



# CaNIOS IN TOUCH

CaNIOS Research Participants Newsletter

VOLUME 1, ISSUE 1

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## Inaugural Issue

### SPECIAL POINTS OF INTEREST:

- **CaNIOS Research Ten Guiding Principles on Privacy.**
- **A brief essay from a HIPP Graduate**
- **Lupus Health Passport**
- **Lupus Research Funds in Canada**

The 6th CaNIOS Principal Investigator's Meeting in Winnipeg last May gave birth to the idea of this patient newsletter. The Research Coordinators and Assistants of various CaNIOS projects thought that keeping you informed through a newsletter is a fitting method to improve

knowledge transfer and exchange between CaNIOS and lupus patients. Appropriately enough, we called the CaNIOS Research Participants Newsletter **In Touch** as a way of keeping study volunteers informed of the progress of different CaNIOS research. Two issues published annually will be

posted on the CaNIOS website ([www.CaNIOS.ca](http://www.CaNIOS.ca)) in July and January or distributed electronically upon request. Hard copies are available from your rheumatologist's clinic or from CaNIOS Centres across Canada.

## SNiPpet Of Your Genome

Three and a half years later and 1613 patients screened, the Genetics and Environmental Factors in SLE (GenES) Study, nationally coordinated by Tamara McKenzie, has achieved and exceeded its recruitment and enrolment goals. The research study headed by Drs. Paul R. Fortin and Joan Wither recruited a total of 259 patient-parents trios from CaNIOS Centres all over Canada. We thank all volunteer families for taking part in this study. Participants will share anonymously their genetic make-up to try to better

understand the genetic basis of lupus. DNA from these individuals are currently being scanned by high throughput robots at the McGill University and Genome Quebec Innovation Centre in Montreal. The first results of these tests look promising for finding the genetic markers called SNP (read snip for Single Nucleotide Polymorphism). Further inves-

tigation using other group of lupus patients will confirm results whether the region we have identified plays a role in SLE. The GenES Team including gene mapper Dr. John Rioux have been talking with international collaborators on how our Canadian lupus cohort (group of lupus patients) can further our collaborative research in lupus. Promising discoveries are ahead of us, thanks for the snippet of your genome.



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## Recently Published

**Montreal.** Do SLE patients who use more health care resources do better? Not so, according to a recently published study headed by CaNIOS member, Dr. Ann

Clarke at the Montreal General Hospital. Although SLE patients in the US incurred 19% and 12% higher direct medical costs than patients in Canada and the UK,

respectively, they did not experience superior outcomes expressed in terms of less disease damage, superior quality of life, or less productivity loss.

**Winnipeg.** In a recent publication, CaNIOS members Hitchon and Peschken evaluated the importance of ethnicity, socioeconomic status, and autoantibodies (proteins normally involved in body's defense that act directly

against an individual's own defense) in 330 lupus patients from three ethnic groups: Caucasians, Asian-Orientals, and Native American First Nations. They concluded that specific important proteins and low income is associated with lupus

organ damage. Additionally, the presence of anti-Sm increases the risk of death in lupus, independent of ethnicity, renal involvement or socioeconomic status.

# Meet The Investigators



From top to bottom: Joan Wither is co-principal investigator for both the GenES Study and LuNNET. She is Associate Professor of Medicine and Immunology at the University of Toronto. She also holds a Senior Scientist appointment at Toronto Western Research Institute. Dr. Christine Peschken is the lead investigator of the 1000 Canadian Faces of Lupus Study. She splits her time between research and clinic at the Winnipeg

Health Sciences Centre. She also holds an Assistant Professor appointment at the University of Manitoba. Dr. Paul R. Fortin is co-principal investigator (co-PI) of GenES, LuNNET and HIPP. He is the principal investigator for ThromboFIL. He is also a Full Professor of Medicine at University of Toronto and co-director of the University of Toronto Lupus Clinic. He is a Senior Scientist at the Toronto Western Research Insti-

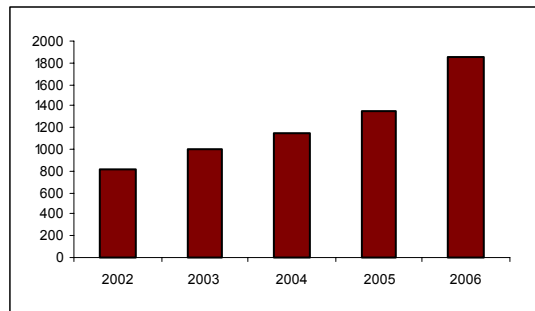
tute, and currently the Chair of the Canadian Network for Improved Outcomes in SLE (CaNIOS). He is the Director of Clinical Research for the Arthritis Centre of Excellence. Dr. Debbie Da Costa is health psychologist specializing in stress management and coping in chronic illness. She is co-PI of the HIPP Study. She is Assistant Professor at McGill University Health Centre.

## National Lupus Registry

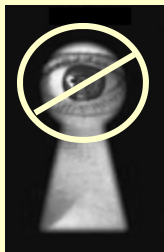
CaNIOS maintains a database of lupus patients through the National Lupus Registry. The idea is to combine data from different centers through a standardized data collection system in order to describe SLE in Canadians, increase the power of medical research, and exchange

valuable clinical information between doctors and researchers. A steady increase in the size of the

database marks the progress of the registry since its inception in 2002. As CaNIOS is the health information custodian of sensitive patient information, the CaNIOS Privacy Officer ensures that CaNIOS is in compliance with both federal and provincial privacy legislations.



**At CaNIOS, we  
take your privacy  
seriously.**



### Our Research Is Guided By 10 Privacy Principles

1. Accountability
2. Identifying purpose
3. Consent
4. Limiting collection
5. Limited use, disclosure and retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual access
10. Challenging compliance

These ten principles are found in the Code for the Protection of Personal Information, Can/CSA-Q830-96, which is now Schedule I of the *Personal Information Protection and Electronic Documents Act*, (PIPEDA) statutes of Canada, 2000, c.6.

# Research Updates At-A-Glance

## HIPP

National Coordinator: Anne Cymet



The goal of HIPP is to demonstrate that a coordinated intervention program will improve health status of patients with SLE compared to usual care. Current total enrolment of 201

patients have shown that HIPP intervention may indeed decrease cardiovascular (heart-related) risk. This preliminary result suggests that knowledge transfer is powerful in providing a proactive and positive attitude among lupus patients. Interestingly, the Lupus Health Passport which was developed as a tool to administer the complex intervention by HIPP is

becoming a big hit not only to HIPP participants, but other lupus organizations abroad. The Lupus Foundation of America has been working with CaNIOS to develop and validate an American edition of the passport. Some pharmaceutical companies have also indicated interest in using the Lupus Health Passport for baseline clinical information on patients participating in drug studies.

*The Lupus Health Passport was developed as a tool to administer the complex intervention by the HIPP Program.*

## 1000 Faces of Lupus

Nat'l Coordinator: Mellissa Moyon

Aboriginal Canadian lupus patients appear to accumulate the most damage compared to Caucasian Canadian, Asian Canadian, and African Canadian patients. It is postulated that this may be due to socio-demographic and behavioral factors rather than to greater lupus activity or severity. The study suggests that aggressive risk management reduction and education may be of benefit in reducing damage accumulation.

## ThromboFIL

Nat'l Coordinator: Carolyn Neville

The ThromboFIL study is looking at the role of factors that increase a lupus patient's chances of developing blood clot. Recruitment for the study involved Centres in Montreal, London, Winnipeg, Sherbrooke, and Toronto. To date, the study has reached its goal of 303 participants. Data are currently being entered into the ThromboFIL database. Analysis will commence shortly, so exciting results are forthcoming.

## LuNNET

Nat'l Coordinator: Thulasi Unnithan

Dr. Carolina Landolt-Marticorena, a rheumatologist working on her Ph.D. with the LuNNET team, won the Ian-Watson Award for Outstanding Lupus Research at the recent Canadian Rheumatology Association (CRA) meeting held at Lake Louise in February 2007. Her study concluded that sustained activation of T cells, a type of white blood cells, in lupus patients promotes disease activity.

LuNNET—Lupus Nephritis New Emerging Team

ThromboFIL—Thrombophilic Factors in Lupus

HIPP—Health Improvement and Prevention Program

GenES—Genetic and Environmental Factors in SLE

# CaNIOS Funding

CaNIOS receives financial support for infrastructure, research and educational activities from the following organizations:

- Lupus Canada and provincial Lupus Organizations
- Canadian Institutes of Health Research (CIHR)
- The Arthritis Society (TAS)
- An anonymous private donor through the Arthritis and Autoimmunity Research Centre Foundation at UHN (AARCF)
- Lupus Clinical Trials Consortium
- Institute of Musculoskeletal Health and Arthritis (IMHA)
- McLean Foundation

## HIPP Graduate: Wendy Singer

**“Through HIPP  
I learnt to exercise  
within my limit . . .  
Wendy Singer**

*The Health Improvement and Prevention Program (HIPP) study involves complex behavioral interventions requiring time commitment on the part of study participants. Prospective patients who want to participate are screened using a string of exclusion criteria. However, distance and lack of time have been major deterrents for lupus patients in committing to take part in or continuing the study. But in Ms. Singer’s essay she tells us of the coping benefits she received from taking part in HIPP.*

HIPP teaches, through mindfulness based meditation, yoga and cognitive behavior therapy, that we all have limits, and that by respecting them and balancing our resources, we can manage our condition.

I have tried to exercise intermittently over the past twenty odd years that I’ve had Lupus, but would invariably over-do it, exhaust myself, and subsequently give up. Through HIPP, I learnt how to exercise within my

limits by using a heart rate monitor and interval training. These tools led me to respect my body and it’s limitation. I’m happy to say that exercise is now an integral part of my life.

## Zane: Bundle of Joy

**“A cute baby boy,  
To cuddle and  
squeeze . . .”**

Andrea Craig, our 1000 Faces of Lupus National Coordinator gave birth to Zane on April 29, 2007 weighing 6 lbs 13 oz and 19.5" long. (Right) Little Zane (aka Canios) loves to cuddle up with his academic mom Dr. Christine Peschken.

While Andrea is away, Melissa Moyon is taking over Andrea’s responsibility.



# Profile: CaNIOS Centre 17

CaNIOS Centres are located throughout different academic hospitals and some community clinics in Canada, with the largest one located in Toronto. Centre 17 is the Centre for Prognosis Studies in the Rheumatic Diseases (CPSRD) located in the Rheumatic Disease Unit of The Toronto Western Hospital, University Health Network. CPSRD consolidates out-patient care, teaching and research of rheumatic diseases with strong focus on clinical practice research through its database dating back in the 70's. The CPSRD Databank allows for long-term epidemiological studies involving long-term observation of clinical features, treatment and its



CaNIOS Centre 17 is located at Toronto Western Hospital, University Health Network.

effects on large number of patients over a long period of time. The Centre staff are headed by CaNIOS members

Dr. Dafna D. Gladman, Dr. Murray B. Urowitz, and Dr. Paul R. Fortin. Staff at Centre 17 includes rheumatology fellows, biostatistician, database programmer and research assistants. Current areas of study include Systemic Lupus Erythematosus (SLE) with The Lupus Databank Research Program being one of the largest databanks of its kind internationally, the Psoriatic Arthritis (PSA) Research Program, the Antiphospholipid Syndrome Research Program (APS), and the Atherosclerosis in SLE (SLICC) Research Program. As of June 2007, the Lupus Clinic has 1333 patients enrolled and being followed according to a research protocol since 1970. (Adapted from the CPSRD website)

*As of June 2007, the Lupus Clinic has 1333 patients enrolled and being followed according to a research protocol.*

## Walk a Block for Lupus

Your CaNIOS Research Team will again participate to the Walk-A-Block For Lupus Event this year along with lupus patients from across Canada. For more information on this activity, please refer to the Lupus Canada website ([www.lupuscanada.org](http://www.lupuscanada.org))



CaNIOS publishes **In Touch** in July and January. If you have any comments, wish to advise of a change of e-mail address, or be added or removed from the mailing list, please contact **In Touch**.

Visit the CaNIOS website to download a PDF copy of **In Touch**.

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## About CaNIOS

CaNIOS is a unique collaboration that brings together widespread scientific and clinical expertise in a coordinated and collaborative spirit which allows Canadian researchers to address several questions important to patients with lupus and their families. Founded in 1995 when the current chair, Dr. Paul R. Fortin was at the Montreal General Hospital, CaNIOS Coordinating Centre moved to Toronto Western Hospital in 2000. CaNIOS maintains a database of lupus patients through its National Lupus Registry which combines data from different centres through a standardized data collection system. CaNIOS has been supported solely by funding from individual operating grants from governmental agencies and non-for-profit organizations and foundations.



## CaNIOS Research Study Enrollments

1000 Faces of Lupus – Enrolled = 1501
Centre 01 MUHC-MGH
Centre 04 Maissonneuve Rsmt
Centre 07 Ottawa General
Centre 08 London
Centre 10 Winnipeg HSC
Centre 15 Vancouver ARC
Centre 17 TWH CPSRD
Centre 19 TWH Non-CPSRD
Centre 20 Sick Kids, Toronto
Centre 21 BC Children's Hosp.
Centre 22 Halifax's IWK HC
Centre 26 Lethbridge
Centre 27 Montreal Child. Hosp.
ThromboFIL – Enrolled = 319
Centre 01 MUHC-MGH
Centre 08 London
Centre 10 Winnipeg
Centre 12 Sherbrooke
Centre 17 TWH-CPSRD
Centre 19 TWH –non CPSRD
HIPP – Randomized = 201
Centre 01 MGH
Centre 08 London
Centre 17 TWH-CPSRD
Centre 19 TWH-Non CPSRD
Centre 28 Mt. Sinai

GenES – Blood/Saliva collected = 259 trios
Centre 01 MUHC-MGH
Centre 03 ND
Centre 04 Maissonneuve Rsmt
Centre 06 QEII Halifax
Centre 07 Ottawa General
Centre 08 London
Centre 09 Calgary
Centre 10 Winnipeg HSC
Centre 12 Sherbrooke
Centre 17 TWH CPSRD
Centre 19 TWH non CPSRD
Centre 28 Mt. Sinai
Centre 20 SickKids, Toronto
LuNET Cohort 2 = 10
Lupus Nephritis
Centre 17 TWH CPS
Centre 28 Mt. Sinai
Non-lupus Nephritis
Centre 17 TWH CPS
Centre 28 Mt. Sinai
LuNET Cohort 3 = 108
Centre 01 MGH
Centre 17 TWH-CPS
Centre 19 Winnipeg
Centre 8 London