

CANAVAN RESEARCH ILLINOIS

NEWSLETTER
SPRING 2007

a family's fight for the cure

Canavan Research Illinois (CRI) is a 501C3 charitable organization. Our mission is to raise enough funds to ensure that a cure for Canavan disease (CD) is discovered in time to benefit children like nine-year-old Max Randell, (pictured below) who are affected by this fatal brain disorder.



Max in his "Buddy Baseball" uniform

CD is caused by an enzyme deficiency in the brain which in turn leads to the malformation and destruction of white matter, or myelin. Myelin acts as insulation around nerve cells to ensure the messages they carry from the brain will reach their destination intact. Without the protective sheath, nerve impulses cannot transmit signals from the brain to other parts of the body. Children afflicted with Canavan disease are trapped, unable to control their own bodies because signals from the brain are not able to reach their destination.

Until now the average life expectancy of a child born with Canavan disease was ten, but we are changing that. Children battling CD usually suffer from low vision or blindness, seizures, and require feeding tubes as basic motor functions such as swallowing become increasingly difficult. But even during the end-stages of this disease

most children remain happy and continue to recognize family, friends and caregivers. Since our inception, almost ten years ago, Canavan Research Illinois has been able to direct about \$100,000 each year towards life-saving medical research.

An all-volunteer work force, and exceedingly low overhead costs, allow us to earmark our budget for programs designed to offer hope and help to children and families affected by this devastating disease. Our research efforts have resulted in gene therapy clinical trials and several pharmacological studies which have yielded interventions that can temporarily slow and even halt the relentless progression of CD. Through our extensive collaboration with research labs within, and outside of the United States, funds raised by CRI to develop treatments for Canavan have the potential to help millions of people suffering from other related brain diseases.

October was Canavan Awareness Month: In an effort to help increase knowledge and understanding about Canavan disease, Governor Rod Blagojevich declared October 2006 as "Canavan Awareness Month". After being approached by residents from their communities, Gene Marks, Village President of Northbrook, and Rita Mullins, Mayor of Palatine followed suit and wrote similar proclamations for their communities as well.

We Won: After a landslide win in "Diet Rite Zero Boundaries Woman" contest, Ilyce Randell and her mother Peggy Shapiro-Nyeholt, donated their prize money totaling \$50,000 to CRI. Thank you to everyone who voted online last summer, we couldn't have done it without you!

The Continental Restaurant: (Located in Buffalo Grove) Please ask to sign "Max's book" and 10% of your bill will be donated to CRI.

Upcoming Event: We are hosting a charity bowling tournament in Chicago at 10Pin on Tuesday, May 15th. *More information on the back side of newsletter.*

Save the Date: The 9th Annual Charity Ball will be held on **Saturday, October 13th, 2007 at the Hyatt Deerfield.** We are planning something extra special in honor of Max Randell's 10th Birthday (October 9th)

Canavan Awareness Bracelets: Bracelets can be ordered on our website, www.canavanresearch.org, or by calling Ilyce at 847-222-0736. They are \$10 each and all proceeds benefit CRI.

Network for Good: Credit card donations can be made on our website. This is a safe and secure way of donating to CRI. *Donations can also be mailed to PO Box 8194, Rolling Meadows, IL 60008.*

Volunteers? If you would like to learn more about becoming a volunteer for one of our events, please contact Ilyce Randell at 847-222-0736, or ilyce@canavanresearch.org.

Donation for 2006: Last year our donations exceeded \$125,000! Our goal for 2007 is to raise a minimum of \$150,000— *with your help we can exceed that goal!*



photos from The 8th Annual Canavan Charity Ball. Above: Max and Ilyce Randell,

Below: Max with his "Gammy", Vice-President of CRI Peggy Shapiro-Nyeholt



Save the Date
The 1st Annual

Tuesday, May 15th, 2007
10pin Bowling Lounge
330 N. State Street, Chicago
6:00PM - 9:00PM

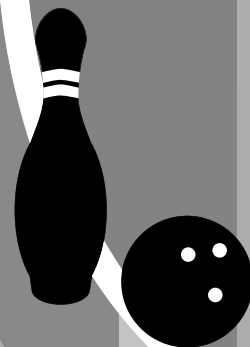
Hosted by Canavan Research Illinois and C & C Event Planning & Mgt., Inc.

Rockin' to the 70's Bowling Tournament

Benefiting Canavan Research Illinois

www.CanavanResearch.org

*Bowling • Dinner & Cocktails
Giveaways • Silent Auction*



Please return bottom half by May 1st with payment, and tickets will be mailed to your address. Thank you!

Ticket price per person \$45 * or Reserve a lane, 6 bowlers for \$270
Includes: Door prizes, Raffle, Silent Auction Bowling for 3 hours, Shoe Rental,
Dinner & Entertainment

of Tickets & Names _____

of Lanes & Names _____

____ I am unable to attend but would like to make a donation

Please use enclosed envelope to respond no later than May 1st

Lane & silent auction sponsorship opportunities available.

**If you are interested in receiving more information
please provide your contact information below.**

Name _____

Company _____

Phone number or email _____

Or call Kristie Sams-Faulkner at 773.450.9455~C & C Event Planning & Mgt., Inc.