



Creating Success Stories—
*Ethan, born in April 2005 with no T-cells,
was successfully treated with a bone marrow transplant.*

Ethan is not as unusual as you might think. In Canada approximately 13,000 individuals, mostly children, suffer from Primary Immunodeficiency Disease (PID).

Individuals with PID often have what seem to be “ordinary” infections. As a result, physicians sometimes treat the infections not realizing that there is an underlying cause. This allows the illnesses to recur, and can leave the individual vulnerable to vital organ damage, physical disability, serious illness, and death. Each year over 1,000 children are referred to one of the five children’s hospitals in Canada to be tested for PID, but 50% of cases still go undiagnosed costing the health care system \$80,000 per child and resulting in unnecessary suffering and premature death.

Early diagnosis and treatment can cure a child and allow them a normal life.

**What is Primary Immunodeficiency Disease, PID,
(commonly called “The Boy in the Bubble disease”)?**

Primary Immunodeficiency Disease is an umbrella term for more than 150 types of inherited defects in the immune system. It is something individuals are born with. It is genetically based and can affect anyone from any culture at any time. There is often no history of PID in family members. Newborns with the most severe form often go undiagnosed until it is too late for treatment. The CI Society is working to change that because, if diagnosed in time, there are treatments that can give children and adults a fighting chance.

The World Health Organization recognizes more than 150 forms of PID ranging widely in severity.

There is an organization for children like Ethan
Working to provide patient support, education and research for a cure for PID.

In 1999, Dr. Chaim Roifman, a global expert on Primary Immunodeficiency Disease, along Mr. Jay Lefton and Mr. John Perl established the Canadian Immunodeficiency Society (CI Society) to ensure that individuals with a PID illness are diagnosed and treated in a timely manner, to guarantee they receive the best possible care and treatments available to alleviate their pain, and to provide compassion and support to them and their families.

The CI Society upholds Imagine Canada’s Ethical Fundraising and Financial Accountability Code.

The CI Society is a registered charity, # 87276 0897 RR0001.



Our Recent Accomplishments

Patient Support

The Alastair Fund, available in Toronto, Montreal and Vancouver, provides emergency financial assistance to families for transportation, accommodations, food, medication and other critical needs. The Resource Guide was produced and distributed to clinics across Canada to assist families access helpful organizations and assistance. Special events, such as the Kids' Picnics and a Family Movie Day, were created to help break the isolation many families experience. Two pilot projects were begun in 2008: *Parent Support Volunteers* matching a committed and trained volunteer with a child in hospital, and *Group Support Meetings* assisting both patients and families.



Education

Physicians from Hamilton and Calgary have participated in the Fellow Training Program for placement at the Toronto Hospital for Sick Children. A Nursing Awareness Program comprised of a lecture series, centered in Ottawa and Edmonton, was initiated for nurses in the primary care of PID patients. A Standard of Care and Guidelines of Nursing Practice for Immunodeficient Patients is under development. To assist physicians with the diagnosis of PID, a physician's web-page on diagnostic tools, case studies and resources with links on PID was launched within the CI Society's website.

Research

Through a CI Society endowment fund, *The Chaim Roifman Scholar Award* has provided two-year research grants to Dr. Francois Le Deist of St. Justine Hospital in Montreal and Dr. Stuart Turvey of B.C. Children's Hospital in Vancouver. In thanks to Talecris Biotherapeutics, a patient survey on home infusion treatment was completed through the Toronto Hospital for Sick Children.



Dr. Francois Le Deist receives the Chaim Roifman Scholar Award from Richard Thompson, Executive Director, CI Society, September 2008.

Network of Specialists

The *Jeffrey Modell Canadian Immunodeficiency Network*, a program of the CI Society to increase physician education and awareness has ten sites.

Capital Health, Edmonton (Dr. Stuart Carr)
IWK Health Centre, Halifax (Dr. Tom Issekutz)
Hamilton Health Science Centre (Dr. Peter Dent)
Montreal Children's Hospital (Dr. Reza Alizadehfar)
CHU Sainte-Justine, Montreal (Dr. Elie Haddad)
Hôpital CHUQ-CHUL, Quebec City (Dr. Aubert Lavoie)
Toronto Hospital for Sick Children (Dr. Adelle Atkinson)
St. Paul's Hospital, University of B.C. (Dr. Amin Kanani)
B.C. Children's Hospital (Dr. Stuart Turvey)
Winnipeg Health Science Centre (Dr. Chrystyna Kalicinsky)



Dr. Eyal Grunebaum talks with James Kovach of Talecris Biotherapeutics at the CI Society's information booth at a CSACI conference.

The CI Society provides these sites local educational grants of up to \$5,000 for activities such as Primary Immunodeficiency Disease rounds. In 2008, the Network launched a series of PID videoconferences attended by site members and colleagues. This series is now accredited by the Royal College of Physicians and Surgeons as an educational forum. For the first time, Canadian statistics on the prevalence of PID are being compiled from each of the sites using a Base Line Survey distributed in partnership with the Jeffrey Modell Foundation. These statistics show that of the estimated 13,000 individuals with PID less than half have been reported.

Our Recent Accomplishments (continued)

Communications

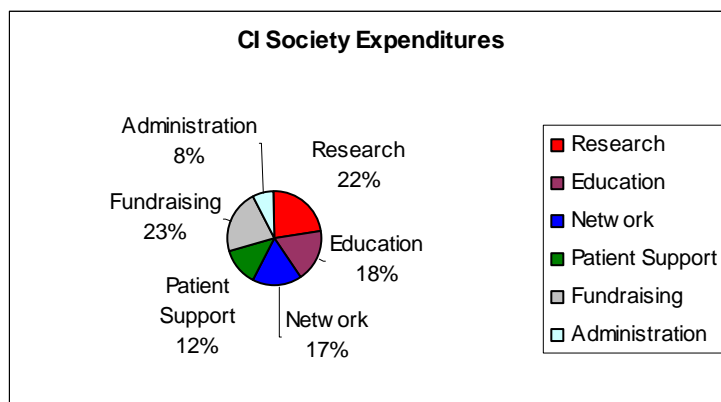
Over 600 national subscribers, including 350 physicians, receive the CI Society's quarterly online Newsletter. News coverage of the 10 warning signs and patients' stories have been published in various print media raising awareness of the disease and the challenges. To date, over 6 million web impressions have been received. Our web audience is spread equally across Canada, the United States and Europe. Our Website and print materials are available in both English and French.

Community Involvement

The CI Society relies upon the support of the community for fundraising and program implementation. In the Spring 2008 over 500 participated in *Shop 'til You Drop* at the Toronto Botanical Garden Centre, and in the Fall over 150 participated in the *Adam's Game Golf Classic* at Carlise Golf and Country Club. These events, raising funds for programs and services and awareness of Primary Immunodeficiency Disease, rely on the dedication and commitment of our volunteers and the generosity of our sponsors.

Fiscal Prudence

The CI Society's leadership is forward thinking and strives to be cost effective in the provision of programs. We use telephone & video conferencing technology to bring together physicians across Canada. Electronic distribution of newsletters and materials is used wherever possible. Our staff of six (most part-time) provide their own offices and equipment. Administration costs for the CI Society are just 8%. In 2008, our programs and services accounted for 69% of our operating budget.



Our Challenges

The CI Society relies on the generous support of individuals, businesses and foundations. We do not receive any government funding. We need your commitment to help us create more success stories like Ethan's.

Some examples of what your donation may help fund:

- \$22 for a child to attend the Kids' Picnic for the day
- \$150 for medication not covered by provincial programs
- \$300 for accommodation for a family to stay at Ronald McDonald House
- \$1,500 for a patient support group
- \$2,500 to fund a fellow for as physician-in-training
- \$4,800 to cover the cost of PID rounds at a hospital for one year
- \$25,000 to launch a province-wide network
- \$50,000 to fund a two-year research grant in the field of immunology



Successful bone marrow transplant recipients watching a magic show at the Kids' Picnic, Toronto

We need your commitment.

"The Canadian Immunodeficiency Society is the most important organization in Canada for the community of physicians and patients addressing Primary Immunodeficiencies. We applaud their significant accomplishments in education, awareness, advocacy and patient support."

Vicki and Fred Modell, Jeffrey Modell Foundation, New York, USA

Donate now and help us Create Success Stories.