

# Keeping In Touch



Fall 2010

## One Solitary Enzyme

By Mary Sue Waisman, CFDR President 2009-10



I'd like to tell you about Elizabeth, my niece. A 28 year-old curly blond-haired, blue-eyed girl with a smile and heart of gold. How she continues to smile perplexes us all – she has struggled through a lifelong ordeal of hundreds of hospital admissions, near deafness and blindness, gastrostomy

feeding tubes, thousands of blood drawings, osteoporosis, kidney failure, weekly vomiting and never, ever enjoying food; not to mention hundreds of thousands of health care dollars. Elizabeth survived a dreadful inborn error of metabolism known as propionic academia – the lack of one solitary enzyme which is involved in the metabolism of 4 essential amino acids. Her younger brother, Richard Joseph, born 30 years ago, wasn't so lucky – he died at the tender age of 8 months, ripping out the hearts of family members.

Elizabeth's birth signifies the value of CFDR. Propionic academia is an extremely rare autosomal recessive genetic disorder, and it's a deadly one. Most children die in infancy or early childhood, but due to the diligence and research efforts of physicians and dietitians, along with a patient, vigilant and caring family, Elizabeth survived into her late twenties. Since the only management of PA is through dietary means (restriction of the offending amino acids) and since I was a dietitian (then a research dietitian at Yale University), I rose to the

challenge of combing the literature and working with metabolic specialists to create a specialized formula that would see Elizabeth through the early years. As I moved on, other dietitians in several states continued to comb the literature, albeit scant, to try and manage Elizabeth's nutritional needs as she aged. One of the many tragedies in this story is the lack of research and evidence. Elizabeth is one of the longest-lived children in history with this disorder and frankly, we've been wondering: Do researchers care anymore? Why bother to research something that affects so few children and leads to certain death? I'll tell you why; the heartache is unrelenting – watching Elizabeth deal with and suffer through these 28 years, having both of my children tested at birth for this genetic disease and watching and listening to my aging parents each time she's in hospital ask, "Will she make it?" This is not a sympathy seeking story, but rather one to point out the value of research, and not just the 'sexy' research on big issues; but think of the little guy: the small studies that may ask, "How can dietitians best offer advice to parents and families of children living with fatal diseases?" or "How can I make low protein diets palatable?" and so on.

This Fall in her last hospital admission Elizabeth didn't make it. She fell ill and passed away, her too-short life over all too soon.

*"This is not a sympathy seeking story, but rather one to point out the value of research, and not just the 'sexy' research on big issues; but think of the little guy: the small studies [that make a big difference]"*

Elizabeth's story is a poignant reminder of the importance of research. I am reminded of the important projects that CFDR funds – projects that make a difference in the lives of so many Canadians. I urge you all to keep kids like Elizabeth alive. Help families to cope. Keep research alive.



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## Evaluation of Taste Sensitivity in Patients Undergoing Coronary Artery Bypass Graft Surgery: Results Published

Results of a CFDR-funded research project were published in the July 2010 issue of the Journal of the American Dietetic Association. **Mary Keith, PhD, RD** and her team from St. Michael's Hospital in Toronto explored the changes in taste sensitivity that occurred following coronary artery bypass graft (CABG) surgery.

The team noted that clinicians report that changes in taste cause distress among patients following CABG surgery both in the hospital and later at home. Changes in taste could influence food choices and, more seriously, might cause patients to eat less at a time when nutritional intake is necessary for recovery and healing. The researchers studied patients at four specific times: pre-surgery, discharge, 5 weeks and 16 weeks after surgery. The team found that detection and recognition thresholds for sweet, sour, salty and bitter were lower at discharge (compared to pre-surgery) and that the difference remained significant four months after surgery. Contrary to what was expected, the data suggested improved taste sensitivity for several tastes in both the immediate and longer-term postoperative period following cardiac surgery. As a result it is important that registered dietitians working with post cardiac surgery patients be aware that changes in taste sensitivity do occur and subsequently provide preoperative education to patients regarding potential changes in taste that can occur after cardiac surgery, in order to help them to select and procure nutritionally rich, acceptable foods both while in hospital and following discharge.

Visit CINDAR for the abstract: <http://ww2.dietitians.ca/cindar/>

### Calls for applications and abstracts

- In partnership with CIHR, CFDR announces a new award for students pursuing a **Master's degree**. Apply by February 1. See research priority area #6 (Nutrition and Dietetic Research). Link from [www.cfdr.ca](http://www.cfdr.ca)
- CFDR presents a dietetic research event at Dietitians of Canada's national conference. We offer both **oral and poster presentations**. Abstracts are invited; visit <http://www.cfdr.ca/conference.html>
- **The Morgan Medal** recognizes dietetic students and interns for their research work. Apply by January 14, 2011. See <http://www.cfdr.ca/morganresearch.html>

## CFDR investigates functional foods – presentation and webcast

CFDR identified functional foods as a priority area for research through its Nutrition Research in Focus (NRF) program, a new program featuring a large-scale grant focused on one specific area of interest. All of CFDR's corporate partners and DC members were invited to identify a topic and functional foods was selected.



To introduce the research project and to examine some of the issues arising in this emerging nutrition area, CFDR assembled a panel of experts to share practical insights at CFDR's Research Breakfast on November 23.

Outline of the presentation:

- What types of questions/concerns arise in this area in dietetic practice? What information are people asking about? Where are they accessing the information about functional foods? What are the communications messages about functional foods that dietitians need to consider? **Jane Dummer, RD**, shared some practical insights.
- From an industry perspective – What are the issues facing corporations? How does a corporation navigate through Canada's regulatory system in this emerging area? What other issues does introducing functional food compounds into food products raise? **Jonathan Clifford**, Regulatory Manager, Unilever Canada Inc. shared insights gained over the past 12 years as the company worked to introduce plant sterols into food products.
- Overview of our CFDR funded research project: **Alison Duncan, RD, PhD** and **Judy Sheeshka, RD, PhD** from the University of Guelph talked about their new research project funded under CFDR's "Nutrition Research in Focus" program: **Exploration of the consumption, awareness, understanding and motivating factors related to functional foods in older adults.**

The presentation will be produced as a webcast on Thursday, December 2, 2010, 1:30 – 2:30 ET. The webcast will be archived on CFDR's website until June 2, 2011.

To register for the live broadcast, or to view the archived version later, visit [www.cfdr.ca](http://www.cfdr.ca).



## Fall fundraising campaign launched

Our mail campaign was sent on November 15, 2010. The package features a distinctive graphic depiction of a dietetic researcher.



The campaign underscores the value of research to dietetic practice and ultimately to the health of Canadians. Dietitians help Canadians to make healthy food choices every day. It's the dietitian's job to translate complex nutrition information into practical advice. Research is fundamentally important to developing nutrition knowledge, and CFDR plays an important role in advancing that research.

This CFDR mailing is designed to provide information about CFDR and the work we do to support dietetic practice. As a charitable foundation, CFDR is totally reliant on donations in order to carry out our work and we ask members of DC to consider making a donation this fall. And we've added a new dimension to this mail campaign: for the first time, we are also sending this package to consumers outside of dietetic practice to enlist their support of nutrition research, too.

Each year, Dietitians of Canada members support CFDR by making personal donations. In our last fiscal year ended August 31, 2010 DC members contributed almost \$53,000 – tremendous support for nutrition and dietetic practice research. In addition, almost 200 DC members participated in CFDR's sixth annual Fun Run/Walk held in Montreal in June 2010. The event raised a net total of \$21,000.

Donors can contribute directly to CFDR today by visiting [www.cfdrr.ca](http://www.cfdrr.ca) and clicking on the "Donate Now" button. All donations are tax deductible.

CFDR thanks the many individuals who support nutrition and dietetic practice research.

## Two partners recognized at CFDR AGM for renewing pledges

CFDR is fortunate to receive financial support from 19 Legacy Leader partners who commit multi-year pledges to the Foundation, and one annual corporate donor (Who are they? See <http://www.cfdrr.ca/partners.html>) At CFDR's Annual General Meeting on November 23, 2010 we recognized two Legacy Leader partners for renewing their support with five year pledges.

**General Mills Canada** is a Legacy Leader of CFDR and has supported the Foundation since the first fundraising campaign. Through the years, the company has also participated in CFDR golf tournaments and supports CFDR with human resources: General Mills' Finance Manager Peter Shin serves as a member of our Finance and Audit Committee. General Mills renewed its pledge at the Patron level. Pierrette Buklis, Senior Manager, Health and Nutrition for Campbell's accepted the recognition plaque. Pierrette is a long-time supporter of CFDR, and a former manager of the Foundation.

**Campbell Company of Canada** has been a corporate partner of CFDR since our first fundraising campaign and is a Legacy Leader. In addition to ongoing pledge support, the company supports our Corporate Golf Challenge each year. Campbell's also supports CFDR with human resources: Andrea Dunn, Nutrition Strategy Manager for Campbell Company of Canada joined CFDR's Board of Directors in November 2010. This year, the company renewed its Sponsor Level pledge to CFDR.



Andrea Dunn, Nutrition Strategy Manager for Campbell Company of Canada, accepts a plaque from CFDR Fundraising Committee co-chairs Lisa Beausoleil (l) and Helen Ann Dillon (r).

## Corporate Golf Challenge raises \$42,000

For the second year in a row, the team from Saputo Food Ltd. and Cascades Tissue Group won the CFDR Corporate Golf Challenge. The big winner, though, was CFDR – thanks to event sponsorship, registration donations and silent auction purchases the September 13th event raised \$42,000.

Special thanks to main event sponsor Nestlé Healthcare Nutrition, dinner sponsor Dairy Farmers of Canada and Lunch Sponsor Campbell Company of Canada.

The event was organized by a tireless committee of volunteers, co-chaired by **Lisa Salonen MacKay** and **Erin Hallinan**. Thanks to committee members **Lisa Beausoleil**, **Maria D'Agostino**, **Georgette Harris**, **Nadean Peskun**, **Mitchell Sinclair** and **Lynn Roblin**.



Co-chairs Erin Hallinan (l) and Lisa Salonen MacKay (r) present the winner's cup to David Pike, Peter Aung Thin, Leslie Perry and Perry Pike.

## Annual Report Available



CFDR's 2009-10 Annual Report was distributed at the Foundation's Annual General Meeting on November 23, 2010 and mailed to all members of Dietitians of Canada with the December issue of *The Canadian Journal of Dietetic Practice and Research*. Read about our successes of 2009-10. To receive a hard copy, contact [isla.horvath@cfdr.ca](mailto:isla.horvath@cfdr.ca). View the on-line version at <http://www.cfdr.ca/annualreports.html>

## CFDR recognizes retiring board members

CFDR is governed by a volunteer Board consisting of 11 representatives of our corporate partners and Dietitians of Canada. They bring expertise in dietetic research, leadership, governance excellence, marketing, fundraising, financial accountability and more. Four Board members completed their terms at the November 2010 AGM, each serving four years on the CFDR Board. As well as their contributions to overall governance, the four were recognized for additional contributions:

**Mary Sue Waisman** (All About Food Nutrition Consulting) – served as CFDR's President Elect, then President for three years.

**Sharon Wong** (Associate Professor, Ryerson University) – served as Chair of CFDR's Scientific Review Committee.

**Helen Ann Dillon** (The Good Food Mavens) – co-chaired CFDR's Fundraising Committee.

**Doris Foster** (ARAMARK at Toronto Rehab) – chaired the Board Nominations Committee.

Cathy Paroschy Harris (c) presents Lifetime Membership plaques to retiring board members Helen Ann Dillon (l) and Doris Foster (r). Board members Mary Sue Waisman and Sharon Wong were not able to attend.



## Coming up:

**December 2, 2010, 1:30 pm ET** - "Functional Foods: what are the issues? What can we learn through research?" Register for the webcast at [www.cfdr.ca](http://www.cfdr.ca).

Comments? Questions?

We're committed to establishing stronger relationships with those who support the Foundation's work. If you have any comments or questions about material in this newsletter, or about CFDR, we want to hear from you. See page 1 for our contact information or send an Email to Isla Horvath, CFDR's Executive Director, at [isla.horvath@cfdr.ca](mailto:isla.horvath@cfdr.ca).