

LIGHTS & INSIGHTS ::

ARTHRITIS & AUTOIMMUNITY RESEARCH CENTRE FOUNDATION



WINTER 2005

“I’M EIGHT AND I HAVE ARTHRITIS...”

AN UPDATE ON TORI LATIMER ::

In 2001 we introduced you to Tori Latimer. Her story reminds all of us that arthritis is not a disease of the aged. Arthritis can affect children and babies – in fact one in 1,000 Canadian children under the age of 16 suffers from the disease.

Tori was first diagnosed with juvenile rheumatoid arthritis (JRA) at the tender age of 15 months. Tori’s mother Kelly instinctively knew there was a problem; Tori hadn’t begun walking, she was no longer able to pull herself up in her crib, and her joints were stiff in the mornings. Little Tori would crawl using her forearms to avoid putting stress on her wrists.

Tests at the Hospital for Sick Children confirmed that Tori had polyarticular JRA. This meant more than five of her joints were affected, including her ankles, a knee, wrists and an elbow. Imagine a mother’s shock upon learning that her baby has a disease often thought of as a ‘disease of the elderly’. Kelly quickly learned the truth about JRA, discovering it is among the most common chronic childhood disorders, including cystic fibrosis and diabetes.

Tori responded well to her treatments, initially in the form of steroid injections in the affected joints, then methotrexate. Tori also began a rigorous physiotherapy program to help her increase mobility in her joints. Kelly and the rest of the Latimer family stayed strong throughout this process and learned as much as they could about JRA, but the experience was frustrating. Kelly found there was sparse information available, and there was little awareness about the fact that arthritis can affect babies and children.

Today, the Latimer family is pleased to report that Tori, now eight years old, is a happy, active child. On biologic treatment to keep her arthritis in check, Tori must make regular trips to Sick Kids for infusions. Kelly is clear that those visits are worth every minute.



Tori Latimer (right) now eight years old, plays with her brother Thomas and baby sister Caitlin

“Thanks to these medications (biologics), kids like Tori have the chance to lead a normal life. I chose to support the Arthritis & Autoimmunity Research Centre Foundation because I can see the incredible difference that research is making in the lives of patients with arthritis.”

- Kelly Latimer

“The scene has changed dramatically in the management of rheumatoid arthritis,” explains Dr. Rob Inman, rheumatologist and Director of the Arthritis Centre of Excellence at Toronto Western Hospital. “It has gone from being a profoundly disabling disease, often with complication-related hospitalizations to now being a manageable disease in which we are shooting for very high quality of life outcomes. The investment in the basic science of arthritis is paying off.”

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AN UPDATE ON TORI LATIMER CONT'D ::

Twenty years ago, Tori's experiences with arthritis may have been vastly different. Thanks to donors who support the AARC Foundation and the progressive research taking place at University Health Network, we can hope for continued improvements in the treatment of rheumatoid arthritis and other arthritis-related autoimmune disorders.

The AARC Foundation thanks the Latimer family for keeping us posted on treatment and experiences with JRA. This is a perfect example of how supporting arthritis research really does make a difference! Thanks to quick diagnosis and medication, Tori Latimer can run and play like every eight-year-old should.

CELEBRATE THIS HOLIDAY SEASON WITH A TRIBUTE GIFT ::

Attending a holiday party, school recital or family get-together? Need a gift for that special someone who has everything? Why not consider making a donation to the AARC Foundation instead of buying a present? Hosting a party... why not ask your guests to make a donation to the Foundation in place of a hostess gift?

Tribute giving is a meaningful way to show you care and provides an opportunity to recognize special people in your life. These gifts are a thoughtful way to remember the passing of a loved one or to celebrate special occasions such as a birthday, wedding, family reunion or anniversary.

The Foundation will send a card to the individual being honoured acknowledging your thoughtfulness, and can include a personalized message. The amount of your gift is confidential, and you will receive a charitable income tax receipt.

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.aarcf-uhn.ca. Thank you!



The Arthritis & Autoimmunity Research Centre Foundation gratefully acknowledges gifts received between June 1, 2005 and October 31, 2005, **in memory of:**

John T. Band
Veronique Benk
Sally Blythe
Barbara May Burrell
Paul Dunbar
Thomas John David Evans

Margaret Gordon
Allan Hermick
Jean Hoover
Viola Kerr
Arthur Lerman
Doreen Mason

Helen Milgrom
Weir Ross
Mrs. Wiele
Ruta Wiseman

The Foundation also thanks those who made tribute gifts or commemorated a special occasion **in honour of** the following individuals between June 1, 2005 and October 31, 2005:

Thomas R. Closson
Dr. J. Rod Davey
Trudy A. Eagan
Sally G. Flintoft
Dr. Dafna Gladman

Dr. Duncan Gordon
Dr. John Graham
Dr. Robert Inman
Heidi Jones
Dr. Ed Keystone

Aimee Rice
Enza Siesto
Catherine Silver



SPOTLIGHT ON MAJOR GIFTS :: SCLERODERMA RESEARCH ENDOWMENT ESTABLISHED

Gary and Ruth Norton have been Governors Circle members for several years and had begun to think about establishing an endowment for scleroderma research when Ruth's father, Thomas D. J. Evans, died. As Mr. Evans had asked that donations in his memory go to AARC this seemed an appropriate time to fund an endowment. Both Gary and Ruth, who has scleroderma, know personally how challenging this illness is and how few research dollars are devoted to it. By establishing The Norton-Evans Fund in Arthritis and Autoimmunity Research Focusing on Scleroderma, they hope to draw some attention to this need.

Dr. Simon Carette, Director of Rheumatology at University Health Network (UHN), was delighted with the news about the Norton-Evans fund. Dr. Carette fully understands the long-term benefit to future clinicians and basic scientists working in this area, and the critical role endowments like this play in attracting young rheumatologists to the field and to UHN.

Endowment funds are very important because they provide a stable source of research dollars affording our doctors and scientists more security as well as a sense of being recognized for their work. This is critically important at UHN because the ongoing investment strengthens the arthritis and autoimmunity research team, now and in the future.

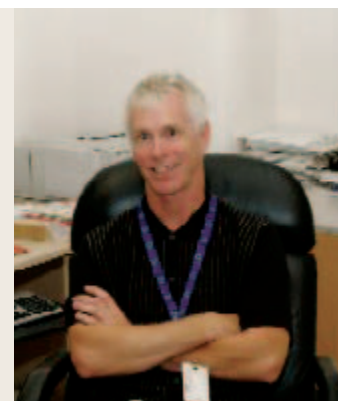
Since August when the Nortons established their fund, there have been other contributions made by friends and family members, including a sizable donation from Franklin Templeton Investments, Mr. Norton's employer. The advantage of endowment funds is not only do they increase in value over time, but they also grow from donations made by many people to commemorate special occasions such as birthdays and anniversaries.

The AARC Foundation is grateful to the Nortons for their longstanding and ongoing support.

NEW DONORS SUPPORT HAND PROGRAM ::

This fall, Kenneth and Sheila McArthur became generous major gift donors to the AARC Foundation. The Foundation is pleased to honour the McArthurs' wishes and will direct their donation to general arthritis and related autoimmune disorder research, a high priority for the Foundation, and the Hand Program located at Toronto Western Hospital.

Dr. Brent Graham, Director of the Program (right), commends the McArthurs for recognizing the important role a hand surgeon can play in the quality of life for those with severe arthritis in their hands.



ARTHRITIS RESEARCH: THE WIRTH ENDOWMENT ::

In 2004, Alfred Wirth (left) and his daughter Elizabeth established the Wirth Endowment in support of research at UHN. With a recent major gift of securities, Mr. Wirth has increased his commitment to help advance scientific discoveries in the area of arthritis and related autoimmune diseases. "We must improve the quality of our longer lives" states Mr. Wirth as his reason for establishing this research endowment, designed to provide a steady stream of research funding.

GLOBAL COLLABORATION ::

Dr. Vinod Chandran is a rheumatologist and clinical research Fellow at Toronto Western Hospital. Dr. Chandran chose psoriatic arthritis as his specialty because it is a less understood disease, often misdiagnosed as rheumatoid arthritis. Psoriatic arthritis usually occurs in patients already suffering from psoriasis and may cause extensive joint damage from destructive arthritis or extra bone formation causing fusion. It can involve nails, cause swelling of the digits and spondylitis (arthritis of the spine).

Before coming to Canada, Dr. Chandran was Head of the Immunology-Rheumatology Unit in the Department of Medicine at Kasturba Medical College in Manipal, India. He moved to Toronto to work with Dr. Dafna Gladman, who manages the largest and longest-running psoriatic arthritis clinic in the world. Since its opening in 1978, clinical data and genetic information have been collected from over 700 psoriatic arthritis patients. Clinical researchers at the Centre for Prognosis Studies in the Rheumatic Diseases have also developed standard protocols to assess patients with this form of arthritis. Most of what is known today about this disease is from studies conducted here.

What makes this so exciting, explained Dr. Chandran, is the possibility to predict future disease outcomes thanks to the patient data collected over 27 years. If a bad outcome is expected, a rheumatologist will know to treat the psoriatic arthritis more aggressively now to help halt disease progression. If a good outcome is expected, then fewer drugs are needed and the costs of living with a chronic illness may be reduced.

His current research includes addressing the issue of uniform assessments and clinical trials. He is also conducting a study comparing the clinical manifestations of psoriatic arthritis seen in Canada and India, collaborating with researchers overseas. Dr. Chandran's ultimate goal is to help establish a psoriatic arthritis clinic and research facility in India.



"I'm passionate about giving patients a good quality of life so that they may function well and participate in their community."
- Dr. Vinod Chandran

"Great strides have been made in the past five years on how to treat psoriatic arthritis – particularly with the arrival of biologic agents. In addition, the first World Psoriasis and Psoriatic Arthritis Conference will be held June 2006 in Stockholm, Sweden. It will bring together patient associations and the medical profession, creating a partnership to improve the understanding and care of patients with psoriasis and psoriatic arthritis."

In October, Dr. Chandran was first prize winner for the best clinical research poster: A Reappraisal of the Effectiveness of Methotrexate in Psoriatic Arthritis: A Clinic Experience, at UHN Research Day. He also presented two projects at the American College of Rheumatology National Scientific meeting held this November.



THE GOVERNORS CIRCLE DINNER ::

This year's Governors Circle dinner hosted both new and long-time leadership donors. Keynote speaker Dr. Murray Urowitz highlighted the important impact clinical research findings from the Lupus Clinic at Toronto Western Hospital have on other disease areas. For example, women with lupus develop atherosclerosis at a higher rate and at a younger age than does the general population. Not only does Dr. Urowitz collaborate with other UHN scientists on this issue, since 1987 he has been working with scientists from 27 centres in nine countries collecting clinical and genetic data from individuals with lupus. In 2001 the group began to focus its research efforts on female lupus patients who have developed heart disease.



Board member Gerry O'Mahoney, clinical research Fellow Dr. Barry O'Shea and Dr. Robert Inman, director of the Arthritis Centre of Excellence

Also at this year's dinner, Dr. Christopher Paige announced the exciting news about The Edward Dunlop Challenge Research Grant. Since the early 1990s, The Edward Dunlop Foundation has generously supported arthritis and autoimmune research – first at the Wellesley Hospital and in 2001 making a generous gift to the AARC Foundation. Thanks to Mrs. Dorothy Dunlop's vision, an annual award will be granted to an AARC investigator to conduct an innovative feasibility study or pilot project in the area of arthritis and autoimmune disease research. The first recipient of The Edward Dunlop Challenge Research Grant will be announced next spring by a peer review committee chaired by Dr. Eleanor Fish, Director of the Arthritis & Autoimmunity Research Centre.



Dr. Eleanor Fish

GOVERNORS CIRCLE MEMBERSHIP ::

The Governors Circle is the AARC Foundation's way of recognizing donors who give \$1,000 or more annually. Governors Circle members who make undesignated gifts for core research help fund the Foundation's annual disbursement to the Arthritis & Autoimmunity Research Centre, providing scientists a stable source of infrastructure support. One area that receives such funding is the division of Outcomes and Population Health, specifically the Arthritis Community Research and Evaluation Unit (ACREU).

Thanks in part to Governors Circle members' financial support, in 2003 ACREU member Dr. Monique Gignac secured a \$1.5 million New Emerging Team grant as a co-principal investigator for a project entitled "Tooling Up for Early Osteoarthritis: Measuring What Matters." In 2005 she received funding from the Canadian Institutes of Health Research to continue her research examining the employment experiences of people with rheumatoid arthritis and osteoarthritis over a five-year period. The study results will provide new measures to assess the impact of arthritis on employment and inform intervention efforts aimed to help people remain working.

To join the Governors Circle or for more information on member initiatives, please contact Pippa Shaddick at 416-340-4989 or pippa.shaddick@aacrf-uhn.ca

HEALTHY LIVING OVER THE HOLIDAYS ::

Over the holidays we're encouraged to eat, drink and be merry! Thanks to busy social calendars and the many demands of the season, it's easy to get out of a regular routine, resulting in less sleep, higher caloric intake, and fewer trips to the gym. Maintaining good musculoskeletal health means making some common-sense choices and taking the time to look after your body's needs.

Diet ::

Like the rest of your body, joints require a healthy diet and plenty of water. During the festive season, try not to overindulge on all the tasty dishes and treats. Have a nutritious bite before heading to social engagements so you're not starving when you arrive. Bring a healthy snack for long shopping trips and remember to drink plenty of water. Finally, don't overdo it at the cocktail-hour. Alcoholic beverages pack loads of calories, so try alternating each drink with a glass of water.

Exercise ::

When it comes to exercise, social engagements and shopping trips can make it difficult to stick to a regular routine but try not to skip workouts altogether. Walk, make a snowman with the kids or take a relaxing yoga class to unwind. If you don't have a regular fitness routine, then this is the time to make it happen. A simple exercise plan is a great step toward good musculoskeletal health. Regular exercise is crucial to keep bones and joints healthy, and carrying excess weight puts unnecessary pressure on your joints.

Exercise programs such as yoga and Pilates promote gentle, deep stretching, helping to build and maintain joint strength and flexibility. Weight-bearing exercises like walking, dancing and tennis, as well as resistance exercises such as weight training, are proven to help build bone mass. Take care to learn and practice proper form to prevent injury, and always consult your doctor before beginning any fitness program. It can't be said enough...getting regular exercise can alleviate stress and help you get a more restful sleep too.



Managing Stress ::

It's a fact: the holidays can be one of the most trying times of the year. The combined pressures of last minute shopping, being the perfect host and anticipating all that entertaining can make the best of us frazzled at times. Take a deep breath and remember that the season is a time for sharing and enjoying.

Maintain balance this holiday season by staying active, getting rest and not overindulging, and you'll feel great about kicking off 2006!

During Arthritis month in September, Moksha Yoga Downtown in Toronto raised money for the AARC Foundation through their Friday night karma classes. Moksha Yoga Downtown plans on raising additional funds for arthritis research in February. www.mokshayogadowntown.com





FABULOUS FALL EVENTS ::

September 20, 2005

"A Formal Enchantment" St. Regis Room Fashion Show and Luncheon



For the second consecutive year, the AARC Foundation was honoured to be the beneficiary of \$35,000 in net proceeds from the sold-out St. Regis Room fall fashion show at the Arcadian Court. Chaired by Marg Franklin, "A Formal Enchantment" was a wonderful success featuring a show of exquisite fall fashions from The Room, thanks to the seamless coordination of Brenda Emslie, Director of the St. Regis Room. Thank you to Liz Tory, Honourary Chair, for introducing The St. Regis Room to the AARC Foundation, and to George Heller, HBC, and Elizabeth Arden Inc. for their support. Event attendees are already looking forward to next year's show.



Terry Brown, Managing Director, Elizabeth Arden Canada, Gerri Grant, Liz Tory, Marg Franklin and Scott Beattie, Chair & CEO, Elizabeth Arden Inc., at the launch of Elizabeth Arden's historical exhibit.

October 1, 2005

The 6th Annual Day at the Races



A wonderful success! This year's Day at the Races marked the next generation of the AARC Foundation's signature event, raising a record breaking \$176,000 in net proceeds. The event moved to trackside, hosting the larger-than-ever function in the marquee at Woodbine Racetrack. More than 300 guests enjoyed cocktails on the marquee terrace, mere steps from the thoroughbreds. First-time Chair Don O'Born and his hardworking committee produced a top-notch event. The Printing House Ltd. generously presented the sixth annual event, with races sponsored by Downtown Fine Cars, Amgen Wyeth, Abbott Laboratories and Blakes, Cassels & Graydon LLP. Thank you to all event sponsors for supporting this year's record-breaking Day at the Races, and to Gord Martineau from City TV for emceeing the event. You won't want to miss next year!



Earle, Sarah and Janice O'Born representing the Printing House Ltd. - this year's presenting sponsor.

HOLIDAY EVENTS

Hosting a holiday soirée? Call Erin Moraghan at 416-340-4800 ext. 6020 for information on easy ways to host a third-party event in support of the AARC Foundation.

FOUNDATION OFFICE NEWS ::



The AARC Foundation office is managed on a day-to-day basis by a team of four full-time, dedicated individuals with expertise in major gifts, annual programs, donor stewardship, events and relationship marketing.

Left to right: Erin Moraghan, Pippa Shaddick, Gerri Grant, and Heather Drinkwalter

In this newsletter we introduce you to Pippa Shaddick.

Pippa has been with the Foundation from its early days in 1998 when the Arthritis & Immune Disorder Research Centre migrated to UHN after the closing of the Wellesley Hospital. In her current role as Development Manager, Pippa is responsible for leadership gifts (donations up to \$25,000), tribute and memorial gifts, donor communications, direct mail as well as board and finance committee administration.

This past July, Pippa attended the 2005 Institute for Healthcare Philanthropy at the University of Wisconsin Madison School of Business, successfully completing the Annual Giving program.

Pippa can be reached at (416) 340-4989 or pippa.shaddick@aarcf-uhn.ca
She would love to hear from you!



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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.

Editor: Pippa Shaddick Designer: Amanda Lawrence
Contributors: Erin Moraghan & Heather Drinkwalter

Arthritis & Autoimmunity Research Centre Foundation

R. Fraser Elliott Building, 5th floor, 190 Elizabeth Street, Toronto, ON M5G 2C4
Telephone: 416-340-4975 Fax: 416-340-3496 Email: aarcf.foundation@aarcf-uhn.ca
Website: www.aarcf-uhn.ca

Charitable Registration #11929 0773 RR0001



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