

UPCOMING EVENTS ::

Thursday September 14, 2006

AARC Foundation's Annual General Meeting

Invitation with details will be mailed in August.

Tuesday September 19, 2006

3rd annual St. Regis Room Fashion Show

Join us for lunch and a preview of the exclusive fall fashions of The St. Regis Room in the Arcadian Court, The Bay Downtown. Tickets are \$100.



Sunday October 15, 2006

7th annual Day at the Races presented by The Printing House

After last year's success in the fabulous trackside marquee, we are delighted to present the event once again at Woodbine Racetrack! Tickets are \$250, tables of 8 or 10 available.



THIRD PARTY EVENTS ::

Join us in our efforts in raising funds and awareness for arthritis and related autoimmune disease research. Any event, intimate or extravagant, is a wonderful way to spread the word about the work supported by the AARC Foundation.

Here are some examples:

Moksha Yoga Downtown in Toronto raised money for the AARC Foundation through their Friday night karma classes. The idea was initiated by an instructor living with lupus, who wanted to give something back in appreciation for the wonderful care she received while an in-patient on 9A Fell at Toronto Western Hospital. www.mokshayogadowntown.com



Thanks to Tiziana Tolfo, her family and friends, **Dance for the Cure** has been an important annual event in support of lupus research. Proceeds from this incredible evening of fine food, dancing and a stellar auction are shared between Lupus Ontario and the AARC Foundation. Since 2002, the Dance for the Cure committee has generously donated more than \$85,000 to the Lupus Databank at Toronto Western Hospital, in support of the Systemic Lupus Erythematosus International Collaborating Clinics and its Registry for Atherosclerosis in SLE.



Tiziana and her husband Louis and Dr. Murray Urowitz (centre)

For information on tickets and sponsorship opportunities for these events or to discuss holding a third party event, please call our Community Awareness & Events Manager, Erin Moraghan at 416-340-4800 ext. 6020.

There is always an answer. *We'll find it.*

Lights & Insights is published twice a year by the AARC Foundation. We welcome your comments and/or contributions. Please contact us if you would like extra copies of this issue, or know of someone who would appreciate receiving it.

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Arthritis & Autoimmunity
Research Centre Foundation
University Health Network

LIGHTS & INSIGHTS ::

ARTHRITIS & AUTOIMMUNITY RESEARCH CENTRE FOUNDATION



SUMMER 2006

WORKING WITH CHANGE ::

Three years ago, Nancy Roper started the year working from home because she *wanted to...* within a few weeks however, she was working from home because she *needed to*. An active person, she'd spent the holidays tobogganing with her nephews. At first, Nancy thought she had pulled some muscles on the slopes but as the holiday progressed, the pain spread throughout her body to the point that she could barely move.

Symptoms continued to be vague. Routine medical tests didn't point to any clear diagnosis or treatment. Nancy thought she might have multiple sclerosis, Parkinson's, or cancer. Late one night Nancy suddenly remembered that her maternal grandmother and paternal grandfather both had severe rheumatoid arthritis (RA).

In her search for a capable rheumatologist, Nancy discovered she had some friends with ties to the arthritis community. They highly recommended Dr. Lori Albert at Toronto Western Hospital.

"I am so appreciative of the outstanding care and compassion Dr. Albert has provided in getting this sometimes frightening disease under control."

– Nancy Roper

2003 was a challenging year as Nancy and Dr. Albert struggled to get a firm diagnosis and her RA under control. "I wouldn't baby sit my young nephews because I was afraid I wouldn't be able to move fast enough in an emergency, let alone carry them. Personally, I don't think I could have saved myself if the fire alarm had gone off in the middle of the night."

Nancy still has some mild disease activity – once an avid swimmer, she now uses a life jacket. Despite the ups and downs of having a chronic illness, she is actively involved in Girl Guides. Nancy is most grateful for the wonderful



Dr. Lori Albert and Nancy Roper during a recent visit

support she receives from family, friends and her employer. Thanks to IBM's Flex Work program and her highly supportive managers in both Canada and the USA, she continues to work full time. "This program allows for flexible work hours, and in my case eliminated the need for a two hour daily commute to and from the office – something I didn't have the stamina for at the height of my illness. My colleagues and customers are all remote, I use a speaker phone and computer to work from home."

Nancy is in training for Patient Partners in Training™, a program in which people with arthritis provide doctors and medical students with invaluable, hands-on training to improve their skills and effectiveness in dealing with their arthritis patients.

Flexible Work Arrangements are just one of the many ways IBM Canada recognizes the diverse needs of its employees and helps people balance their obligations to work, family, education and their health. This program is particularly welcomed by individuals like Nancy, who has been able to continue her productive work life despite her health challenges. IBM also has an employee matching gift program, doubling the impact of Nancy's donations.

LIGHTS & INSIGHTS ::

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SHOWING YOU CARE WITH A TRIBUTE GIFT ::

"My sister and I have rheumatoid arthritis as did our mother. We have all been fortunate to be patients of Dr. Edward Keystone. When our mother Ruta passed away, my sister and I suggested that if family and friends wanted to make a charitable donation in her memory that they make donations to the AARC Foundation. "Rheumatoid arthritis deeply affected our mother's life and we hoped these memorial donations, large or small, would help Dr. Keystone and the other researchers at AARC. Those of us affected by arthritis understand first hand the importance of their work and hope it continues."

— David Wiseman



Ruta holding her daughter Rebekkah, husband Joseph with son David circa 1960.

TRIBUTE GIVING IS A MEANINGFUL WAY TO HONOUR AND RECOGNIZE SPECIAL INDIVIDUALS ::

The Arthritis & Autoimmunity Research Centre Foundation gratefully acknowledges gifts received between November 1, 2005 and April 30, 2006, **in loving memory of:**

Kimie Aoki
Joe Blaschek
Aileen Coppin
Thomas David John Evans
Gina
Ben Javasky
Earl Linton

Joanne A. McNabb
Helen Milgrom
Dianne Miller
Mary Nobel
Betty M. Ottley
Niels Petersen
Doris Porter

Frances Redmond
Carl Silverstein
June Skimin
Patricia Trehearne
Ruta Wiseman

The Foundation also thanks those who made tribute gifts or commemorated a special occasion **in honour of** the following individuals between November 1, 2005 and April 30, 2006:

Dr. Lori Albert
Dr. Simon Carette
Kelly Dalton
Gordon Duncan
Trudy A. Eagan
Eileen Esposti

Dr. Dafna Gladman
Dr. Duncan Gordon
Dr. Robert Inman
Dr. Edward Keystone
Barbara MacGowan
Dr. Nizar Mahomed

Roy McMurtry
Dr. Jack Reynolds
Jane Wilson
Dr. Hugh Smythe

Attending a wedding, milestone birthday or family reunion? Buying a gift for that inspiring teacher?

A donation in lieu of gifts is a unique way to show you care and support important research at the same time. A tribute gift may also be made in honour of that special health care provider, a dear friend or family member.

Making a tribute gift is easy: just fill out the reply coupon and return it to the Foundation office, or phone, fax or visit our website at www.beatarthritis.ca Thank you!

The Foundation will send a card to the individual being honoured acknowledging your thoughtfulness, and will include a personalized message if you wish. The gift amount will not be disclosed, and you will receive a charitable income tax receipt.

WAIT TIME STRATEGY WORKING ::

Ontario's wait time strategy is working, and the proof is in the numbers, says the Minister of Health and Long-Term Care. At a press conference at Toronto Western Hospital in late April, George Smitherman provided an update on the province's wait time strategy and announced phase three funding allocations.

The total investment is \$222.5 million, which will allow for 154,000 more procedures, including hip and knee joint replacements, cataract surgeries, MRI exams, cancer surgeries and cardiac procedures. University Health Network received \$14.8 million.

"When we started, all the wait times were going up, since then, they have all gone down," said Alan Hudson, lead of Ontario's wait times strategy.

"I would have had to wait 18 months to do things I love to do, but now it's amazing, I can do the things I love and I am not on any drugs."

— Nancy Yapp

Since the Ministry of Health started publishing their wait times data, hip replacement wait times are down by 39 per cent and knee replacements are down by 23 per cent.

Nancy Yapp, a patient of orthopaedic surgeon Dr. Nizar Mahomed, can attest to the fact that the wait times strategy

and initiatives undertaken by UHN are working. Last year she needed a hip replacement and was referred to a surgeon whose wait time was 18 months. After doing some of her own research Ms. Yapp was referred to Dr. Mahomed whose wait time was only three months.

"We now have something to celebrate," said Mr. Smitherman. "On behalf of our patients I thank you because I know Health Care Ontario is up to the task." For more information on wait times in Ontario, please go to www.ontariowaittimes.com.



Nancy Yapp, orthopaedic surgery patient, and Dr. Nizar Mahomed, Medical Director of UHN's Musculoskeletal Health & Arthritis program and Deputy Director of the Arthritis & Autoimmunity Research Centre

THE AMERICAN FRIENDS OF UHN, INC. ::

Due to an increased interest from donors with properties and businesses in the United States of America, The American Friends of UHN, Inc. has been formed to accept charitable gifts for programs at the Arthritis & Autoimmunity Research Centre, Toronto Western Hospital, Toronto General Hospital and Princess Margaret Hospital. This U.S. foundation is exempt under Internal Revenue Code 501(c) (3) and issues tax receipts the same as those provided by other charities.

For more information about this and other giving opportunities, please contact: Gerri H. Grant, Executive Director, 416-340-3937

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HONOUR ROLL ::



In February, **Dr. Ioannis Dimitriou** received the inaugural **AARC Postdoctoral Fellow Award**, providing him with a \$50,000 stipend. He was selected because of his strong academic background and the originality of his research proposal. "This is exciting news," says Ioannis. "My research can be applied to both the autoimmune response and that against infectious agents."

From Greece, Ioannis received his PhD in 2001 looking at the role salivary gland epithelial cells play in Sjögren's Syndrome. Before coming to Toronto last November to work in Dr. Rob Rottapel's lab, he attended Drexel University in Philadelphia, investigating how CD8+ T-cell responses are regulated.

In March, **Dr. Lori Albert**, a rheumatologist and clinician-educator at University Health Network, celebrated the publication of the *Canadian Resident's Rheumatology Handbook*. Edited by Dr. Albert, the 223-page pocket-sized manual is a handy reference for the diagnosis and initial management of rheumatic disorders, from conducting physical exams to interpreting lab tests and administering injections. The approaches to clinical problems were gathered from rheumatologists across Canada.

The first annual **Edward Dunlop Challenge Research Grant** has been awarded by the AARC Foundation to fund innovative studies arising from a very effective collaboration between basic and clinician scientists – **Eleanor Fish, Ed Keystone, Vivian Bykerk**. The \$25,000 grant will allow for the development of a proposed mouse animal model of arthritis. This translational research project, to be undertaken in the laboratory of Dr. Fish, examines whether a rare cell population in the blood may contribute towards the onset and progressive nature of rheumatoid arthritis.

The Foundation and Mrs. Dorothy Dunlop would like to thank the external reviewers and congratulate this team and the other applicants who submitted. A call for 2007 entries will be made in early November.

IMPORTANT TAX INFORMATION ::

The 2006 federal budget eliminates the capital gains tax on gifts of appreciated securities.

According to the Association of Fundraising Professionals, donations to Canadian charities could rise as much as \$500 million annually because of a tax change announced in the Federal budget in May.

The 2006 budget provision calls for the elimination of capital tax gains on donations of publicly traded securities to charities. Stock donations will receive tax credits based

on the value of the stock donated with no capital gain applied. In total, the government said the budget measure will provide substantially more tax incentive for donations of securities.

This is wonderful news as foundations like the AARC Foundation want to ensure their donors get the very best tax benefits available. The budget announcement applies to charities and public foundations. Please contact Gerri H. Grant, Executive Director, at 416-340-3937 for more information.

COPING WITH ARTHRITIS ... LITERALLY ::

Janie McLeod and her husband Jock had a personal reason for attending the Governors Circle Lecture in April, featuring Dr. Monique Gignac and entitled "Coping with a Chronic Illness."

Janie has lived with rheumatoid arthritis for thirty years. "Jock and I were both interested to hear what Dr. Gignac had learned in her research studies. I've had to adapt over the years as my hands become less and less functional. In fact, we've renovated parts of our home to accommodate my physical limitations. We found Monique's presentation a wealth of information, and were amazed at how other people are adapting their home and workplace activities."

In addition to supporting arthritis research, Janie also does her bit advocating on behalf of people with physical limitations. While great advances have been made to make buildings more accessible, and assistive devices created to aid independent living, there is still much to be done. "I go into public buildings and find I can't open a door because I can't get my hand around the knob. Recently a perfect stranger had to scoop my change out of a change machine – it was just too awkward for me to manage on my own. When things like these happen, I always make a point of speaking to someone involved with facilities



Governors Circle members Jock and Janie McLeod

management, asking them to consider bathroom doors with levered handles for example."

The AARC Foundation truly appreciates the generous support it receives from the McLeods, who have been Governors Circle members since 1999.

GOVERNORS CIRCLE MEMBERSHIP ::

The Governors Circle is a special leadership giving program which provides vital infrastructure funding to support our outstanding clinicians and researchers. Donors who annually contribute \$1,000 or more are considered members of the Governors Circle. One area it supports is the Arthritis Community Research & Evaluation Unit of which Dr. Gignac is a senior investigator.

In recognition of your special contribution, you will be invited to join other Governors Circle members at an annual recognition dinner, research lectures, and your generosity will be recognized in the Annual Report and on the web site. You will also receive the Foundation's Annual Report and an invitation to the Annual General Meeting held in September.

Governors Circle members are putting the power of research to work today.

For more information on how to become a Governors Circle member, please call Pippa Shaddick at 416-340-4989 or pippa.shaddick@aacrf-uhn.ca or go to our new website www.beatarthritis.ca and click on *donate now*.

LIGHTS & INSIGHTS ::

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PUT THE POWER OF RESEARCH TO WORK YEAR ROUND ::



Barbara McCulloch playing with her granddaughter Meg

"The main reason I decided to become an AARC Foundation monthly donor was to thank my incredible rheumatologist, Dr. Ed Keystone, for the wonderful attention, care and treatment he's given me over the past 14 years. With my quality of life back, I am able to partake in most of the activities that make me happy, such as playing with my grandchildren, golfing and traveling. Through my donation, I'm pleased to support important arthritis research funded by the AARC Foundation, a cause with special meaning to me. It gives me peace of mind knowing this research will continue to help me and all those afflicted with arthritis today and in the future."

– Barbara McCulloch, monthly donor since 2003

Did you know that you can spread your donation over the year and help provide a reliable source of funding for research every month? It's called the AARC Foundation M*D* (monthly donor) program. As an M*D*, your contribution is convenient, automatic, affordable, effective – and helps in these ways:

- Ensures a steady flow of funds helping our scientists maintain momentum for their current research,
- Helps the Foundation meet its annual funding commitment to the Research Centre; and,
- Saves on postage, envelopes and administrative costs.

Monthly giving is easy. Simply pre-authorize a monthly deduction from your bank account or credit card. You can donate \$10, \$25, \$35 or an amount of your choice. Monthly donations may be adjusted at any time with a simple phone call or e-mail. A single tax receipt will be sent to you in February, and you'll receive *Lights & Insights* newsletter twice a year. M*D*s also receive special recognition in the summer issue of our newsletter. You can also call us at 416-340-4989 and speak with Pippa Shaddick.

INSPIRED BY HER PATIENTS AND RESEARCH ::

Dr. Mandana (Mandy) Nikpour, a Clinical Fellow in rheumatology who specializes in lupus, is passionate about her job. "I enjoy treating my patients. Lupus is a chronic disease that can affect many organs in the body and its complications have an impact on how a person functions. Therefore the care of patients with lupus needs to be holistic. This is often challenging and rewarding at the same time. Working with patients over a long period of time is gratifying in that it enables me to learn about the many different manifestations of lupus and their treatment as well as allowing me to get to know my patients better as people. To see someone recover from a flare, and learn how they cope with their illness is inspiring."

From Australia, Dr. Mandy Nikpour joined the Division of Rheumatology at Toronto Western Hospital (TWH) in 2003 because it offers young rheumatologists from around the world the unique opportunity to undertake subspecialty training with supervision and mentorship from some of the world's leading experts in rheumatic diseases.

Mandy is able to care for her patients, conduct longitudinal research studies, and receive mentoring from specialists in this field – Drs. Dafna Gladman and Murray Urowitz. Her research projects are focused on determining the frequency and risk factors for silent heart disease in lupus and defining factors associated with lupus flares.

"I spend two days a week in lupus clinic. Important research questions are generated in the clinic and it is the information collected from our patients that helps answer these questions. So, the clinical care of my patients is closely linked to my research."

Mandy is an accomplished clinician scientist in her own right. She was the winner of the Ian Watson Award for the best lupus-related research. Dr. Nikpour had numerous abstracts accepted for presentation at the American College of Rheumatology Annual Scientific Meeting last November, including a podium presentation. Mandy holds the Arthritis Centre of Excellence Merck Frosst Research Fellowship and is currently enrolled in a Master's degree at the Institute of Medical Science, the University of Toronto.



"At the end of the day, research ultimately helps individuals living with arthritis and related autoimmune disorders, and the role our patients play is key to the success of that research."

– Dr. Mandy Nikpour

A sincere thanks to our M*D*s (monthly donors)

Harvey Acheson
Wilma M. Baker
Sydney Barnes
Gordon T. Bowie
Jennifer Brown
Edward Clancy
James N. Connolly
Dimitra Economou
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Pearl Veenema
Elizabeth & Thomas Walker
Muriel Ada Walters
Oliver W. Watson
William E. Wilson
Helen Yeman

There is always an answer. *Help us find it.* Become a Monthly Donor today.

"As a former nurse at TWH and now a patient who's been through many clinics, I can honestly say Dr. Nikpour is among the best physicians I've known. One of the reasons my quality of life has improved so much is thanks to the excellent care I receive from Dr. Nikpour. She is genuinely interested in all my health concerns and addresses them in a thorough, thoughtful and easy manner. With her professional guidance, I hope to continue my present state of health for a long time to come."

– Jean Bonner,
a Mandy Nikpour patient