

CaNIOS Newsletter

VOL. 9 NO. 4

April 2009

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CaNIOS: Non-share Capital Corporation

CaNIOS officially became a non-share capital corporation on April 3, 2009 as members gathered during the 8th CaNIOS Principal Investigators' meeting in Toronto to approve the by-law of the corporation, elect directors, appoint an auditor, and approve the Chairman of the Board, Dr. Paul R. Fortin. A total of 17 voting members were present in addition to 5 voting members who were represented by proxies.

The members elected the 6 nominated directors unanimously. Drs. Paul R. Fortin, Janet Pope and C. Douglas Smith were voted to serve for a 2-year term, while Drs. Christine Peschken, Christian Pineau, and Joan Wither were voted to serve for a 4-year term. After the members' business meeting, the 6 directors met to elect among themselves the officers of the corporation. Drs. Paul R. Fortin and Janet Pope

were elected President and Vice-President of CaNIOS, respectively. Dr. Christian Pineau was elected Secretary; Dr. Christine Peschken as Treasurer, and Dr. Joan Wither as Translational Research Director. The Chair announced to the assembly that the next business meeting of the corporation was scheduled for June 24, 2010 in Vancouver, British Columbia.



Important Dates

April 29, 2009 – CaNIOS-CPSRD-TWH Walk-a-Block for Lupus 2009.

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

INSIDE:

Abstracts submitted	p2
Papers submitted	p2
Manuscripts in preparation	p2
Recruitments	p3



Annual Meeting a Success

The 8th annual CaNIOS Principal Investigators Meeting held in Toronto on April 2-3 has by far been the most successful meeting in terms of attendance and outcome. There were 17 members and 1 trainee who were present. Five pharma representatives also attended the scientific sessions as observers, together with Jacquie Grech who came to represent Lupus Canada and Lupus Ontario. Mr. André Vincent, President of Lupus Canada, also came to share his vision for the coming year of the partnership between Lupus Canada and CaNIOS. During the scientific meeting, Dr. Janet Pope updated members on the 2000 Faces of Lupus; Drs. Fortin, Wither, and Landolt-Marticorena on LuNNET, and Dr. Fortin

and Wither on the GenES study. Dr. Pope talked about past mistakes on drug clinical trials in lupus and Dr. John Rioux reviewed the genetics of SLE and other inflammatory diseases in the era of genome wide association studies. Both speakers led very stimulating discussions among those present.

A total of 15 research coordinators and associates also attended the 4th RA/Coordinators meeting where they shared success stories, and discussed common issues encountered in their different studies. Despite the uncooperative weather, the Café Scientifique was also well attended with over 70 in attendance. The interactions were lively, and patients were very appreciative of the opportunity to talk to

experts. Lastly, by our own standard, with about 100 paying registrants, the 8th Annual Lupus Patient Symposium could be called a hit. Patients were presented with varying interesting topics - from heart to kidney disease, from ethnic faces to pediatric cases of lupus, from nutrition to personal triumphs, from gentle yoga to the Power of Movement™. The Power of Movement™ founder, Erin Moraghan, came by to introduce participants to the successful nationwide yoga fundraising Power of Movement™ event, and walked the attendees through mindful stretching and breath work. In the future, we hope to incorporate the concept of the Power of Movement™ in our events.

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 & 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.

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.

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 .

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 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
Important Predictors of CKD - Dr. Heather Reich/ Paul R. Fortin

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

HIPP Study: FMD—Please contact Dr. P. Fortin

CaNIOS STUDY ENROLLMENT

1000 Faces of Lupus – Enrolled = 1909	
Centre 01 MUHC-MGH	300
Centre 04 Maisonneuve Rosemont	92
Centre 07 Ottawa Hospital	85
Centre 08 London	246
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	
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)	

LuNET Cohort 2 (Including 2B and 2C) = 63		
Centre 17 TWH CPS	58	Cohort 2 n = 26 Cohort 2B n = 28 Cohort 2C n = 9 Total n = 63
Centre 19 TWH non-CPS	4	
Centre 28 Mt. Sinai	1	
Total	63	
LuNET 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 = 32 In-active SLE without History of Lupus Nephritis: n = 27
Centre 08 London	7	
Centre 10 Winnipeg	5	
Centre 17 TWH CPS	89	
Centre 19 TWH non-CPS	4	
Total	125	

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.