Welcome to the University of Toronto Lupus Clinic

The purpose of this newsletter is to provide our patients, their families and clinic supporters with information on the latest activities of the University of Toronto Lupus Clinic. We will include some background information about why the Lupus Clinic is special, updates on our Clinic staff and results of some of our recent research studies as well as future directions.

We hope you find this publication useful.

What is Lupus?

Since there are continually new patients entering the Clinic, we will start by providing some basic information about the disease.

Most patients know that systemic lupus erythematosus (SLE) is considered an autoimmune disease. Under normal conditions, the immune system plays a key role in protecting the body from harmful agents such as viruses and bacteria; in SLE however, antibodies are directed against oneself.

In patients with SLE, the immune system produces a number of antibodies that react with cell components resulting in chronic inflammation in different parts of the body. Lupus strikes 1 in 1000 Canadians, mainly women in the child-bearing years.
Meet the Clinic Doctors

Dr. Murray Urowitz is Director of the University of Toronto Lupus Clinic, Professor of Medicine, Senior Staff Physician, Toronto Western Hospital and Senior Scientist with the Toronto Western Hospital Research Institute. He is also Principal Investigator for the Systemic Lupus International Collaborating Clinics (SLICC) Registry for Atherosclerosis in SLE.

Dr. Dafna Gladman is Co-director of the University of Toronto Lupus Clinic, Professor of Medicine, and Senior Staff Physician, Toronto Western Hospital. Dr. Gladman is also the Director of the HLA Laboratory and Senior Scientist with the Toronto Western Research Institute. Dr. Gladman is also director of the University of Toronto Psoriatic Arthritis Clinic.

Dr. Paul Fortin is Co-Director of the University of Toronto Lupus Clinic. He is an Associate Professor of Medicine and Senior Staff Physician, Toronto Western Hospital. He is a Senior Scientist at the Toronto Western Research Institute. Dr. Fortin is Director of the Canadian Network for Improved Outcomes in SLE (CaNIOS) and Director of Clinical Research for the Arthritis Centre of Excellence. Dr. Fortin is also Director of the Antiphospholipid Syndrome Clinic.

Education and Training for Future Care & Research

The Lupus Clinic is part of the University of Toronto Rheumatology Training Program and hosts several trainees from Canada and abroad who have completed their specialty training in rheumatology and who come to our Clinic to gain further training and expertise in the management of patients with SLE and in clinical research. Our Clinic encourages the participation in research of students at all levels of their medical training by participating in summer student programs and supervising research electives for general medical residents.

Dr. Mandana Nikpour who trained in rheumatology in Australia joined our program in October of 2003 and sees patients in our Tuesday clinic. Dr. Nikpour is completing a PhD in clinical epidemiology which will involve her research in heart disease in SLE. Dr. Nikpour was awarded the Lupus Ontario, Geoff Carr Lupus Fellowship in 2004 and 2006-07.

Dr. Sergio Toloza who is a rheumatologist from Argentina, joined our clinic in November 2005 and sees patients on Tuesdays and Thursdays. During his time with us Dr. Toloza has become involved in several research projects including studies of osteoporosis and metabolic syndrome in SLE.

Dr. Carol Landolt is a research fellow from Toronto who is working in the Laboratory of Dr. Joan Wither. Dr. Landolt has been awarded a Canadian Institutes of Health Research Fellowship to complete a study looking at genetic, molecular and clinical aspects of renal disease in lupus. (See LuNNET Study, page 4)

Dr. Desiree Tulloch-Reid the recipient of the Geoff Carr Lupus Fellowship for 2007-08, is a rheumatology trainee from Jamaica who plans to work one to two years Lupus Clinic. She will be continuing a research project looking at classification of renal disease in Lupus and pursuing a Masters degree in clinical epidemiology.

In addition, two to three senior fellows from the Rheumatology Training Program of the University of Toronto work in the Clinic for a period of six months as part of their rheumatology training. These fellows often go on to practice rheumatology in the community or pursue further research or academic postings.

The Clinic also involves training of allied health professionals such as epidemiologists, biostatisticians, and psychology students. We also participate in the University of Waterloo co-operative education program for Health Science students.
Research Update

In this section of the newsletter we will provide a brief summary of results of some of our recently completed studies and those currently underway or planned for the near future. On pages 9 and 10 we provide a complete list of current studies and contact information for each study.

Metabolic Syndrome and Risk for Heart Disease in SLE

A major focus of our research over the last few years has been in the area of heart disease in SLE patients. Women with SLE are known to develop atherosclerotic heart disease (thickening of arteries) earlier than the general population. Because of these changes, women with SLE are at an increased risk of developing related problems such as heart attacks and angina up to five times more frequently than the general population.

Dr. Sergio Toloza is interested in exploring if there is an association with this increased risk of heart disease for patients who also have features of metabolic syndrome. Metabolic syndrome is a clustering of risk factors that include central obesity (increased waist circumference, increased lipid levels, high blood pressure and elevated blood sugar. The presence of metabolic syndrome may provide a better tool for predicting if a patient is more prone to develop heart disease. The first step in this study was to ascertain the frequency of metabolic syndrome. Dr. Toloza was able to do this using the clinic database and the initial analysis showed that metabolic syndrome is prevalent in SLE and that its presence is also associated with older age at diagnosis and the accumulation of damage. Dr. Toloza presented the results of this study at the American College of Rheumatology Scientific meeting in Washington in November 2006 and plans further studies that will examine the role of metabolic syndrome in the development of atherosclerosis.

Systemic Lupus Endothelial Dysfunction (SLED) STUDY

Together with colleagues in our Cardiology Division we received funding from the Heart and Stroke Foundation of Ontario to carry out a study to assess the effectiveness of a drug called Quinapril for the treatment of coronary artery disease. One hundred and forty patients from the clinic were screened for this study by undergoing Sestimibi heart scans and brachial artery ultrasound to assess the function of blood vessels. If an abnormality was detected in the Sestimibi scan, the patient was then be able to participate in the drug trial phase of this study.

Information that was gathered in the screening phase of this study has resulted in several reports that were presented by Dr. Nikpour at various scientific meetings describing the type of abnormalities found and the relationship between endothelial functioning and abnormalities on Sestimibi scan. This information has added to the general understanding of coronary artery function and the usefulness of these tests in picking up coronary artery disease before the patient has an event. Analyses of results for the trial phase of this study are still ongoing.

Osteoporosis in SLE

We received a grant from The Arthritis Society to carry out a study looking at risk factors for osteoporosis in patients with SLE. Women with SLE are predisposed to the premature development of osteoporosis or reduced bone mineral density (BMD) at a much earlier age than the general population. Osteoporosis has a significant impact on long-term outcomes and quality of life in these women. This increase in bone density loss may be due to their underlying inflammatory condition or standard SLE therapies which predispose to bone loss. The role of vitamin D deficiency may also be a factor. The objective of this current study is to assess risk factors for osteoporosis in a large cohort of women with SLE. Patients in this study underwent dual X-ray absorpiometry testing (DEXA) to measure bone density which is done as part of routine care every one to two years. Clinical and laboratory factors including levels of vitamin D were then compared between patients identified with osteoporosis and patients without osteoporosis. Blood was also drawn to screen for genes which are known to regulate vitamin D absorption. Initial analysis of bone density testing results showed that osteoporosis was more prevalent in pre-menopausal women at a younger age, particularly in those who had received higher doses of steroids over time. In post-menopausal women osteoporosis was associated with higher levels of damage. Dr. Toloza presented the results of these initial analyses at the American College of Rheumatology National Scientific meeting in November 2006. Analysis of vitamin D levels and genetic testing is currently underway.
Prediction of Flare in Systemic Lupus

A continuing challenge for doctors treating lupus patients has been the difficulty predicting when a patient is going to flare. Patients with SLE can have a complex disease course which varies over time. Some patients have persistently active disease, periods of no disease activity and then periods of disease flare. To date blood tests that are routinely used to monitor lupus have a limited ability to predict when a patient is going to flare or what organ system will be involved. Preliminary genetic studies have identified sequences of genes or proteins in the blood thought to be associated with SLE disease development. The presence or absence of a combination of these genes or proteins may also be able to predict disease flare or organ involvement in SLE over time.

In 2005-2006 we carried out an initial study in collaboration with MetriGenix Corporation which investigated the usefulness of a newer technology called genomic microarray in predicting flare in patients with SLE. The technology identifies multiple gene sequences or protein expression in the blood that may be related to disease activity or specific organ system involvement. This study involved 253 patients who provided a blood sample at the time of their clinic visit which was then submitted for microarray analysis. The results showed that patients who had a higher interferon (IFN)-regulated gene expression profile (known to play a role in the immune response) had a higher level of disease activity at the time of study. In particular arthritis and positive anti-DNA antibody and low complement tests were significantly associated with this high INF-regulated gene expression.

In order to further determine the usefulness of this technology in predicting flare in SLE it is necessary to perform this test in a group of SLE patients, with varying disease activity, at multiple visits over an extended period of time. The results can then be associated with any changes in disease activity over that period. We are now more than half-way through a second study where 50 patients are being assessed monthly and having blood drawn at each visit for microarray analysis so that we can compare how this gene expression changes over time in correlation with disease activity.

The long term goal is to develop clinical diagnostics to predict flare in SLE patients. Such a diagnostic tool could facilitate a more rapid disease diagnosis and by potentially allow for treatment of flares before they occur.

LuNNET – Lupus Nephritis Network

Kidney disease is one of the most common and severe manifestations of lupus. Today, only a kidney biopsy can lead to an accurate diagnosis of lupus nephritis. This procedure, which consists in collecting a piece of the kidney with a needle, is unpleasant and may rarely be associated with life-threatening complications. Although treatments are improving, they remain aggressive and associated with problems. If unresponsive to treatment or untreated, the kidneys may shutdown and the need to use a machine called dialysis or to transplant a kidney to keep the person alive may arise. The impact on the quality of life and the cost associated with this are tremendous.

The LuNNET study is a CaNIOS initiative funded through the Canadian Institutes of Health Research, which has created a unique Canada-wide team of experts in lupus and kidney disease that will work together to answer several questions with the ultimate goal of improving our understanding, diagnostic tests, and treatment of lupus nephritis. For the patients, this will potentially result in the use of less invasive tests instead of kidney biopsy, allowing their physicians to better modify treatment in response to changes in their disease. This will lead to a significant improvement in the quality of life and the burden of illness of those with lupus.

Two groups of patients are required to participate in this study. The first group will be newly diagnosed patients who have yet to receive treatment with steroids for their lupus. The second group will be patients who currently have active disease with or without kidney disease.

Thulasi Unnithan is the research coordinator for this project and she will be approaching patients in the lupus clinic to explain the study. Patients who agree to participate will be required to complete a series of questionnaires and provide blood and urine samples.
The Systemic Lupus International Collaborating Clinics (SLICC) is an international group of rheumatologists and lupologists from centres in 11 countries who have been working together on lupus research since 1987. In the past they have collaborated to develop standardized outcome measures so that physician-researchers could better measure and describe the course of lupus and its response to new therapies. These outcome measures are now widely used by lupus researchers throughout the world and allow comparison of patient populations among centres. The SLICC group has been working on the important area of heart disease in SLE through the development of the Registry for Atherosclerosis. The long-term goals of this registry are to allow researchers to determine the frequency in the population and nature of early atherosclerotic coronary artery disease in SLE, and to identify associated risk factors and develop preventative interventions.

The Registry includes patients who are newly diagnosed with SLE and involves the collection of clinical and laboratory data as well as family history and lifestyle information related to heart disease on an annual basis for a minimum of five years. In addition laboratory samples are being collected for centralized testing of inflammatory measures and banking of DNA. The University of Toronto Lupus Clinic is the co-ordinating centre for the SLICC Registry for Atherosclerosis.

Over 1000 patients are now enrolled in the Registry. These individuals represent an ethnically, culturally and geographically diverse group of newly diagnosed SLE patients. This unique resource will allow us to determine the nature of early atherosclerotic heart disease and identify risk factors early, leading to preventative therapies.

The Registry is now being recognized as a valuable resource that can be made available for additional clinical and genetic studies and a formal process to facilitate this data sharing to promote further collaborative research is being developed by the SLICC group.

Members of The Systemic Lupus International Collaborating Clinics are from:
Canada, Great Britain, Iceland, Korea, Mexico, Spain, Sweden, Switzerland, and U.S.A.

In addition to the SLICC Registry for Atherosclerosis the SLICC group is carrying out research in neuropsychiatric SLE, malignancy in SLE and development of updated diagnostic criteria.
CaNIOS
Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus

The Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) is a pan-Canadian network created in 1995 through the leadership of current chair, Dr. Paul R. Fortin. It is a group of Canadian clinician investigators and research scientists coming together to improve the outcome of lupus patients across Canada through collaborative research. The CaNIOS Coordinating Centre is located at Toronto Western Hospital. CaNIOS exists through limited peer-reviewed funding from individual operating grants obtained from government agencies and not-for-profit organizations. Since September 2001, a donor in partnership with Lupus Canada and the Arthritis and Autoimmune Research Centre Foundation (AARCF) at University Health Network have supported CaNIOS infrastructure, including the development of the National Lupus Registry that is essential for efficient lupus clinical trial network in Canada. CaNIOS has up to a total of 57 clinicians and scientists affiliated with 28 Canadian academic-based rheumatic disease units and community rheumatology clinics. Currently, the US-based Lupus Clinical Trial Consortium partially supports infrastructure funding that facilitates the conduct of randomized clinical trials in lupus in Canada.

The University of Toronto Lupus Clinic continues to contribute to ongoing CaNIOS projects including:

a) HIPP, a randomized controlled trial aimed at comparing the Health Improvement and Prevention Program versus usual care with the goal of improving health status, decreasing cardiovascular risk and improving endothelial function in persons with lupus. Eighty two of the total 221 patients recruited into this study are from the University of Toronto Lupus Clinic.

b) ThromboFIL studies factors that increase the chances of developing a blood clot in persons with lupus. One hundred and sixty seven of the total 294 patients enrolled in this study to date are from the University of Toronto Lupus Clinic.

c) GenES is a research program to identify genes, environmental factors, and gene-environment interactions that influence the risk of lupus. 86 of the 255 trios enrolled in this study are from the University of Toronto Lupus Clinic.

d) 1000 Canadian Faces of Lupus aims to establish a longitudinal multi-ethnic Canadian lupus cohort to characterize ethnic differences in clinical manifestations and disease outcome. Data on 575 patients followed at the University of Toronto Lupus Clinic has been included in this study.

e) LuNNET, unites a nation-wide team of experts with unique expertise working towards the discovery and definition of the mechanisms that lead to disease expression and damage in lupus nephritis, an inflammation of the kidneys that may lead to kidney failure in lupus. The LuNNET study is further described on page 4.

The Lupus Health Passport is a recent CaNIOS project developed to serve as a tool to administer and monitor an ongoing program on HIPP in SLE.

More information about CaNIOS can be accessed at www.CaNIOS.ca, or by contacting its Coordinating Centre: Toronto Western Hospital – University Health Network
399 Bathurst Street, MP 10-303, Toronto, Ontario M5T 2S8
Tel: 416-603-5800 extension 3158, Fax: 416-603-6288
e-mail: jclaudio@uhnresearch.ca
Clinical Trials in SLE

Although better management of patients with SLE has resulted in improved outcomes over recent years, there have not been any dynamic new drugs for the treatment of SLE until recently. We are now entering an exciting time with several new medications being developed and tested for treatment of other autoimmune diseases such as rheumatoid arthritis. These new therapies include “biologic” drugs that target a specific cellular process in the immune response.

Pharmaceutical companies are now carrying out randomized clinical trials of these newer therapies in lupus. Drs. Fortin, Gladman and Urowitz are actively involved as consultants in the development and execution of these study protocols. There will be as many as 10 new drugs ready for testing within the next one to two years.

We are happy to introduce Vicki Lapp and Joan Blair, our clinical trials nurse coordinators, who both have extensive experience in managing clinical trials and have recently moved to an expanded facility which is located directly across the hall from the Lupus Clinic.

If you are interested in participating in a clinical trial of new therapies in SLE or would like more information please contact Vicki or Joan at 416-603-5800 ext. 2077.

Laboratory Research

This aspect of our program takes place at our Research Laboratory on the 14th Floor of TWH, which is managed by the laboratory technologist, Fawnda Pellett and is directed by Dr. Gladman. We have continued to perform HLA (Human Leukocyte Antigen) typing on our SLE patients and we have now collected samples on over 500 patients. This bank of samples forms the basis for genetic analyses that can be linked with the extensive clinical data allowing us to examine the association of these particular genetic markers with disease susceptibility as well as disease progression.

In November of 2005 Fawnda presented the results of a study carried out by herself and a University of Toronto summer student, Iva Vukin, at the 14th International Histocompatibility and Immunogenetics Workshop, held in Melbourne Australia. This study looked to see if KIRs (Killer Immunoglobulin-like Receptors) were associated with autoimmune disease, specifically Systemic Lupus Erythematosus and Scleroderma. Indeed one of the activating KIRs was increased in both patient groups. Our group was the first to report this increase in an activating KIR in SLE. KIRs help regulate the immune response and must interact with HLA alleles in order to function.

This discovery prompted our group to examine the frequency of the KIR alleles in association with acute vascular events (such as heart attack, angina and stroke), vasculitis or autoantibodies. In the 304 patients tested, an increase of activating KIR2DS2 was detected in the SLE patients with acute vascular events or with anticardiolipin antibodies. Dr. Toloza participated in the analysis of this study and presented the results at the American College of Rheumatology meeting in November 2006. There have been no reports in the literature to date of these disease manifestations in SLE and the increase in these KIR alleles. Additional studies are planned in this area to help elucidate the role played by KIR genes in SLE and hope to be successful in obtaining funding to pursue this novel area of research.
AWARDS

Dr. Mandana Nikpour was the recipient of the Canadian Rheumatology Association Award for the best original research presented at the combined Mexican and Canadian Rheumatology Associations Annual General Meeting held in Mexico in March of 2006. This was for her work in microarray analysis in the prediction of flare in SLE.

Mandy was also awarded the Ian Watson Award for best original research in lupus presented at the Canadian Rheumatology Association Annual Scientific meeting held in March of 2005 for her research looking at coronary angiographic findings in SLE.

Mandy has been actively involved fundraising activities and patient education seminars with Lupus Ontario and the Lupus Society of Alberta and has received a research grant from the Lupus Society of Alberta to her work in heart disease.

Acknowledgements

Once again we would like to extend our thanks to the many supporters of the University of Toronto Lupus Databank Research Program. This includes the Lupus Foundation of Ontario who continue to provide support for the SLICC Registry for Atherosclerosis and Lupus Ontario who provide support through the Geoff Carr Lupus Fellowship as well as many private donors.

Flare for Fashion

The second annual “Flare for Fashion” fundraiser was held on October 19th, 2006. This amazing event was organized by Diana Bozzo, Director of Public Awareness for Lupus Ontario and proceeds from this event went to the Lupus Clinics at Toronto Western Hospital and Hospital for Sick Children as well as Lupus Ontario. Thanks go to Diana and the organizing committee for the tremendous amount of work that goes into this event. Preparations are well underway for next year’s event which is scheduled for October 18th, 2007 at the Mississauga Convention Centre and promises to be even bigger. More information and photos from last year’s show can be seen at www.flareforfashion.ca.

Dance for the Cure

The 11th Annual "Dance for the Cure" took place in January of 2007. The event organized by Tiziana Tolfo, her family and friends, raises funds for lupus research and awareness. For the past six years, part of the proceeds has been donated to the SLICC Registry for Atherosclerosis. We would like to gratefully acknowledge the hard work that Tiziana her family and friends put into this wonderful event and their continued support. Further information can be found at www.danceforthecure.ca.

A Special Thanks to Our Patients

We have completed several exciting projects over the past year which have expanded the overall understanding of SLE and which have lead to further planned studies. None of this research would be possible without the continued participation and support of our patients and their families. If you would like any further information or are interested in participating in any of these studies, please speak to your Lupus Clinic physician or the Research Office at 416-603-5800 ext. 2511.
SUMMARY OF CURRENT RESEARCH STUDIES

STUDY NAME: SLICC REGISTRY FOR ATHEROSCLEROSIS IN SLE (SLICC-RAS)

STUDY OBJECTIVES
To determine the frequency and nature of early atherosclerotic coronary artery disease in SLE.

WHO CAN TAKE PART?
All patients diagnosed within the last 15 months.

WHAT IS INVOLVED?
One study visit per year for up to five years. Study visits will include collection of clinical and laboratory information; completion of quality of life and family history questionnaires, and collection of 4 - 6 tubes of blood.

CONTACT INFORMATION
Principal Investigator:
Dr. Murray Urowitz
Co-investigators:
Dr. P. Fortin & D. Gladman
and members of SLICC
Research Assistant:
Samantha Janes
Ph: 416-603-5800 ext. 2481

STUDY NAME: SLICC REGISTRY FOR NEUROPSYCHIATRIC SLE (NP-SLE)

STUDY OBJECTIVES
To determine the frequency and nature of neuropsychiatric (central nervous system) manifestations of SLE.

WHO CAN TAKE PART?
Patients who qualify for the Registry of Atherosclerosis (above) may also choose to participate in this study.

WHAT IS INVOLVED?
At the same time as your annual SLICC Registry for Atherosclerosis study visit additional information concerning any neuropsychiatric events will be collected.

CONTACT INFORMATION
Principal Investigator:
Dr. John Hanly, Halifax
Co-investigators: Members of SLICC
Research Assistant:
Samantha Janes
Ph: 416-603-5800 ext. 2481

STUDY NAME: GENETIC AND ENVIRONMENTAL FACTORS IN SLE (GeNES)

STUDY OBJECTIVES
To identify genes, environmental factors and gene-environment interactions that may contribute to the development of SLE.

WHO CAN TAKE PART?
All SLE patients:
- Patients with both parents living will qualify for the gene component of this study.
- Patients who do not have both parents living may qualify to complete an environmental questionnaire.

WHAT IS INVOLVED?
For SLE patients the study will involve one clinic visit where 5-6 teaspoons of blood will be drawn (at the time of their usual clinic bloods) for DNA isolation. They will also be asked to complete a series of questionnaires that gather information regarding environmental exposures. The questionnaires will take approximately 1 hour to complete. Family members participating in this study will be asked to provide 9 tubes of blood. This may be arranged at a laboratory close to home.

CONTACT INFORMATION
Principal Investigator:
Dr. Paul Fortin
Co-investigators:
Members of CaNIOS
Research Assistant:
Tamara McKenzie
Ph: 416-603-5800 ext. 2822

STUDY NAME: HEALTH IMPROVEMENT AND PREVENTION STUDY (HIPP)

STUDY OBJECTIVES
To demonstrate that a coordinated intervention program will improve health status in SLE compared with usual care.

WHO CAN TAKE PART?
Women with SLE and no previous history of heart disease or osteoporosis.

WHAT IS INVOLVED?
In addition to their usual clinic care, patients who participate in this study will take part in a Health Improvement and Prevention Program (HIPP) and be followed for a 24 month period. Patients will participate in the HIPP program either in the first 12 month or second 12 months of the study. The HIPP program will be lead by a case-manager nurse, and will include a 4 week, 6 hour educational course followed by development of an individualized program. Several outcome assessments including questionnaires on health status, cost and coping, and blood vessel and bone density studies will be performed at baseline, 12 and 24 months. This will allow us to determine the effectiveness of a formal intervention program over usual care.

CONTACT INFORMATION
Principal Investigator:
Dr. Paul Fortin
Co-investigators:
Members of CaNIOS
Nurse Co-ordinator:
Anne Cymet
Ph: 416-603-5800 ext. 2895
STUDY NAME: LUPUS NEPHRITIS NEW EMERGING TEAM (LuNNET)

STUDY OBJECTIVES
To examine lupus nephritis (kidney involvement) and potentially develop new diagnostic tools for the identification of lupus nephritis.

WHO CAN TAKE PART?
Newly diagnosed patients prior to treatment with steroids, as well as patients previously diagnosed who are currently have active lupus.

WHAT IS INVOLVED?
Once a year clinical and laboratory information will be collected as part of your routine clinic visit. Some extra blood and urine will be obtained.

CONTACT INFORMATION
Principal Investigator
Dr. Paul Fortin
Co-investigators: Members of CaNIOS
Research Associate:
Thulasi Unnithan
Ph: 416-603-5800 ext. 6140

STUDY NAME: THE ROLE OF THROMBOPHILIC FACTORS IN PERSONS WITH SLE (ThromboFIL)

STUDY OBJECTIVES
To measure how often blood clots occur in persons with SLE, and explore how antiphospholipid antibodies (aPL) may increase the risk of these clots.

WHO CAN TAKE PART?
Patients diagnosed with SLE within the past 5 years, and who have not had any blood clots for more than 1 year before the diagnosis of SLE.

WHAT IS INVOLVED?
One study visit per year for up to three years. Study visits will include completion of family history and health status questionnaires, collection of 4 tubes of study bloods for clotting factors and DNA storage. Telephone interviews will also be carried out at 6, 18 and 30 months.

CONTACT INFORMATION
Principal Investigator:
Dr. Paul Fortin
Members of CaNIOS
Research Associate:
Erika Chang
Ph: 416-603-5800 ext. 3157

STUDY NAME: PROSPECTIVE COHORT OF PATIENTS WITH ANTIPHOSPHOLIPID ANTIBODIES (TAPS)

STUDY OBJECTIVES
To examine the clinical and laboratory mechanisms and long-term outcomes of patients with antiphospholipid antibodies, which are associated with abnormal blood clotting.

WHO CAN TAKE PART?
All patients who have antiphospholipid antibodies with or without lupus.

WHAT IS INVOLVED?
Once a year clinical and laboratory information will be collected as part of your routine clinic visit. Some extra blood will be drawn for future testing of specific antibodies.

CONTACT INFORMATION
Principal Investigator
Dr. Paul Fortin
Co-investigators:
Drs. D. Gladman & M. Urowitz
Research Associate:
Erika Chang
Ph: 416-603-5800 ext. 3157

REVISING ACR DIAGNOSTIC/CLASSIFICATION CRITERIA FOR SLE

STUDY OBJECTIVE
To revise the existing diagnostic/classification criteria for lupus.

WHO CAN TAKE PART?
Patients with SLE as well as patients with other rheumatologic diagnosis to act as a control group.

WHAT IS INVOLVED?
This is a collaborative multi-centre study of the SLICC group and will involve approximately 10 to 12 patients from the University of Toronto Lupus Clinic and 10 to 12 controls. Clinical data that is collected as part of a regular lupus clinic visit and one set of blood samples will be submitted to the study co-ordinating centre at Johns Hopkins University in Baltimore.

Principal Investigator:
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Johns Hopkins University, Baltimore
Co-investigators:
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Web Site: www.uhnres.utoronto.ca/cpsrd

If you are interested in making a donation to the Lupus Databank Research Program
contact Anne MacKinnon at 416-603-5800 ext. 2511