

child Foundation

News

Spring 2013



INSIDE UPDATES

Canadian Children Inflammatory Bowel Disease Network:

A Joint Partnership of CIHR and CH.I.L.D. Foundation.

Snowbirds Fly for CH.I.L.D. Coming to Nanaimo, B.C.!

Doormen's Dinner Sold Out Success!

CANADA'S FIRST BILIARY ATRESIA REGISTRY IS BORN!

Thanks to matching funds generously granted by the CH.I.L.D. Foundation, the Canadian Biliary Atresia Registry will be established in Canada. Biliary Atresia is a potentially lethal pediatric liver disease and is the most common reason for liver failure in young children. The development of a national Biliary Atresia Registry governed by both pediatric surgeons and hepatologists would be one of the first of its kind in the world. See Story: Page 4 and 5; Natalie's Story on Page 10.

Pictured from left: Mary Parsons, President & Chief Executive Officer, CH.I.L.D. Foundation, Biliary Atresia patients Natalie, Sariya and Callum, Grace M. McCarthy, O.C., O.B.C., Chairman of the Board, CH.I.L.D. Foundation with Dr. Rick Schreiber, M.D., C.M., FRCP (C).



CANADIAN CHILDREN INFLAMMATORY BOWEL DISEASE NETWORK: A JOINT PARTNERSHIP OF CIHR AND THE CH.I.L.D. FOUNDATION

The full application to create the *Canadian Children Inflammatory Bowel Disease Network: A Joint Partnership of the Canadian Institute of Health Research and the CH.I.L.D. Foundation* – was received on December 20, 2012. The International Peer Review Panel reviewed the full application on January 24, 2013. Per the peer review process, the panel's rating and comments with regard to the full application have been given to the Researchers. CIHR, the CH.I.L.D. Foundation and the Research Leadership have met this April to begin the process of establishing the strategies and advisory structures required to guide the networks' successful development.

*Tim Murphy, MHS, MBA, CA
Executive Director,
CH.I.L.D. Foundation,
Pediatric IBD Network*

On December 8, 2012, I had the privilege of being a presenter and panelist to the CIHR Institute of Nutrition, Metabolism and Diabetes – New Investigator Meeting held at Niagara on the Lake. The session was entitled “Citizen and Patient Engagement in Setting Research Priorities to Demonstrate Accountability to Citizens and Donors.” The session was moderated by Aida Fernandes – Chief Scientific and Education Officer with the Crohn’s and Colitis Foundation of Canada, and my co-panelists were: Dr. Andreas Laupacis, Canada Research Chair in Health Policy and Citizen Engagement; Executive Director, Li Ka Shing Knowledge Institute, St. Michael’s Hospital; and Mr. Paul Shay, National Executive Director, Kidney Foundation of Canada. The presentation and subsequent panel discussion was well received by the key stakeholders and new investigators from across Canada, who had been assembled for this meeting.

CH.I.L.D. FOUNDATION SCIENTIFIC RESEARCH DIRECTOR

Erika Goldt has joined the CH.I.L.D. Foundation as Scientific Research Director to help the CH.I.L.D. Foundation ensure its investment in the *Canadian Children Inflammatory Bowel Disease Network: A Joint Partnership of CIHR and CH.I.L.D. Foundation* aligns with the Foundation's Mission by evaluating the Network's progress, demonstrating success, and liaising to communicate results and support strategic decisions. Erika will be working conjointly with the Maternal, Infant, Child, and Youth Research Network of Canada (MICYRN).

This collaboration will allow sharing of information, resources, and partnerships with other Canadian research networks, meaning the IBD Network can act on best practices in child health to maximize its success and take advantage of existing resources without duplication.

Prior to this role, Erika spent six years working to strengthen the connection between research strategies and health outcomes by leading analyses on the impact of research at the Michael Smith Foundation for Health Research. She worked with many different research networks to understand how they can work efficiently and achieve results. Erika has also provided evaluation expertise on strategic planning as a consultant to private and public health service organizations over the past few years.

Erika has a scientific research background with a Masters of Public Health in Epidemiology, a Bachelor of Science in Molecular Biology, and previous first-hand work in conducting clinical research.



L to R: Dr. Aubrey J. Tingle, MD, PhD, FRCPC, FCAHS, Professor Emeritus, University of British Columbia, Department of Pediatrics, Chair, Board of Directors, Maternal, Infant, Child & Youth Research Network; Anne K. Junker, MD, FRCPC, Associate Professor, Department of Pediatrics, Scientific Director, MICYRN; Erika Goldt, MSc, MPH, Scientific Research Director, CH.I.L.D. Foundation; Grace M. McCarthy, OC, OBC., LLD, DTECH, FRAIC (Hon), Chairman of the Board, CH.I.L.D. Foundation; Mary Parsons, President & Chief Executive Officer, CH.I.L.D. Foundation.

A MESSAGE FROM THE PRESIDENT & CHIEF EXECUTIVE OFFICER



The CH.I.L.D. Foundation has lost a very valued Board Member in Wendy McDonald. Wendy helped us through all our deliberations, supporting our hopes and dreams and our focus to find a cure for I.B.D. As a volunteer Director, she attended every meeting and fundraising event while simultaneously working at expanding her worldwide company which became one of Canada's best managed businesses. Wendy McDonald was a very special friend, and her legacy will live on with her 10 children, 27 grandchildren and 36 great grandchildren. We will always cherish Wendy's work with our Foundation and remember her always.

In this issue of *CH.I.L.D. Foundation News*, please take time to read the remarkable story of young liver patients who have been helped immensely by Dr. Richard Schreiber and his team at Children's Hospital. How something so simple as a 'stool colour card' given to every newborn's family can change a child's life is quite remarkable. And British Columbia will be the first Province to propel this astounding research to action. Let's hope all Provinces in Canada will follow suit!

We look forward to visiting the City of Nanaimo at the end of July for our annual Snowbirds Fly for CH.I.L.D. event. The Canadian Forces Snowbird Demonstration Team (Squadron 431) are the CH.I.L.D. Foundation's Ambassadors, bringing awareness to North American audiences for the need for a cure for Crohn's Disease, Ulcerative Colitis and liver disorders.

Working For A Cure,

Mary Parsons
President & Chief Executive Officer
The CH.I.L.D. Foundation



IN MEMORIAM: CH.I.L.D. FOUNDATION DIRECTOR WENDY MCDONALD, C.M., O.B.C., LL.D., D.TECH.

A Memorial Service for CH.I.L.D. Foundation Director Wendy McDonald was held on Thursday, January 10, 2013 with hundreds paying tribute to a good friend and a remarkable, accomplished lady. Wendy constructed and headed a worldwide engineering enterprise and volunteered in a great many leadership roles, including the Vancouver Board of Trade and the Whitecaps Soccer Association, all the while raising ten

children. A great Canadian and British Columbian builder, Wendy lived with enthusiasm, generosity of spirit and humour. Our deepest sympathy goes to all of her family, friends and associates.

CH.I.L.D. FOUNDATION

**The Foundation for Children
with Intestinal & Liver Disorders**

Suite 201, 2150 Western Parkway
UBC Campus,
Vancouver, BC V6T 1V6
Telephone: 604 736 0645
Facsimile: 604 228 0066
Email: info@child.ca
Website: www.child.ca

Mission Statement

To find a cure through research for children who suffer from the debilitating diseases of Crohn's Disease, Ulcerative Colitis and liver disorders.

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We are determined to be successful.

THE BIRTH OF A CANADIAN BILIARY ATRESIA REGISTRY

Written by Richard Schreiber, MD, CM, FRCP(C)

Thanks to a large private donation and the support of the CH.I.L.D. foundation, an exciting and first collaboration of the Canadian Pediatric Hepatology Research Group (CPHRG) and the Canadian Pediatric Surgery Network (CAPSNet) has been initiated to establish a Canadian Biliary Atresia Registry (CBAR).

The CBAR project was proposed to a Montreal family of a child with biliary atresia by Dr. Jean-Martin Laberge, former head of Pediatric Surgery at McGill University, and Dr. Rick Schreiber of the Division of Gastroenterology, Hepatology and Nutrition at BC Children's Hospital. The family, whose child was successfully operated by Dr. Sherif Emil and treated by Dr. Najma Ahmed at McGill, had donated to the Montreal Children's Hospital Foundation for research in pediatric surgery and liver disease; they enthusiastically agreed to assign a portion of their gift towards the establishment of this national registry. Thanks to matching funds generously granted by the CHILD Foundation, CBAR was born.

The development of a national BA registry governed by both pediatric surgeons and hepatologists would be one of the first of its kind in the world.

The CPHRG is a national collaborative of pediatric hepatologists created in 1999 that aims to research and improve the care of Canadian children with liver disease. Since 2005, the pan-Canadian collaboration of pediatric surgeons within CAPSNet has advanced an EPIQ (Evidence-based Practice for Improving Quality) process to further improve the surgical care of Canadian children. The development of a national BA registry governed by both pediatric surgeons and hepatologists would be one of the first of its kind in the world.

The rationale for creating CBAR stemmed from an initial project of the CPHRG that detailed the Canadian experience with biliary atresia 1986-2002. This was one of the largest national BA studies ever published worldwide and it identified several important challenges regarding the management and outcomes of Canadian children with biliary atresia.

WHAT IS BILIARY ATRESIA?

Biliary atresia (BA) is a potentially lethal pediatric liver disease resulting from a progressive, obstructive injury to the bile duct (the main draining pipe for eliminating bile and other toxic substances from the liver). This condition, of unknown cause, clinically manifests in the first weeks after birth with persisting jaundice (yellowing of the skin and eyes) and pale chalk white stools. While biliary atresia is a rare disease, seen in about 1:18,000 live births in Canada, it is the most common reason for liver failure in young children and the leading indication for liver transplantation in the pediatric population.

HOW IS BILIARY ATRESIA TREATED?

There is no cure for BA. The current standard of care is sequential surgical management: First a Kasai portoenterostomy in early life - at this operation, the blocked bile duct is removed and there is reconstruction of a new conduit in the hopes of re-establishing bile drainage from the liver with subsequent clearance of the jaundice and normalization of the stool colour; next a liver transplant- for those BA cases who have marked delay in their diagnosis and the Kasai operation fails largely due to advanced infant age at surgery and established end-stage liver disease and cirrhosis. Left untreated, all infants with BA will die by two years of age.

BILIARY ATRESIA IN CANADA

Based on the recent CPHRG national biliary atresia study, each year there are 20-25 new cases of biliary atresia in Canada. Currently, the average infant age at the time of the Kasai operation in Canada is 62 days with almost 20% of cases presenting late, having their operation after 90 days, at an age when the chance for the Kasai operation to be successful is low and, in turn, the long term patient survival without the need for a liver transplant is markedly reduced.

Thanks to matching funds generously granted by the CH.I.L.D. Foundation, CBA was born.

Editor's Note: Dr. Rick Schreiber, Clinical Professor of Pediatrics at Children's Hospital, Division of Gastroenterology, Hepatology and Nutrition, is a leading liver disease specialist in Canada and co-director of the newly established Canadian Biliary Atresia Registry (CBAR). His teams' recent research with 6000 families, funded by CIHR, conducted a pilot study to assess the use of stool colour cards to prompt earlier identification of newborns affected with Biliary Atresia. The Province of British Columbia will implement this screening program proposed by Dr. Schreiber's research team for all newborns in the Province. "I believe the study results strongly support implementation of a provincial screening program that will improve the lives of newborns in B.C. if not eventually across Canada," says Dr. Schreiber.

IMPORTANCE OF AGE AT DIAGNOSIS FOR OUTCOME IN BILIARY ATRESIA

EARLY AGE AT DIAGNOSIS IS KEY FOR LONG-TERM SURVIVAL OF PATIENTS WITH THEIR OWN LIVER WITHOUT THE NEED FOR LIVER TRANSPLANT

One of the most important factors influencing the success of the initial Kasai procedure is the age of the infant at the time of the operation. If the surgery is performed early, within the first 60 days of life, there is a 40-50% chance that the child will live into adulthood with their own native liver. In contrast, if this operation is performed late, after 90 days of age, there is an 80% chance that the Kasai operation will fail and the child will require a liver transplant to survive (Figure 1).

THE PROBLEM OF DELAYED DIAGNOSIS

Timely diagnosis and early Kasai operation remains a challenge in Canada as it does elsewhere in the world. Jaundice is a very common symptom affecting more than 2/3 of newborns, and the vast majority of these babies have benign self-limited jaundice of no consequence. Identifying the yellow newborn with liver disease among otherwise healthy newborns with jaundice is like finding a yellow needle in the yellow haystack. The rare case of biliary atresia is often not recognized until late, well after the infant is over 2-3 months of age. Delayed age at diagnosis predicts worse long term outcome for these infants (Figure 1).



BETTER HEALTH OUTCOMES WITH EARLY DIAGNOSIS

Figure 1: Baby on the left had a successful Kasai operation at 42 days of age. He is well without jaundice at 6 months of age. In contrast, the baby on the right was diagnosed late and had the Kasai operation at 98 days of age. Now at 6 months of age, he has advanced liver disease with deep jaundice, a distended abdomen filled with fluid (ascites) and failure to thrive. Without a liver transplant in the next few months, he will die.



WHAT ARE THE GOALS OF CBAR?

(Canadian Biliary Atresia Registry)

The primary aims of CBAR are to:

1. Provide capacity to collect prospective data for biliary atresia in a uniform fashion throughout Canada;
2. Examine prospectively the current assessment, management and outcome of biliary atresia in Canadian children;
3. Standardize best practices for the Kasai procedure and the post-Kasai management of biliary atresia in Canadian children to optimize outcome;
4. Provide a platform to determine the feasibility and cost effectiveness of novel diagnostic or therapeutic strategies for Canadian children with biliary atresia to bring about earlier diagnosis and better outcome;
5. Compare age at diagnosis, resource utilization and outcomes across Canada and in different patient populations, to identify the best and most cost-effective practices that will lead to practice improvement;
6. Promote education and enlightened public policy for Canadian children with biliary atresia through knowledge translation with local agencies, national foundations and provincial health authorities.



Dr. Rick Schreiber shows a "Colour Card" to Grace M. McCarthy, O.C., O.B.C., CH.I.L.D. Foundation Chairman of the Board. These cards will be available to all parents of newborns in British Columbia in 2014. Parents can then easily compare their infant's stool colour to normal and abnormal colours on the card. Abnormal stool colour reflects liver disease, enabling their child to receive prompt medical attention within two months of age.

CH.I.L.D. FOUNDATION 22ND ANNUAL DOORMEN'S DINNER ANOTHER SOLD OUT SUCCESS!



The 22nd Annual CH.I.L.D. Foundation Doormen's Dinner was once again a sold-out success! On October 26th, we honoured Hoteliers and Humanitarians Wendy Lisogar Cocchia & Sergio Cocchia, whose dedication to ill children in the community and spirit of good will in the hospitality industry has been an inspiration.

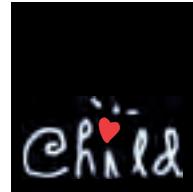
Held at the Marriott Pinnacle Downtown Ballroom, over thirty uniformed Doormen from Hotels across Metro Vancouver, along with those who specially flew in from New York City, gathered and celebrated together with this year's honourees and their quests.

A very special thank you to emcee Peter Legge, O.B.C., as well as Auctioneer Howard Blank and The Dal Richards Orchestra who entertained the crowd throughout the evening. Our Gold sponsors, Concord Pacific, HSBC Bank of Canada, The Jessoma Foundation & The Vancouver Sun are very much appreciated, along with our friends from WESTJET and sponsors Pacific Blue Cross and Dawson Group Enterprises.

The Doormen's Association of Greater Vancouver has raised nearly \$900,000 for The CH.I.L.D. Foundation, to find a cure through research for very ill children with Crohn's Disease, Ulcerative Colitis and Liver Disorders. This years' event was truly a dazzling success, and could not have been possible without the kindness of all our sponsors & donors, and the generous time and hard work of our volunteers!



The Cocchias receive official Honourary Doormen Hats from Fairmont Hotel Vancouver Doorman Paul Atwater and Marriott Pinnacle Downtown Doorman Taylor Crowe Photo Credit: Jason Ho, Pure White Studio



Child Foundation News

Doormen from all around Metro Vancouver welcome New York City Doormen Calvin Herry (left) & Adrian Greenidge (right) for a group shot, before the Parade of Doormen enter the room to signal the start of the evening!



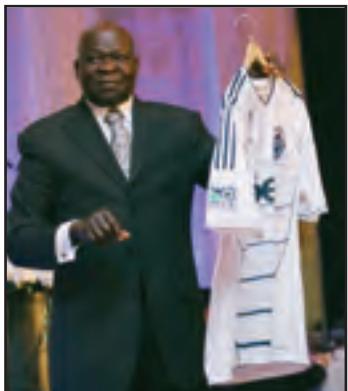
Grace McCarthy, O.C., O.B.C., Chairman of the Board, CH.I.L.D. Foundation, acknowledges Wendy & Sergio Cocchia.



Doorman Abdul Said, Century Plaza Hotel, raises his glass for the evening's Toasts.



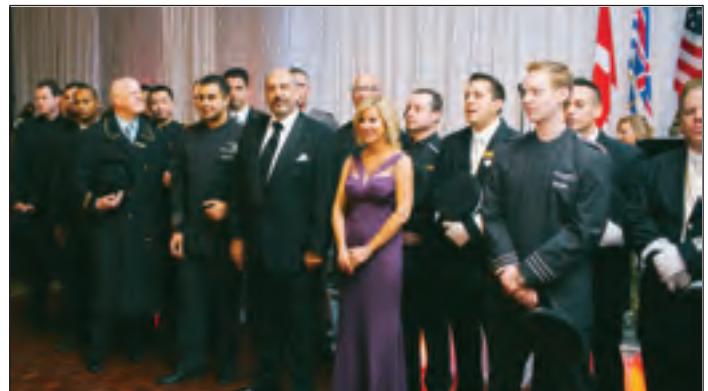
Dal Richards and his Orchestra never miss a beat as they entertain the crowd!



Many Doormen kindly helped display items for the Live Auction. Thanks guys!



Howard Blank, Vice President Communications, Entertainment & Responsible Gaming, Great Canadian Gaming Corporation, our wonderful Auctioneer!



Over thirty of Vancouver's finest Doormen stand with the Cocchias while the National Anthems play.



Dale Noble, Hotel Rosewood Georgia, reads the Invocation to the crowd.



Emcee Peter Legge, O.B.C., LL.D, D.TECH, Canada Wide Publications, once again does a magnificent job at the podium!



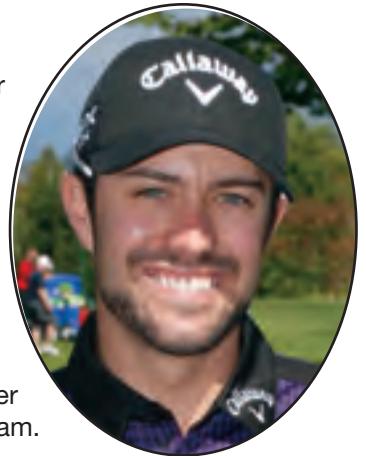
Band "Penelope Above" gets the dance floor moving as they supply the end of evening entertainment!

All photos courtesy of Jason Ho, Pure White Studio.

CONGRATULATIONS ADAM!

The First Tee of Greater Vancouver announced on March 27, 2013, the appointment of four outstanding British Columbians as Ambassadors of The First Tee of Greater Vancouver: Dawn Coe Jones, BC Hall of Fame; Abbotsford's Adam Hadwin, winner of two PGA TOUR Canada events; Langley's Sue Kim, second in 2010 CPGA Championship; and North Vancouver's Eugene Wong, two-time PGA TOUR Canada winner and 2012 Greater Vancouver Open Champion. Each of these outstanding British Columbians exhibits the core values of The First Tee: Honesty, Integrity, Sportsmanship, Respect, Confidence, Responsibility, Perseverance Courtesy, and Judgment.

The four Ambassadors all have had outstanding provincial, national and international careers in professional golf. The First Tee of Greater Vancouver partners with the YMCA of Greater Vancouver and the Vancouver Board of Parks and Recreation to support and administer The First Tee program.



The CH.I.L.D. Foundation is thrilled and honoured to have Adam Hadwin's ongoing endorsement for The Foundation for Children with Intestinal and Liver Disorders. At the age of 25, Adam has had a great year of opportunity and personal achievement, as he now strives toward the Canadian Open and PGA Tour. Best of luck Adam!

SOURCE: <http://www.pgtourcanada.com/leagues/newsletter.cfm?clientID=3776&leagueID=0&page=69216>



Pat Milino
May 26, '13
LIVE at:
FEDERICO'S SUPPER CLUB
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\$65 Reservable Seating
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Federico's Supper Club, 1728 Commercial Drive, Vancouver
www.FedericosSupperClub.com

Best Wishes to Lindsay!

Lindsay Gordon, Co-Founder of the CH.I.L.D. Foundation, has retired this year from HSBC Bank Canada after nine years as President and Chief Executive Officer. Lindsay has accomplished so much in nearly thirty years in the banking industry.

We wish Lindsay and Liz a relaxed retirement in Vancouver, spending time with family and friends and the CH.I.L.D. Foundation.



CH.I.L.D. Foundation Governor
Lindsay Gordon



SNOWBIRDS FLY FOR CH.I.L.D. COMING TO NANAIMO HARBOUR!

Presented By the Government of British Columbia



The Canadian Forces Snowbirds, Ambassadors for The CH.I.L.D. Foundation, are pleased to announce they will be performing their thrilling aerial show for thousands of spectators this July 31st, over beautiful Nanaimo Harbour.

This will be the eleventh year that the CH.I.L.D. Foundation and the Snowbirds have collaborated together, in hopes of bringing community awareness to the importance of finding a cure for children with Inflammatory Bowel Disease (I.B.D.).

Snowbirds Fly for CH.I.L.D. is a free family event that grows in popularity each year. We encourage people from all areas to come support the Foundation, purchase your Snowbird T-shirts and WESTJET raffle tickets, while being dazzled by the wonderful Canadian Forces Snowbirds Aerial Team!



Pictured Right, Mayor John Ruttan presents CH.I.L.D. Foundation President & Chief Executive Officer Mary Parsons the City of Nanaimo Proclamation deeming "Snowbirds Fly For CH.I.L.D. Day" in Nanaimo on July 31, 2013. Photo Credit: Matt Hunt



DONATE ON LINE!

Donations are accepted through our quick and easy online PAYPAL system.

Visit our website at www.child.ca and simply click on 'Donate'!

We also accept donations by phone at 604-736-0645, or by mail at Suite 201, 2150 Western Parkway U.B.C. Campus, Vancouver, B.C. V6T 1V6.

Enjoy a Happy and Healthy Spring!



Fashion for Child



**Luncheon &
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Fairmont Hotel Vancouver
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Tickets \$110

FRIDAY MAY 10.2013.11:30AM

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The Foundation for Children with Intestinal & Liver Disorders
Working For A Cure through Research for Children
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IN THE NEWS...



Wonderful Donor Jeff Hayes surprised CH.I.L.D. Foundation Executive Assistant Nancy Trentalance with a useful Binding Machine for the office. Thanks again Jeff!



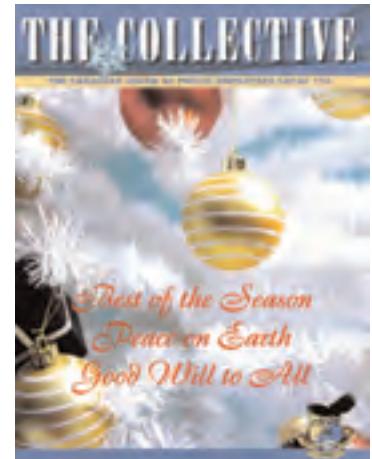
Pat Riccardi (centre), a good friend of The CH.I.L.D. Foundation, raised money through the Silent Auction of his 80 year old Yucca Plant in Edgemont Village in North Vancouver, B.C. Congratulations Daren Adams (right) for the winning bid, and to Julia Church (left) of DAVIDsTEA for hosting this unique auction!

Thanks to Unipharm Wholesale Drugs Ltd. and Medicine Centres in British Columbia and Alberta for supporting the CH.I.L.D. Foundation through Medicine Centres' coin bank programme in stores to June 30th of this year. When visiting your nearest Medicine Centre be sure to make a donation!



Thank you to **CUPE Local 116** for donating a WHOLE PAGE of advertising to the CH.I.L.D. Foundation in their Winter Newsletter *The Collective* AND for donating 1000 CH.I.L.D. Foundation Volunteer T-Shirts!

Our appreciation to Marsh Canada for their kindness to the CH.I.L.D. Foundation.



Kudos to Natalie (on front cover), the young president of the Biliary Atresia Awareness Research Society who tells her story on Facebook: **Biliary Atresia Awareness & Research**. "I was born in 1997 alongside my twin sister. At first we were both declared healthy but I soon began to show signs of a seriously sick baby. At first doctors ignored my parents' worry about my jaundice but finally a doctor noticed my dark yellow skin and eyes and I was rushed to Children's Hospital. My parents heard the words "Worst case scenario would be Biliary Atresia". After many tests and scans I was diagnosed with BA at nine weeks and at nine and a half weeks I underwent a major operation, the Kasai procedure, which gave me a second chance at life. Although I am doing quite well for a Biliary Atresia Fighter I have still been in and out of hospitals and doctor's offices all my life. I have lots of procedures, ultrasounds, blood tests, scans and right now we are discussing another surgery for me, but we stay strong and positive and I continue to fight. I will never give up and I hope and pray every day, that even though the odds are stacked against me, I will never need a liver transplant". Natalie's goal is to have everyone aware of Biliary Atresia and KNOW THE SYMPTOMS: prolonged jaundice with chalky grey/white stools.

A 'KNOCK- OUT NIGHT' IN THE RING FOR CH.I.L.D.!



This past November 22 at the Italian Cultural Centre in Vancouver, members from boxing clubs all around the lower mainland came together and challenged each other in the ring, with a full house of spectators cheering on their favourite athletes.

The CH.I.L.D. Foundation proudly accepted to be the charity of choice for the 50/50 draw that evening. Grace McCarthy, Chairman of the Board for CH.I.L.D., stepped into the ring at half time to draw the winning ticket, with help from Rocky Milino Jr, who so kindly wore The CH.I.L.D. Foundation logo (left) on his boxing shorts, to help bring awareness to our cause to find a cure.



Pictured Right, Rocky Milino Jr. & Emcee Dale Walters (R) with Grace McCarthy, Chairman of the Board, receiving applause from the crowd at the half time break.

SPECIAL THANKS TO THESE SPECIAL PEOPLE!

The Printing of *CH.I.L.D. Foundation News*
has been generously donated by
Global Securities.

We thank Art and Aline Smolensky
for their gracious continued support
over many years!



Yes I will help!



THE FOUNDATION FOR CHILDREN WITH
INTESTINAL & LIVER DISORDERS

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And enclose a cheque payable to CH.I.L.D. Foundation

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WORKING FOR A CURE

Contributions can be designated to The CH.I.L.D. Foundation via

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