

CaNIOS Newsletter

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Important Dates

May 9-10, 2009 – Walk-a-Block for Lupus 2009.

June 26, 2009 - ACR Abstract deadline

June 24, 2010 – CaNIOS Business Meeting

June 24-27, 2010 – 9th International Congress on SLE, Vancouver, BC

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Successful Walk a Block Team

Our Walk a Block Team at TWH has been so pleased to exceed its fundraising goal. This year we raised \$2,585. We are so grateful to all our sponsors for making our Walk a Block for 2009 a success. Photos of our walk are now posted on the CaNIOS website under Events and then Photo Albums.



CaNIOS Membership Renewal

Since we are now a non-share capital corporation, we have been asking all CaNIOS members to renew their membership. We thank all those who have

responded and paid their annual dues. We are also now in the process of re-organizing our committees. In the coming months, the Executive will be deciding

on re-activating old, and creating new committees. Expect an announcement requesting your participation in one of these committees soon.

GenES Revival

We have learned that our collaboration with Dr. Tim Vyse in the UK for funding of a genome-wide association study (GWAS) in SLE through the Wellcome Trust has not been funded. However, in a surprising turn of events, we have

recently learned from CIHR that our GenES Phase 2 application in September 2008 has been awarded an interim funding through the National Strategy on Patient Oriented Research (NSPOR) Priority Announcement. Although

this interim funding is insufficient to fulfill the GWA objective of the study, we hope to use this funding to position us for the full blast revival of GenES should our application to CIHR be funded in the fall.

Defining Vulnerable Population

Who belongs to vulnerable population? The spring issue of CAPA's newsletter, **Voices** defines it so accurately from a consumer's perspective. "Vulnerable populations are people from any socio-economic level, but particularly with lower socio-

economic status. They are members of any chronic disease group who can no longer function at full capacity, with the same earning power, the same level of physical and mental activity and the same access to health care, services, education, and social

support networks as other members of society." For more on this topic, check the latest **Voices** issue at www.arthritispatient.ca/index.php/voices/spring-2009/.

CaNIOS Authorship Definition

To be a named author in any CaNIOS publication, one must meet conditions 1, 2, and 3 below:

- (1) Substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;
- (2) Drafting the article or revising it critically for important intellectual content; and
- (3) Final approval of the version to be published.

Manuscripts Submitted or Under Revision

Arthritis Care & Res. (LuNNET and HIPP)

Aghdassi E; Morrison S, Marticorena Landolt C, Su J, Clarke Ann, Gladman D, Urowitz M, Pope J, Peschken C, Pineau C, CaNIOS LuNNET & HIPP Investigators, DaCosta D, Wither J, Fortin PR. The Use of Micronutrient Supplements: Relation to Quality of Life & Disease Activity in Canadian Patients with Systemic Lupus Erythematosus.

Arthritis & Rheumatism (LuNNET Cohort I Study)

Reich, H et al. Modifiable risk factors for chronic kidney disease in patients with systemic lupus erythematosus.

Rheumatology (1000 Faces of Lupus)

Baker K, Pope J, Silverman E, Cooper G, Fortin PR, Zummer M, Smith CD, Petty, R. Tucker L, Albert L, Huber A, Ramsey S, Arbillaga H, Chedéville G, Hudson, M, CaNIOS Investigators; Peschken C. Work Disability in Systemic Lupus Erythematosus is Prevalent and Predicted by Socio-demographic and Disease Related Factors: Results from a Multi-Ethnic Cohort..

Lupus (1000 Faces of Lupus)

Yuen SY, Mok MY, Wong WS, Silverman ED, Pope JE, Fortin PR, Smith CD, Zummer M, Hudson M, Pineau C, Clarke A, Bernatsky S, Urowitz M, Gladman D, Canadian Network For Improved Outcomes In Systemic Lupus Erythematosus (CaNIOS), Peschken CA. Systemic Lupus Erythematosus: A Comparative Study of Clinical Manifestations and Damage in Two Chinese Populations. Feb 2009.

Journal of Rheumatology (1000 Faces of Lupus)

Mittoo S, Gelber A, Hitchon C, Silverman ED, Pope JE, Fortin PR, Pineau C, Smith CD, Arbillaga H, Gladman D, Urowitz M, Zumer M, Clarke A, Bernatsky S, Hudson M, Tucker L, Petty R, Canadian Network For Improved Outcomes In Systemic Lupus Erythematosus (CaNIOS), Peschken CA. Systemic Lupus Erythematosus-Related Serositis is Associated with Ribonucleoprotein Antibody: Finding from a Multi-Ethnic, Multi-Center Canadian Cohort . Feb 2009.

Journal of Rheumatology (1000 Faces of Lupus)

Colangelo K, Pope J, Peschken, C. The minimally important difference (MID) for patient reported outcomes in systemic lupus erythematosus (SLE) including the HAQ-DI, pain, fatigue and SF-36. Feb 2009.

Journal of Rheumatology (1000 Faces of Lupus)

Lalani S, Peschken C, Pope J, CaNIOS 1000 Faces of Lupus Investigators. Clinical Features and Prognosis of Late Onset SLE. Under revision.

Recently Published

Journal of Rheumatology (1000 Faces of Lupus)

Peschken CA, Katz S, Silverman E, Pope J, Fortin PR, Pineau C, Smith CD, Arbillaga H, Gladman D, Urowitz M, Zummer M, Clarke A, Bernatsky S, Hudson M, Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). The 1000 Canadian Faces of Lupus: Determinants of Disease Outcome in a Large Multi-Ethnic Cohort .

In Press

Clinical Medicine: Arthritis and Musculoskeletal Disorders

Law G, Pope J, Lalani S, Silverman E, Cooper G, Fortin PR, Zummer M, Smith CD, Petty R, Tucker L, Albert L, Huber A, Ramsey S, Arbillaga A, Chedéville G, Hudson M, CaNIOS Investigators; Peschken, C. Barriers to Healthcare in a Multiethnic Cohort of Systemic Lupus Erythematosus (SLE) patients: Patient and Physician Perceptions.

Manuscripts In Preparation (Contact senior author if you wish to be included as author.)

GenES Study : Serology Studies - Dr. Joan Wither;
Environmental Data (i.e., UV light, smoking, and radiation) - Dr. Glinda Cooper
Analysis of Candidate Genes and SNPs - Drs. J Wither/Dr. PR Fortin/Dr J Rioux

LuNNET Study: BAFF Expression in Lupus - Drs. J Wither/PR Fortin
Gene expression from renal biopsies - Dr. H. Reich

1000 Faces of Lupus Study: Pediatric Lupus - Dr. L.Tucker/Dr. C. Peschken

CaNIOS STUDY ENROLLMENT

1000 Faces of Lupus – Enrolled = 1914

Centre 01 MUHC-MGH	301
Centre 04 Maisonneuve Rosemont	94
Centre 07 Ottawa Hospital	85
Centre 08 London	248
Centre 10 Winnipeg HSC	263
Centre 15 Vancouver ARC	22
Centre 17 TWH CPSRD	575
Centre 19 TWH Non-CPSRD	35
Centre 20 Sick Kids, Toronto	148
Centre 21 BC Children's Hosp.	62
Centre 22 Halifax's IWK HC	11
Centre 26 Lethbridge	27
Centre 27 Montreal Child. Hosp.	20
Centre 33 Jewish General Hosp.	23

HIPP – Randomized = 287

Recruitment Closed

Centre 01 MGH	133
Centre 08 London	47
Centre 17 TWH-CPSRD	91
Centre 19 TWH-Non CPSRD	9
Centre 28 Mt. Sinai & Community	7

GenES Phase I (Recruitment Closed)

ThromboFIL (Recruitment Closed)

LuNNET Cohort 2 (Including 2B and 2C) = 65

Centre 17 TWH CPS	59	Cohort 2 n = 26 Cohort 2B n = 29 Cohort 2C n = 10 Total n = 65
Centre 19 TWH non-CPS	5	
Centre 28 Mt. Sinai	1	
Total	63	

LuNNET Cohort 3 (Prospective Cohort) = 125

Centre 01 MGH	20	Active SLE with Lupus Nephritis: n = 74 Active SLE with out Lupus Nephritis: n = 55 In-active SLE with History of Lupus Nephritis: n = 34 In-active SLE without History of Lupus Nephritis: n = 27
Centre 08 London	7	
Centre 10 Winnipeg	5	
Centre 17 TWH CPS	90	
Centre 19 TWH non-CPS	4	
Total	126	

Privacy

If you wish to be unsubscribed from the CaNIOS monthly newsletter e-mail list please contact Jaime O. Claudio, CaNIOS' National S&D Coordinator at:

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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.