

THE MCGILL UNIVERSITY HEALTH CENTRE (MUHC) LUPUS CLINIC NEWSLETTER

Issue 3

July/August 2004

INTRODUCTION

We are happy to present our third issue of the "MUHC Lupus Clinic Newsletter." Patients from the clinic will be receiving two issues a year.

Support for this newsletter is courtesy of the "Singer Family Fund for Lupus Research" established by Mr. and Mrs. Ron Singer. We would like to extend a special thank-you to Louise O'Donnell, Monique Martineau, Sally Drummond, and Helen Constantine for their energy and enthusiasm in helping to raise funds for the Singer Family Fund for Lupus Research.

All the staff from the lupus clinic would like to take this opportunity to wish you and your family a safe and healthy summer.

7th INTERNATIONAL LUPUS CONGRESS

Our Researchers

The 7th International Lupus Congress was recently held in New York City where Drs. Clarke, Pineau, Bernatsky and Panopalis of the MUHC were selected to present their research findings.

1) Drs. Clarke and Bernatsky presented their research at the patient symposium portion of the International Scientific meeting.

They have shown that the risk of developing a cancer in patients with lupus is very slightly increased. This risk may be a little greater for cancers of the blood, but the likelihood of a lupus patient developing any cancer is still quite low. It is not known if some of the medications used in the treatment of lupus are

responsible for this increased risk and we are currently studying this question.

Several papers have been published in scientific journals regarding this study. Please contact Dr. Clarke if you would like to receive a copy at 934-8037.

2) Dr. Panopalis is a rheumatology fellow working with Drs. Clarke and Pineau. They described how the physical and mental well being and work productivity of lupus patients worldwide changes over time.

They showed that the health status of lupus patients remained stable over the four year study period.

Other Researchers

Dr. Ellen Ginzler from Brooklyn, New York presented results of a large study comparing the use of Cellcept to Cyclophosphamide in the early treatment of lupus kidney diseases. This study suggests that Cellcept may be able to be used in some patients in place of Cyclophosphamide.

ONGOING PROJECTS

As many of you are already aware, there are ten on-going research projects at the Lupus clinic. You may be invited by a member of our research team to participate in one or more of these projects. If you are not approached by anyone but would like to learn more about these projects, please contact Dr. Ann Clarke or Dr. Christian Pineau at 934-8037.

They are as follows:

1) The Annual Assessment: "The Collection of Data and Extra Blood on Patients with

Systemic Lupus Erythematosus.” The goal of this study is to identify markers in patients’ medical history or blood tests that will allow us to predict the progression of the disease. Almost 500 patients from the MUHC Lupus Clinic are participating in this study.

2) “The Systemic Lupus International Collaborating Clinics (SLICC) Registry for Atherosclerosis in Systemic Lupus Erythematosus”. This study is open to newly diagnosed Lupus patients and involves 25 lupus centres worldwide. This study, otherwise known as the “SLICC”, is establishing an international registry of patients to study heart disease in lupus. To date, there are 500 patients enrolled in this study, 45 from the MUHC Lupus Clinic.

3) “The Systemic Lupus International Collaborating Clinics (SLICC) Study of Involvement of the Nervous System in SLE.” This study will help provide more information about involvement of the nervous system (brain, spinal cord, and peripheral nerves) in SLE. To date, there are 360 patients enrolled in this study, 34 from the MUHC Lupus Clinic.

4) “A Randomized Control Trial on Lymphostat B, a New Agent for Treatment of Lupus”. We are now recruiting patients for a pharmaceutical study involving a possible new treatment for lupus. Michelle Tobaly is the research coordinator for this study and Michèle Bibey is the study nurse.

5) “GENES: Genetic and Environmental Factors in SLE.” We are collaborating in a study coordinated by Dr. Tom Hudson of the MUHC, Dr. Glinda Cooper, a scientist visiting the MUHC from the National Institutes of Health, and Dr. Paul Fortin of the University of Toronto. This study examines the role of genetic and environmental factors in SLE. Three patients are currently enrolled and we anticipate enrolling 150 patients.

6) “Health Improvement and Prevention Program (HIPP).” The objective of this study is to determine whether HIPP will improve health status in patients with lupus and will lead to a reduction in heart disease and bone loss. Twenty patients have been enrolled and we anticipate enrolling 120 patients.

7) “The Role of Thrombophilic Factors in Persons with Systemic Lupus Erythematosus (ThromboFIL).” The objectives of this study are to determine the risk of thrombosis (clotting) in persons with lupus and to demonstrate that the risk for thrombosis is greater in persons who have antiphospholipid antibodies. Seven patients are currently enrolled and we anticipate enrolling 60.

8) “A Multi-Centre Nested Case-Control Study of Immunosuppressive Agents and Malignancy in Systemic Lupus Erythematosus.” This study will determine if the immunosuppressive therapy used in the treatment of lupus increases the risk for cancer.

9) “Hematologic Cancers in SLE.” Dr. Bernatsky along with Dr. Clarke and MUHC hematologists, Dr. Cournoyer and Dr. Lachance, will examine the features of cancers of the blood in persons with lupus.

10) “SOLE: Study of Osteoporosis in Lupus Erythematosus.” A study looking at the risk of developing osteoporosis in patients with newly diagnosed lupus is being planned. This will be a pan-Canadian study that will look at the role of lupus and its treatment on the development of osteoporosis.

COMPLETED PROJECTS

1. "Factors associated with abnormal Pap tests in SLE". We are publishing an analysis of the factors associated with abnormal Pap results in SLE. Pap smear tests, done during a gynecological exam, can detect changes that predict cervical cancer. If these changes are

detected, treatment can be given, to prevent cervical cancer occurrence. Pap tests are thus believed to be an effective way to prevent cervical cancer development. Previous studies have suggested that women with SLE are at greater risk for cervical dysplasia than are women in the general population. However, the factors associated with abnormal Pap test results in SLE have not been well studied. We attempted to determine the factors associated with the occurrence of an abnormal Pap test in women with SLE. Information from three SLE clinic registries were used; these clinics were the MGH, a lupus clinic in Chicago, and a lupus clinic in Birmingham UK. The information from the MGH came from a questionnaire completed by SLE clinic patients in 1998. The results of this study showed that a history of sexually transmitted diseases and use of oral contraceptives were associated with abnormal Pap reports in our sample of women with SLE. Immunosuppressive exposure (that is, drugs such as cyclophosphamide, Imuran (azathioprine) and methotrexate) was another factor associated with the occurrence of abnormal Pap tests. If you currently take these medications, or medications like them (such as CellCept-mycophenolate) you should be sure to get your Pap test done yearly. All women who are sexually active should have regular Pap tests. Please speak with your doctor about this if you have any questions.

2. "The Contribution of Disease-Related, Behavioral and Psychosocial Factors to Fatigue in Systemic Lupus Erythematosus: Evaluating a Biopsychosocial Model." Enrollment is completed and 115 patients have participated. A paper on this work will soon be published. Look for further information in our next newsletter.

Our thanks to the patients who are participating in any of our research studies. We hope that it will help physicians to provide optimal care to lupus patients everywhere.

OUR SPECIALISTS

We have specialists that come to our clinic.

Dr. Neil Colman – Respiratory diseases
Dr. Suzanne Morin – Osteoporosis
Dr. Elizabeth O'Brien – Dermatology
Dr. Susan Solymoss – Haematology
Dr. Murray Vasilevsky – Nephrology
Dr. Martin Veilleux – Neurology

RESOURCE MATERIAL

- Lupus: The disease with 1000 faces by Jean-Luc Senécal, Lupus Canada 1991, 2nd edition. A new edition is being published this fall.
- The Lupus Book; A guide for Patients and Their Families, by Daniel J. Wallace, M.D
- Lahita, Robert G.; Phillips, Robert H. (1998) Lupus: Everything you need to know. Garden City Park, NY: Avery. WR 152 L183 1998

For further information about Lupus, you may also log on to the Lupus Canada website, www.Lupuscanada.org

MISCELLANEOUS

We would like to thank the Singer Family Fund for Lupus Research for providing the patients of the Lupus clinic with refreshments.

As many of you may be aware, most provinces have a support group except for Quebec. If any of you are interested in becoming involved in forming Lupus Quebec, you may contact Lupus Canada at 1-800-661-1468.

We are attaching an article written by one of our patients that may interest you.

If you do not wish to receive future issues of this newsletter, please inform the lupus clinic secretary at 934-8037.