height in inches and weight in pounds, BMI is calculated as follows:

\[
\text{Weight} / \left[\text{Height}\right]^2 \times 703
\]

Standards for interpreting BMI:
- Under 18.5: Underweight
- 18.5-24.9: Normal Weight
- 25-29.9: Overweight
- 30 or greater: Obese

You can also link to one of the websites below to calculate your BMI.

http://www.nhlbisupport.com/bmi/
Estimating the Costs of Lupus

Peter Panopalis, MD

Health care costs

The rising cost of health care in the United States has received a great deal of attention over the past few years. Patients, health care providers, and governments at all levels are searching for ways to get the most out of health care expenditures. Lupus is a complex disease with an unpredictable course and a wide spectrum of clinical manifestations. Therefore, it is not surprising that the health care costs associated with this condition can sometimes be very high.

Analyzing the costs associated with lupus is important for several reasons. First, estimating the magnitude of the cost of lupus will help policymakers make better decisions about the allocation of resources. Second, a better understanding of the costs associated with lupus will give us insight into how to best use health care dollars in order to both improve health outcomes and maximize efficiency. For example, increased funding of preventive care services may both improve health outcomes of patients and reduce overall costs by decreasing the need for expensive hospitalizations. Finally, analyzing these costs will become increasingly important over the next few years as new therapies are introduced that will likely be more effective, but will almost certainly come at an increased cost.

The information in the LOS will allow us to complete one of the largest lupus cost studies in the United States. The analysis currently underway takes advantage of the wealth of information gathered from the LOS participants, which includes data on visits to physicians and to other health care professionals, visits to the ER, hospital stays, surgeries, diagnostic procedures, and medication use. Coupled with other information provided by the LOS participants, we will be able to determine which factors are most predictive of higher costs.

In prior studies, estimates of the annual average cost of medical treatment for a person with lupus have ranged from $6,000 - $10,000.

Preliminary results from the LOS indicate that these costs may now be approaching $12,000.

The cost of work disability

In addition to costs of health care, an even larger economic impact to individuals with lupus and to society may result from work disability. In an earlier newsletter, we reported that employment rates of LOS study participants were over 70% at the year of diagnosis (which is comparable to national averages) but are currently at 48%. Now, our investigators are using information from the LOS to estimate the costs resulting from this decrease in employment. Taken together, health care costs and costs due to work disability will approximate the total monetary costs associated with lupus.

Gaining a better understanding of the costs associated with lupus will help us focus our attention on finding ways to improve both access to health care services and the quality of health care. The hope is that learning to use health care resources in the most efficient and cost-effective manner will help improve health outcomes and the quality of life of people with living with lupus.

Peter Panopalis is a rheumatologist from Montreal, Canada, currently doing a research fellowship at UCSF. His research interests include the economic burden and health resource utilization in rheumatic disease.
Lupus is a disease that can affect almost any organ in the human body, including the brain and nervous system. One relatively common symptom of lupus is cognitive dysfunction, which is a reduction in the ability to think, remember, concentrate and reason.

Lupus may affect cognitive functioning for a number of reasons. First, it can directly cause damage to the nerve cells in the brain (called neurons). Other causes of cognitive dysfunction in lupus include depression, anxiety, fatigue and pain. Each of these symptoms can compromise thinking skills and lead to cognitive dysfunction.

Although a comprehensive assessment of cognitive functioning is not possible in the LOS telephone interviews, we have introduced some very brief screening measures of cognitive functioning. These short tests of memory and word finding will help us to understand the relationship between cognitive functioning and other symptoms of lupus. In addition, these measures can help us better understand how problems in memory and cognition can affect the daily lives of people with lupus. With this information, we can learn improved ways to detect cognitive problems and help people with lupus to better manage their symptoms.

Just as lupus disease processes can affect every patient differently, cognitive symptoms can also vary widely from person to person. Sometimes these changes are very subtle and have little impact on daily functioning. Other times these changes can be more serious and are an important cause of disability. One of the LOS investigators has just completed a study looking at the relationship of memory functioning and employment in lupus. He found that memory problems were an important factor affecting the work-life of many of the LOS participants. These results show that the more severe the memory problems, the greater the impact on the ability to work. These findings suggest that cognitive functioning, as well as physical symptoms can affect the work-life of people with lupus.

Cognition and Mood
Depression is a common disorder characterized by depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. About 1 in 4 of our LOS participants reported symptoms consistent with a possible depressive disorder, and about 42% reported symptoms consistent with at least milder forms of depression. Our LOS researchers have found that as depression symptoms worsen, cognitive symptoms increase among our LOS participants.

These results indicate that depression is an important problem in lupus. It is important for patients and their families to talk to their doctor if they are experiencing these symptoms of depression. There are effective treatments for depression. Not only can patients feel better, they may also experience some improvement in cognitive function when depressive symptoms are alleviated.

Cognition and Fatigue
Fatigue not only affects physical functioning, it can affect mental functioning as well. Fatigue can influence the ability to sustain attention over long periods, and can make it difficult to get started on tasks, especially when they are mentally demanding.

Although treating fatigue is difficult, behavioral strategies can be an effective way to manage fatigue in lupus. Improving sleep habits, exercise, and nutri-
Genetics Studies Update
Cooperation Among Lupus Researchers Expected to Speed Pace of Discovery

This month, rheumatologist Lindsey Ann Criswell, MD, MPH is hosting members of the International SLE Genetics (SLEGEN) Initiative, a group of scientists from around the world working together to unravel the genetics of lupus. By pooling data from many DNA collections, these scientists are able to use new technologies to rapidly analyze large numbers of DNA samples, which may help speed the identification of genes shared by people who have lupus. This effort is expected to yield new insights into the relationship between genes and the risk of developing lupus and specific complications, such as kidney involvement.

The blood samples generously provided by those participating in the UCSF Lupus Genetics Research Project are an important part of this international effort. Lupus patients from all ethnic backgrounds are still needed and can enroll by calling toll free (888) 223-3067 ext. 1.

Cognitive Functioning

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...tion can reduce fatigue substantially. In addition, strategies such as the ones listed on the following pages can be extremely helpful.

Future Directions for LOS

Thanks to our LOS participants, we have already learned important new information about the relationships between cognitive functioning and other common symptoms of lupus (e.g., depression). In addition, we have learned that physical symptoms are not the only symptoms that cause changes in work and life roles. This year, we will be looking into these symptoms more closely, inviting some participants to undergo MRI studies at UCSF. This will help us understand cognitive and mood symptoms related to underlying brain changes that are detectable by brain imaging.

Meet Our New Interviewer!

Stephen King joined the study as an interviewer in August 2006. He has worked in the Public Health field since 1996. He was formerly working as a Project Coordinator for an HIV research and prevention program at UCSF. “As an interviewer for this study I have learned a great deal about lupus and it’s effects on the population. I enjoy hearing the stories of people’s lives and how they are able to cope with their illness in its different stages.”

Stephen grew up in Northern California and went to college in San Francisco. Currently, he lives in San Francisco and enjoys writing and playing guitar.

Lupus Clinical Trials Update
UCSF Division of Rheumatology Clinical Trials Center

The Clinical Trials Center (CTC) currently has two clinical trials for patients who have kidney involvement from their lupus, one using rituximab and the second using etanercept. Both medications are currently approved for patients with rheumatoid arthritis. These medications suppress the body’s autoimmune activity. Three more clinical trials for lupus patients with or without kidney involvement will begin soon.

The CTC continues to enroll patients in the Natural History and Disease Activity study. The purpose of this study is to better understand how lupus begins and how it affects patients.

If you live in the SF Bay Area and are interested in hearing more about the CTC and upcoming trials, or if you would like to be added to the Lupus Database for future contact, please contact the CTC at (415) 502-1886.
Many lupus researchers in the U.S. are exploring treatments for cognitive dysfunction caused by lupus. To date, there is not a cure for cognitive dysfunction. However, patients can learn effective ways to compensate for cognitive problems and can learn ways to manage other lupus symptoms that can compromise thinking skills.

**Compensatory Strategies**

1) **Take your time:** People with lupus often say that their thinking skills can sometimes feel slow or ‘foggy.’ It might be important to adjust your expectations so that you can have more time to complete tasks when necessary.

2) **Keep it simple:** Multi-tasking is a struggle for many patients with cognitive impairment. All of our lives are so busy and we are accustomed to adopting more and more demands on our time. Unfortunately, the clock does not seem to be growing more and more hours, so we compensate by multi-tasking. It is critically important to prioritize and complete one task at a time. Try to minimize distractions when you need to do a task (don’t watch TV while doing your finances). Also, sustaining attention on one task for a long time is difficult. Building in breaks will help you to rejuvenate your mind and enable you to completing the task.

3) **Use cues and reminders:** Our lives are complicated and any compromise to cognitive functioning can be frustrating. When memory is weak, the best strategy is to increase organization. Develop a centralized organizer that contains a calendar, to-do lists, phone numbers, driving directions, etc. A large family calendar is also very important to keep up with activities and appointments. When learning something new, give yourself extra time to practice or memorize the information. Make sure you have a specific place in your home for keys, office supplies, medications, records, etc.

4) **Plan ahead:** Many people with lupus feel better at different times of the day, often depending on the level of fatigue they experience. In a typical work or school day, some tasks require more thinking skills than others. Therefore, it is important to plan your most demanding mental activities at your best time of day. Scheduling in breaks can help you conserve physical and mental energy.

**Ensuring a “Brain Healthy” Lifestyle**

The brain is one of the most vital organs of the human body and, like all organs, it needs maintenance and protection. Even with lupus, you can take two very important steps towards maintaining a healthy brain.

1. **Get Moving!**
   Physical exercise does not have to be strenuous or require a major time commitment. Staying as active as you can helps to maintain blood flow to the brain. It also reduces the risk of certain conditions including heart disease and diabetes, which can put you at a greater risk for cognitive dysfunction.

   It is never too late to start an exercise program. Exercise can reduce joint pain and stiffness and increase flexibility, muscle strength, cardiac fitness, and endurance. Exercise can also help with weight reduction.

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Recommendations for individuals with lupus include first consulting with your doctor to get a sense of what exercise program is safe and effective for you. There are three types of activities that can be highly beneficial:

- **Range-of-motion** to maintain joint movement, reduces stiffness, and increase flexibility. These activities can include swimming, dancing, yoga, tai chi
- **Strengthening** exercises help keep or increase muscle strength which is important for supporting the joints
- **Aerobic or endurance** exercises that increase your heart rate improve cardiovascular fitness, help control weight, and improve overall function.

2. **Food for Thought!**
Just like every organ in the body, a healthy brain requires healthy fuel. A balanced diet can maintain brain health. A healthy diet is one that is low in fat (especially saturated fat), cholesterol, and includes such nutrients as protein, fruits, vegetables, and whole grains.

- **Lower your fat intake.** Diets high in fat appear to increase the risk of a variety of brain problems as we get older.
- **Increase your nutrients.** Here are some nutrients that may have specific brain-healthy effects:
  - **Omega 3:** Some fats are good for us, for example Omega-3 fatty acids are polyunsaturated fatty acids that are considered essential because our body cannot make them; they must be obtained from food. Evidence suggests that these compounds reduce inflammation, can prevent heart disease, and may improve brain related aging. Foods with Omega 3 include oily fish, flax seed, grape seed oil, fish oil.
  - **Antioxidants:** These are substances that can counteract the damaging effects of oxygen in the tissues. They help to maintain cardiovascular health (which helps brain health). Foods with the highest antioxidant levels include dark-skinned fruits and vegetables (kale, spinach, broccoli, beets, blueberries, blackberries, plums, red grapes). In addition, some nuts in moderation (almonds, pecans, walnuts) are a good source of vitamin E, another antioxidant.

**Know when to talk to your doctor**
If you are concerned about cognitive dysfunction, you should speak with your doctor. Often times, a referral to a **neuropsychologist** might be helpful. A neuropsychologist is a specialist trained to evaluate cognitive functioning. They can help to find possible problems with brain functioning, identify specific strengths and weaknesses, can guide treatments, and follow patients over time to document improvement or worsening. A neuropsychologist would conduct an evaluation that includes a battery of standardized tests of memory, attention and concentration, problem solving, reasoning, language functioning, and visuospatial skills (visual perception and construction abilities).
Websites of Interest

http://www.lupus.org – The Lupus Foundation of America is a non-profit voluntary health organization dedicated to finding the causes and cure for lupus, whose mission is to improve the diagnosis and treatment of lupus, support individuals and families affected by the disease, and increase awareness of lupus among health professionals and the public.

http://www.arthritis.org – The Arthritis Foundation is a national not-for-profit organization that supports all types of arthritis and related conditions with advocacy, programs, services and research.

http://www.cdc.gov - Centers for Disease Control and Prevention is the lead federal agency for protecting the country’s health and safety.


http://www.healthfinder.gov - Health information from the U.S. Department of Health and Human Services that can be searched by condition, organization, or drug names.


Research Update

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they need, particularly some of the costlier medicines that will increasingly be part of lupus care.

One of the aspects of this disease that has not received much attention, but that we know has a big impact on people living with lupus, is the relationship between lupus and mental health. That is why we ask questions about your emotional state and include memory and word finding exercises in the interviews. We know that some of you may find these parts of the interview difficult or personal, and we appreciate your willingness to share these aspects of yourself with us.

Thanks again for being a part of the Lupus Outcomes Study!