



# Neutropenia Support Assoc. Inc.

P.O. Box 243, 905 Corydon Ave. Winnipeg, Manitoba R3M 3S7  
Local Winnipeg # 489-8454 Toll Free # 1-800-6-NEUTRO (633-8876)

President: Lorna Stevens (204) 989-5000 Treasurer: W. Lorne Stevens Medical Advisor: The Hon. Dr. Jon Gerrard  
Vice President/Editor: Mike Carlson Directors: Janis and Jim Benzelock Legal Advisor: Rick Stefanyshyn  
Canadian SCN Disease Registry: Dr. Bonnie Cham Dr. Melvin Freedman

*Please join us at  
the third annual*

## FASHION SHOW

### LUNCHEON

• MAGIC & MEDICINE •

RADISSON SUITE HOTEL BALLROOM  
**Oct. 30th, 1994 12:30 - 3:00**

**Tickets: \$25.00**

Proceeds to U. of M. Neutrophil Lab and other neutropenia projects

**FEATURING AS GUEST SPEAKER**

"Best Doctors in America" honored

**Dr. Laurence Boxer**

from Ann Arbor, Michigan

**ALSO**

Famous Magician & survivor of leukemia

**Dean Gunnarson**

**AND**

• **The Calendar Firefighters!!!** • **Panache** • **Peepers** • **Danali**

• **Braemar** • **Gotcha Lingerie** • **Moore's** • **Teri's Furs**

• **"Tom Q" Milroy from Q'94 FM**

• **Neutropenia Auction with incredible prize table**

**AND MORE!!!**

TICKETS AVAILABLE FROM:

Irene Zakala 668-8779; Mike Carlson 253-9948; Brian Gamley 663-6964; Janis Benzelock 667-0324; Lorna Stevens 989-5000; Radisson Suite Hotel 783-1700.

MAJOR CREDIT CARDS ACCEPTED.

## Dr. Laurence Boxer returns to Winnipeg!

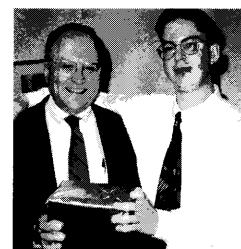
In April, Dr. Laurence Boxer, of Ann Arbor, Michigan, was well received in Winnipeg, Manitoba, Canada. He returns for our "Big Event", The Fashion Show Luncheon, October 30th.

### IN APPRECIATION

- He offers his genuinely caring support quietly, in an unpretentious manner.
- He helps families as much as he can, and parents do not forget those who have touched them with a respectful, hopeful and encouraging approach.

*This gives us, the families, during the difficult times, the strength to deal with the unknown.*

- He shares vital information between physicians and believes in the parent-family-child-physician team being the most effective way to handle the medical circuit with any chronic disease.
- We greatly appreciate and respect his ability to listen and act on parent concerns—valuing our opinion.
- Because of physicians such as Dr. L. Boxer, we can together do what is needed for our children and families' well being.



Jamie Benzelock thanks Dr. Boxer

### University of Michigan Hospitals

I would like to express my gratitude and appreciation for the opportunity to speak to the Neutropenia Support Association and at Pediatric Grand Rounds. Your hospitality, as well your lovely gifts touched me. Additionally those very kind remarks that you made in the evening were undeserved. The privilege of serving my patients is the only honor I need.

I look forward to rejoining the group again at the end of October. Best wishes for the rest of year with all of your activities.

Sincerely yours,  
Laurence A. Boxer, MD  
Professor and Director  
Pediatric Hematology/Oncology

**Dr. Boxer** (cont'd)



L-R: Dr. Laurence Boxer, Lindsey Stevens, Jamie Benzelock, Cal Murphy



Lorne Stevens, Jim Benzelock, Dr. Laurence Boxer

## Thank you Xerox Canada

The Neutropenia Support Association gratefully received a \$500.00 donation from **George Sykes** and Xerox Canada Inc. We appreciate and acknowledge the volunteerism of George Sykes and Xerox Canada's vital role in our Canadian Society by way of supporting many charities. We have a special project in mind for these funds and shall in due course report on progress. ■



George Sykes, Don Kuryk, and Jamie

# "Giving is rewarding"

*Thanks to the "Oldtimers" for choosing our motto*



Pictured from left: Don Kuryk, Lorna Stevens, NSAI; Grace Thomson, CWF; and Jim Benzelock

**Mr. Don Kuryk** and The Winnipeg Oldtimers Hockey team certainly gave back to society by organizing a social function with Line Dancing and Karaoke contests judged by celebrities.

They raised over \$7,000.00 to be donated to The Children's Wish Foundation of Canada and the Neutropenia Support Association Inc. The Chinese Auction and prizes were outstanding.

**WAY TO GO GUYS!! ■**

—WINNIPEG SUN



Don Kuryk and Ab McDonald



Top: Stan Kubicek, L-R: Joe Poplawski, Doc Holliday, Joe Aiello (Judges)



N.S.A.I. volunteers: The Ericson and DeMarco families popped the corn for "Oldtimers Event"

## FACES & PLACES

LAURIE MUSTARD

### Team Spirit of Giving

Letters...

"Dear Laurie... Our Oldtimers Hockey Team, The Winnipeg Club Oldtimers, has conducted many fund-raising activities over the years, raising in excess of \$30,000 for such charities as Juvenile Diabetes, the Christmas Cheer Board, Manitoba Cancer Society and others. We do this out of a sense of responsibility toward the hardships faced by others in our society who are not as fortunate as we are.

"Our most recent fund raiser was held on April 30 at the Red River Community College gymnasium. With the help of the college, the support of the community, and the volunteer time of local celebrities, we were able to raise almost \$7,000 and turned over 100 per cent of the proceeds equally to Grace Thomson of the Children's Wish Foundation, and Jim Benzelock of the Neutropenia Support Association (NSA). We presented each of them with \$3,496."

"Thanks...yours truly, Campbell McIntyre, Winnipeg Oldtimers Hockey Club."

Congrats to everyone connected with the club for your caring community involvement. Send me a pic of the team sometime, Campbell.

Oh, yeah, and a PS to Jim Benzelock...the big barbecue at Bob Irving's place was terrific, sorry you missed it. Next time...■

## GOOD NEWS!

POINT LEAMINGTON—A dart tournament was held at the Ponderosa Lounge in Point Leamington May 7, with all money raised going to research for Neutropenia—a blood disorder that affects 14-year-old, Krista Cooper of Point Leamington.

An all-out effort was made by many generous people.

Food was served, prizes were won, and a total of \$1,011 was raised.

Plans are to purchase a microscope with special lenses, that will benefit, not only Krista, but also cancer patients. The day ended with a dance. Money made on the door went to Neutropenia.

...



Krista Cooper

It was a day that caused quite a swelling of the heart.

A special thanks to those who participated in the sport itself, went to the Lounge, spent the day or bought our food to support our cause.

In a small town people show they care and it helps very much.

Through most of her life, Krista has had broken wings—through research, we believe there will be a mending of broken wings for many children throughout our country.

Botwood area is doing fund raising also. Already there has been a mini dart tournament and a card game. ■



**Dianne Cooper, representing the Neutropenia Support Association in Newfoundland made a donation of \$1,000 to the South and Central Health Foundation for the purchase of a TV, VCR, and Super Nintendo Game to be used in the Isolation Room of the Paediatric Room at the Central Newfoundland Regional Health Center. Nursing Supervisor Christine Grey accepted the item on behalf of the Paediatric Unit. Witnessing the event were patient Stephen Moores and Beverly Rose. ■**

Pediatric Hematology/Oncology  
Newfoundland

I was glad to hear that Mrs. Diane Cooper was able to raise such a significant amount of money in her community and that she is willing to help out here at the Janeway. You asked about a project for this fund and one area of concern that I have is the microscopes that we are using presently. Our senior hematology technician, Mr. Bill Hayward, tells me two of them came with the hospital twenty-seven years ago. I would hope to eventually purchase one with these funds to better enable us to look at blood films as well as do research.

Yours sincerely,  
L. Ingram  
Associate Professor  
of Pediatrics

*Note: Microscope Project Janeway given to date \$536.00. Goal of \$5000.00. A challenge, teamwork and enthusiasm!!!*

# Thanks for helping us help sick children

The Children's Hospital  
Research Foundation

Dear Members of the Neutropenia  
Support Association:

THANKS FOR HELPING US  
HELP SICK CHILDREN!

Through the generous and active support of groups such as yours, the Children's Hospital Research Foundation is able to fund researchers like Dr. Bonnie Cham. As you know, she has conducted extensive research on neutrophils and has established a Canadian registry for people with neutropenia.

Thanks to your contribution, children in Manitoba benefit from the most up-to-date knowledge and treatment in this area. Only through this type of generosity and commitment can we hope to maintain a standard of excellence in meeting the special health care needs of children.

On behalf of the Children's Hospital Research Foundation, Winnipeg's Children's Hospital and, above all, the children of Manitoba, thank you for your donation. Your help means a brighter future for many young Manitobans and their families.

Sincerely,  
Colin Ferguson  
President

The Hospital for Sick Children

I am very grateful for the generous donation in support of our research efforts in neutropenia. Every little bit helps and, in this case, the funds should help us finish the studies on why G-CSF didn't work in a patient with SCN.

Thanks for your support. An official receipt from our Research Institute will follow shortly.

Very sincerely,  
Dr. Mel Freedman

**Editor's note: To date the N.S.A.I. has donated over \$35,000 in support of neutrophil research projects.**

## Article changes lives

I would like to comment on an article in the Free Press in December, 1993, concerning the presentation of a 1993 Canada Volunteer Merit Award from the federal government to Lorna Stevens who founded the Neutropenia Support Association.

As a result of that story five new families were identified, one of which has four members suffering from this rare life threatening disease caused by a low white cell count in the blood which results in difficulty combating infections, anything from cold sores to pneumonia.

One feels very much alone when you're diagnosed with something as uncommon as neutropenia.

We have many questions but few answers. As members of the support group, we share our problems and anxieties and find comfort in working together on an association newsletter that goes out to medical professionals, friends and relatives in an effort to educate everyone about this disorder.

We also try to help raise funds for cancer research by holding an annual fashion show dinner.

I would just like you to know that a little article in your paper has changed the lives of so many people, and it's very much appreciated.

We are grateful too to people like Stevens for her tireless efforts and without whom none of this would be possible.

Irene Zakala  
Winnipeg



Irene Zakala and Betty Girard

Dear Lorna;

Congratulations on your nomination to the Family Advisory Committee (FAC). Your extensive experience with the Neutropenia Support Association, as well as your knowledge of hospital care and parenting skills provides you with an excellent background for a position on this committee. I wish you the best of luck in this new endeavour.

Sincerely,  
Dr. Jon Gerrard, P.C., M.P.  
PORTAGE INTERLAKE  
Secretary of State  
(Science, Research and  
Development)

## WHAT IS THE FAMILY ADVISORY COMMITTEE?

*The Family Advisory Committee (FAC) is a group of parents, with the assistance of pediatric health care professionals, whose purpose is to help maintain and strengthen the focus of family centred care. The parents represent diverse backgrounds and interests in Children's Hospital.*

*A collaborative effort of parents, professionals and hospital administration can only serve to enhance the care of children.*

*For parents it is a way to make sense out of what has happened and a way to give back to an institution that played a very big role in the life of a "family" served by Children's Hospital.*

*Please send us suggestions to benefit other parents so their hospital experience will be less overwhelming.*

*For example;*

*Streamline admitting procedures*

*Parking, Ward rules?*

*Patient Handbook "Tips for Parents; The Workings of Hospital"*

*Speakers Bureau*

*Medical Passport*

*Sibling Daycare*

*Easier access to records/charts*

*Big difference between acute and chronic care*

## Of interest...

I have read with great interest the recent newsletter of the Neutropenia Support Association, Inc. As a former Winnipegger (trained and inspired by Dr. Agnes Bishop), it gives me special excitement to see such good things emanating from my home town.

As a full time pediatric hematologist/oncologist, much of my professional activity revolves around the care of children with neutropenia (constitutional, acquired, and, of course, chemotherapy and transplant related).

I am writing to encourage you to continue the outstanding work which you have launched and to offer my services to assist you in any way possible down here at Cook-Fort Worth Children's Medical Center. I would also be grateful to receive copies of the educational materials which you have prepared and to be placed on your newsletter mailing list. I also enclose a donation and wish to become a member of your organization. I wish you most success in this vital project.

Yours sincerely,  
W. Paul Bowman, M.D.  
Medial Director, Department of  
Hematology/Oncology

## Thanks for the good work...

I want to thank you for the correspondence, and newsletters which your support group has been sending to me. They are quite informative and assuring, especially when one is a victim of this disease. I had this disease for 30 years before it was properly diagnosed and then began Neupogen treatments in Feb. '93. As was the case with other people with this disease, I had all the symptoms and infections, hospitalizations, and was on death's doorstep a couple of times.

Thanks to a caring Doctor and Neupogen I am back on both rails now. Let's all pray that for those who depend upon this drug there will be no serious side effects, whereby the "cure" is worse than the illness.

Thanks again for the good work you and your staff are doing.

Sincerely  
Bill Nelson

**EDITOR'S NOTE:** We receive many interesting and inspiring letters. We are 100% volunteers. We rely on the efforts of many in the community. We sincerely appreciate the wonderful contributors giving of their time and energy.

**Note:** Our telephone number is now listed in many major cities across Canada to provide easier access.

## 50/50 Raffle Tickets

From Shirley Cox (ONTARIO)

The Alliston Street Toys is a small local "antique" car group who hold a show once a week in the summer months. During these shows they have a weekly 50/50 raffle and at the end of the season a Grand Finale 50/50 draw. These tickets are sold throughout the season with equal amounts of the proceeds going to The Ontario Chapter of the Neutropenia Support Association Inc. and The Canadian Cystic Fibrosis Foundation. There is a limit of 1,000 tickets to be sold at \$2.00 a piece and the prizes range from \$300.00 down to the 13th prize of \$50.00.

**KEEP UP THE GOOD WORK!**

## Cox Family History Produces Amazing Discovery...

From Shirley Cox

Neutropenia is extremely rare and a very hard disorder to diagnose, therefore there may be more extended family members who may not have achieved a firm diagnoses, and therefore will not be receiving the latest and most effective therapy

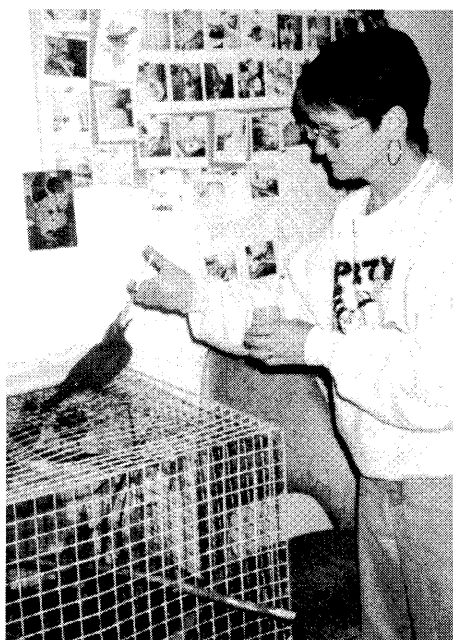
I require as much information and clues about each family member in order to properly track, trace and link up our family trees.

This job is time consuming, but very worth while.

Guess what?? So far two maritime

families with children diagnosed with Neutropenia appear to be related!

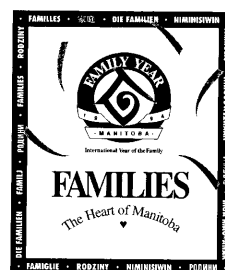
*Editor's Note: Send "Family names" list to N.S.A.I. We can enter into computer. Recently we found out 6 Maritime families diagnosed with neutropenia are related to each other. Wow! Our total diagnosed with neutropenia count across Canada is still under 100. There are hundreds more to surface!*



Lyn Noble uses the "Cox Family" syringes to feed the birds.

## Recycle Your Syringes

Foster Home for Animals in Lisle Ontario Canada uses syringes (without needle) for Wildlife Sanctuary. During the nestling stage, birds injured and abandoned need to be fed every half hour with a specially made mixture through a syringe. ■





# Caring Contributors

The Manitoba Government  
Employees'  
All Charities Campaign

Dear Sir/Madame:

On behalf of Manitoba's government employees and pensioners, it is my pleasure to forward the attached cheque. The cash donation was collected during the 1993-94 All Charities Campaign.

Pledges made through the 1993-94 Manitoba Government Employees' All Charities Campaign total \$827,108.43. Of the total, \$80,979.95 was donated by cash and designated to 173 agencies. The remaining funds were pledged through payroll deduction. Payroll pledges will be collected throughout the 1994 calendar year and disbursed in the spring of 1995. More than 400 agencies will receive funds because Manitoba's government employees and pensioners have personally chosen to support one or more charitable organizations through the All Charities Campaign.

Sincerely,  
Debra Laturnus  
Campaign Administrator

**Editor's note: We encourage all Government Employees to choose the N.S.A.I. as your "Special Charity". Thanks to the thoughtfulness of one of our supporters, we are now registered!**

The Seven Oaks Optimist Club

Thank you for the interesting presentation you made on Neutropenia at our meeting on February 17th. The literature you handed out to the members is very informative.

Enclosed is our donation.

We wish you all the best in your endeavours.

Yours truly,  
The Seven Oaks Optimist Club

**Editor's note: We can provide a speaker for your Club or organization to help promote awareness.**

## Way to go!!

The Manitoba Public  
Insurance Corporation  
Social Club

A fund raising event was recently held by the Manitoba Public Insurance Corporation Social Club. From the proceeds of this event, the Social Club wishes to donate the enclosed in the name of Brian Gamley, to Neutropenia. Please find enclosed a cheque for the said amount.

Yours truly,  
Sandra Chrusch, President  
MPIC Social Club



*Lisa Lemire with draw at the  
Boeing Recreation Ball Tournament  
in August. Neutropenia Raffle  
raised \$163.25. **JOB WELL DONE!***

## Cyclist Boosts Child Life

*Editor's note: The Neutropenia Support Assoc. Inc. in memory of Andrew Kuryk supported the efforts of Tim Mercer and helped promote awareness in Winnipeg. The media coverage was much appreciated and benefited Child Life. "Child Life is a sanctuary for children who need a place to be where nobody can poke or prod them," said Dawn Kidder, a program staff at Children's Hospital.*

**Tim Mercer** is a 27-year-old Queen's University student who is cycling from Vancouver to Kingston, Ont., to raise money for child-life centres at children's hospitals across the country.

He has been involved with Child Life as a volunteer for four years and has begun the cycling project to try to make Canadians aware of the needs of sick children and their families.

Anyone interested in helping Mercer's effort can send a donation to the Children's Hospital, Child Life Department, 840 Sherbrook St., Winnipeg R3A 1S1. ■



*Tim Mercer with North American Trust volunteers*

# Chemotherapy and Neutropenia

By Lorna Stevens (excerpts of article printed in *CONTACT* 1994 (Candlelighters Newsletter, Canada))

We are often asked for information pertaining to, in particular, the types of neutropenia (NEW-TROH-PEE-NEE-AH) caused by cancer chemotherapy.

Neutropenia is a common side effect for as many as one in three patients receiving chemotherapy treatment.

The neutrophils are the main white blood cell defense against infections, and are, along with the cancer cells, killed by the chemotherapy.

The most common symptoms include fevers, mouth sores, ear infections, pneumonia and other sores and infections. The mouth, a major entry point for bacteria, can be a real trouble spot.

Chemotherapy may have to be delayed until the body can produce more neutrophils and a lower dosage may have to be given, resulting in the treatment being less effective.

The longer the neutrophil level remains low, the greater the chance of getting an infection with potentially serious results.

When infection develops, antibiotics are given and hospitalization can occur for an average 10 day stay per occurrence of potentially life-threatening infections.

It is much harder for the doctor to treat the patient as every occurrence of potential infection saps the strength and greatly affects the total quality of life.

New drugs have been produced which help the bone marrow to make neutrophils, and help restore the body's defense against infection. These drugs are known as granulocyte colony stimulating factors. They help keep the number of neutrophils in the blood above the danger level all or most of the time. The shorter the time the neutrophil count is low, the less chance there is of developing fever or infection.

These drugs may improve the lives of patients with neutropenia by decreasing the number and severity of infections and reducing hospitalizations. These and other treatment options should be discussed with the doctor.

These drugs are expensive but less expensive than the potential hospital stays. The compassionate value is immeasurable. Here are some comments from families and physicians:

*"There is no question that G-CSF is keeping these patients out of the hospital and away from doctors' offices. Because our hospital budget is being reduced every year, we are forced to find ways to meet the budgetary restrictions. Reduction in hospitalization is a major strategy and keeping neutropenic patients out of the hospital has had an important impact on cost-savings."*

*"As physicians our goal is to practice preventative medicine. This is a very exciting drug. We can provide medication to avoid frequent serious infections. The impact on the patient's quality of life will be dramatic."*

*Her chemotherapy began and remission was achieved.*

*She relapsed and chemotherapy was re-started, remission again achieved. Chemotherapy continued for 2 1/2 years and had to be stopped because of a severe case of chicken pox. The 2nd remission lasted 6 months. The option of a bone marrow transplant was present as her best chance to live at the age of seven.*

*She was hospitalized 32 days and as it turned out, cyclic neutropenia was transplanted. Thankfully to Neupogen's experimental use, she is now 19 and doing very well.*

We received this letter from a Mom last month:

*My son was diagnosed with Burkitts Lymphoma October 1993. The disease was advanced; he was a Stage Three and the chemotherapy treatments were intense with only two weeks between each. As a result, we spent most of the five months in the hospital. The side effects were severe, coupled with neutropenia. My son had his braces on and the window was so small between recoveries that they could not be removed. Hence, he had the worst case of mouth sores ever seen, and they just couldn't heal.*

*I read every piece of literature available. Luckily, one of them was the booklet provided by the Neutropenia Support Association. A phone call offered me information about Neupogen, and some options that had not even been presented to me by any of the hospital staff.*

*The battle began, and it was all uphill. Most of the staff were unfamiliar with this approved drug and tried to persuade us to consider an experimental, free drug. Finally, our staff doctor listened, read the information I offered, and agreed that my son was too sick to risk the chance of more side effects. Even so, he had to override the wishes of the Oncology Head, who resisted the use of any colony stimulating factor drugs.*

*Neupogen provided a necessary option and throughout the rest of his treatment, the side effects eased completely in one of the blocks, and lessened them by at least 60% in the other. During one session, my son did not even experience any neutropenia effects other than low counts, and was able to go home for almost a week.*

*The frustration, battling, additional stress, and more significantly, my son's suffering were unnecessary. Hospitals should not be making decisions for the patients, but rather, should be educating their staff to present all the options available.*

## Editor's note:

**Health Protection Branch approved :**

**March 3, 1992: Neupogen, a new drug which significantly reduces the risks of life threatening infections in cancer patients treated with chemotherapy.**

**October 28, 1993: Neupogen, for long term use in the treatment of patients with severe chronic neutropenia, to increase neutrophil counts and reduce the incidence and duration of infection in patients with a diagnosis of congenital, cyclic and idiopathic neutropenia.**

**June 23, 1994: The first GM-CSF product was approved for chemotherapy use. The Hoescht Pharmaceutical Co. has not yet made this product available. We hope to have more info available in the future.**

#### ALLIANCES—

- Partners Childhood Cancer Alliance
- Jeffrey's Folks Winnipeg Manitoba
- Family Advisory Committee, The Children's Hospital
- The Neutropenia Support Association Inc. was invited to participate at the Atlantic Canada's 1st International Candlelighters Conference in Halifax Nova Scotia July 8th - 10th, 1994, and National Childhood Cancer Conference in Kingston, Ontario 1993.

Video tapes of physician presentations are available by calling 1-800-6-NEUTRO ■

## Chemotherapy and Neutropenia; Information for persons with cancer and their families

This booklet has been prepared for people of all ages who are receiving chemotherapy for cancer. It is also written for family members.

Many children receiving chemotherapy experience periods of neutropenia, fevers and infections. This information in this booklet explains the causes and basis of neutropenia and offers practical suggestions for preventing infections and dealing with neutropenia when it occurs.

The information was reviewed by five Canadian paediatricians and reflects the approach in children's centres in Canada.

The publication of this booklet was made possible through a grant from AMGEN Canada, Inc. Copies of Chemotherapy and Neutropenia can be obtained at no charge through Candlelighters Canada, 10 Alcorn Street, Toronto, Ontario M5V 3B1, or The Neutropenia Support Association Inc. 905 Corydon Avenue, P.O. Box 243, Winnipeg, Manitoba R3M 3S7. ■

*Candlelighters Canada is a national volunteer organization serving families of children with cancer. By providing information, engaging in advocacy, and encouraging the development of local parent support groups.*

# Bone Marrow Transplant

The need for bone marrow donors was highlighted in Vol. 6, Neutropenia Support Assoc. Inc. Newsletter. Again, this need is stressed as one of the S.C.N. children has developed A.M.L. and continues to search for a match. Please call (U.S.) 1-800-MARROW-2 in the U.S. or contact The Canadian Red Cross Society to find out more information about becoming a bone marrow donor.

### SOME FACTS about Bone Marrow and Bone Marrow Donation

- Bone marrow is a pulpy tissue found inside the long bones such as the ribs, breastbone or pelvis. Bone marrow can be compared to a factory where red blood cells, white blood cells and platelets are made.
- Bone marrow transplants are used to treat patients suffering from some forms of leukemia and other diseases affecting the function of the bone marrow. Many of these diseases, if untreated, are fatal.
- A bone marrow donor provides the replacement marrow used in a transplant.
- A bone marrow donor must be compatible with the recipient or the marrow will be rejected by the recipient, or may possibly attack the other tissues in the recipient's body.
- Compatibility is determined by matching specific protein markers or HLA-type on the cells of the donor and the recipient.
- HLA-type or Human Leukocyte Antigens are proteins carried on white cells, platelets and other cells of the body, including bone marrow.
- Family members are usually used as bone marrow donors because HLA-type is inherited.
- However, only 30 to 40% of patients needing a bone marrow transplant have a compatible donor in their family.
- An unrelated bone marrow donor is less likely to be compatible with a recipient because HLA-type is determined by inherited genes, which may

or may not be shared outside a family.

- A registry of unrelated bone marrow donors provides a large data base of potential donors by HLA-type. The larger the list, the greater the chances of finding a compatible donor.
- A computer search of a registry of donors will increase the chance of finding an unrelated compatible bone marrow donor.
- Unrelated bone marrow donors must meet the same eligibility requirements as a blood donor. Generally donors are less than 60 years of age because donating marrow involves minor surgery. ■

### RECOMMENDED READING

## The Candlelighters Guide to Bone Marrow Transplants in Children

The Candlelighters Guide to Bone Marrow Transplants in Children, 1994, is published by the American Candlelighters Childhood Cancer Foundation, 7910 Woodmont Ave., Suite 460, Bethesda, Maryland 20814-3015. The book will be available shortly from Candlelighters Canada through the generosity of the Candlelighters US. Please contact Candlelighters Canada, 10 Alcorn Avenue, Suite 200, Toronto, Ontario M4V 3B1. ■



# National Neutropenia Network (UNITED STATES)

## OVERVIEW

For more than 5 years, 128 people with a rare disease known as Neutropenia, have participated in a research study which revealed that the use of G-CSF was a viable drug in the treatment of this life-threatening blood disorder. During this time, the families whose lives have been affected by neutropenia have come to learn of the rarity this disorder and the lack of knowledge among those in the field of medicine in recognizing and diagnosing this condition. With the help of Amgen and the Canadian Neutropenia Support Association, Inc., nine people came together and determined that there exists a need for such a group for families in the United States.

## PROGRAM OBJECTIVES

The primary objective of the National Neutropenia Network (NNN) is to serve as the link for sharing of information, coordination of efforts nation wide.

## PROGRAM TASKS

1. To promote general and clinical research related to Neutropenia
2. To provide information to educate families, the medical community and the general public about management risks and needs of neutropenic patients
3. To collect and distribute the latest medical data on neutropenia, including long-term effects, heredity factors, effects of other treatments, information resources for medical and psychological expertise
4. To provide information about working with hospitals, physicians, nurses and other health care professionals in order to make neutropenic patients medical care as positive as possible and give their families skills to be effective in the medical environment
5. To increase and support general public awareness
6. To identify patients and families whose lives are affected by neutropenia
7. To facilitate recognition of the psychological effects of dealing with chronic illness and encourage families to seek professional help

8. To increase awareness and understanding of neutropenia in the medical community

9. To act as an advocate for the National SCN Registry

## United States Report

Since meeting with Amgen representatives and doctors in early January 1994, volunteers have already been working to develop the National Neutropenia Network (NNN).

The National Neutropenia Network was created to promote awareness, education and research about SCN and provide a support system for patients with neutropenia and their families. Thanks to volunteer **Silke Deeley**, Chicago, Illinois, for the technical proposal, and education grant request. Thanks to volunteer **Ed Nicola**, Whittier, California, liason with U.S. Corporate Sponsor Amgen Inc. Thanks to volunteer **Lee Reeves**, Pinckney, Michigan, for writing the articles of incorporation.

Thanks to volunteer **Beth Jacobs** for diligently managing the U.S. toll free Info-Line 1-800-NEUTRO-8.

Thanks to N.S.A.I. for input and encouragement.

## Co-operation Makes Things Happen!

Sonja Cary, volunteer from Santa Ana, California (617 East Bishop St., 92701) would like to prepare for a U.S. N.N.N. newsletter to be written by Barbara and Stephen Johnson, volunteers from Oak Harbor, Washington. Please send names of physicians, families and friends in the United States. The Canadian Neutropenia Support Association will continue to assist with issues and needs worldwide.

The generous Amgen Inc. education grant received will help facilitate the N.N.N. development. Once the N.N.N. (U.S.) has acquired registered charity status, official tax deductible receipts can then be provided.

### CALL

U.S. Toll Free Info Line  
1-800-NEUTRO-8

### WRITE

P.O. Box 205  
Chicago, Ill. U.S.A. 60630



*Silke Deeley, and Beth Jacobs at Conference, Halifax, Canada "Compassion and Caring"*

## Networking...

On behalf of the NNN, Silke Deeley and I (Beth Jacobs) would like to thank Lorna Stevens and the Canadian Neutropenia Support Association for sponsoring our registration to the "Childhood Cancer and The Family Compassion & Caring" Conference in Halifax, July 8-10, 1994!

Dr. Mel Freedman, Dr. Lewis Ingram, Dr. Kaiser Ali spoke on "Treatment of Congenital & Chemotherapy-Induced Neutropenia". They all presented a comprehensive discussion of the course, true effects and treatment. We met together with the doctors and members of the Canadian Neutropenia Support Association.

*Please call if you are interested in organizing a conference statewide and give us your suggestions for speakers.*

Beth Jacobs



Some weeks ago you were good enough to send me some useful information about the National Neutropenia Network after we had spoken by telephone about my wife's situation. We both appreciate your thoughtfulness and thank you very much for the material and we have enjoyed reading some of the stories.

My wife's need for the G-CSF was highlighted during a life-threatening stay in hospital last Christmas. Ruth is 69 years old. She has had rheumatoid arthritis for many years and something called Felty's Syndrome which required removal of her spleen some years ago. After much illness last summer, when low white counts were not heeded, she had to be admitted to hospital with heavy fever. Her neutrophils were at zero for about 10 days and she was given G-CSF daily. The neutrophils were stimulated after 19 days with many ups and downs in between. Her white counts seem to have stabilized and we hope the recovery continues. We think you might be interested in this brief outline of her situation.

Please accept this small contribution to the expenses of the N.N.N. with best wishes.

Sincerely,  
Herbert and Ruth Langley

## The Atlantic Canada First International Candlelighters Childhood Cancer Conference

HALIFAX, NOVA SCOTIA—Session: **"Treatment of congenital and chemotherapy induced neutropenia"**. Volunteer speakers: Dr. Melvin Freedman, Hospital for Sick Children, Toronto, Ontario; Dr. Kaiser Ali, Saskatoon Cancer Centre; Dr. Lewis Ingram, Janeway Children's Hospital, St. John's, Newfoundland. Lorna Stevens, parent N.S.A.I., Moderator:

Eleanor Pask, Executive Director, Candlelighters Toronto, Ontario. Organizers: Neutropenia Support Association Inc. (Manitoba and Maritimes) "A most successful and *memorable* opportunity." Thank you to Candlelighters Canada for helping this collaborative event enhance the care of children. Heartfelt thanks to the voluntary speakers!! ■



*All these "moms" from Canada and United States have children born with Neutropenia "Networking Together"*

*(below) Eleanor Pask, and Dr. L. Ingram*



*(above) Dr. Melvin Freedman, SCN International Disease Registry, Hospital for Sick Children, Toronto*

*(left) Dr. Kaiser Ali, Medical advisor N.S.A.I. Saskatoon, Sask.*



*(above) Dr. Freedman, Lorna Stevens and Harry Lake, Exec. Dir. Can. Cancer Society, Nfld. & Labrador*



*Roy Bonisteel and Shirley Cox*

# International Neutropenia (SCN) Disease Registry

This protocol involves the establishment of a disease registry for patients diagnosed with SCN and is intended to represent current standard care guidelines as developed by experts in the field of SCN. This registry will allow for long term surveillance in this patient group including patients receiving chronic treatment with colony stimulating factors and/or other therapies.

## Objectives:

Document the clinical course of Severe Chronic Neutropenia (SCN).

Monitor and assess long term safety of primary treatments in SCN patients in the US, Canada, Europe and Australia.

Study the incidence and outcome of the following previously identified adverse events: osteoporosis, splenomegaly, cytogenetic abnormalities, myelodysplastic syndrome and leukemia.

Evaluate growth and development and hematologic parameters.

Monitor for clinically significant changes in primary treatment response over time.

Establish a physician network to increase the understanding of SCN.

Establish a demographic database to allow for future research.

Please call:

1-800-6-NEUTRO in Canada

1-800-NEUTRO-8 in the United States

for more information on Data Coordinating Centres.

*Editor's Note: We encourage participation! The ULTIMATE dream... **more successful research** producing gene therapy and other courses of treatment. The goal... to eradicate this, and other related, diseases. We live in very exciting times!!*

The Neutropenia Support Association supports the position of a yearly bone marrow. Chromosome testing is necessary to monitor SCN patients receiving long term G-CSF (neupogen). Kostmann Syndrome and SHWACHMAN/DIAMOND/OSKI SYNDROME for example, have shown inherent 4% risk of leukemia.

I have been self-administrating r-metHuG-Csf (Neupogen) for almost six years, my anniversary being this coming November.

I wish to become a part of not only a national, but an international registry. Any assistance which you could provide would be much appreciated.

## For Patients in Europe:

Prof. Karl Welte  
Med. Hochschule Hannover  
Abt. Kinderheilkunde IV  
Konstanty Gutschow Str. 8  
G 3000 Hannover  
Germany

Tel: 49511 5326020

Fax: 49511 5326120

## For Patients in Canada:

Dr. Bonnie Cham  
Manitoba Cancer Treatment and  
Research Foundation  
Cell Biology  
100 Oliva Street  
Winnipeg, Manitoba  
Canada R3E 0V9

Tel: (204) 787-2188

Fax: (204) 783-6875

or

Dr. Melvin Freedman  
Hospital for Sick Children  
555 University Avenue  
Toronto, Ontario  
Canada M5G 1X8

Tel: (416) 813-6152

Fax: (416) 813-5327

## For Patients in Australia:

Dr. George Kannourakis  
Department of Hematology  
Royal Children's Hospital  
Flemington Road  
Parkville, VIC 3052

Tel: (613) 345-5656

Fax: (613) 349-1124

## For Patients in the United States:

### West

Dr. David C. Dale  
University of Washington  
Department of Medicine  
AS 522 RG22  
1959 Pacific Street, N.E.  
Seattle, WA 98195

Tel: (206) 543-7215

Fax: (206) 685-4458

### East

Dr. Mary Ann Bonilla  
Memorial Sloan Kettering  
Cancer Center  
1275 York Avenue  
New York, NY 10021

Tel: (212) 639-8451

Fax: (212) 717-3447

### Central

Dr. Laurence Boxer  
University of Michigan  
F6515 Mott Children's Hospital  
Box 0238  
Ann Arbor, MI 48109-0008

Tel: (313) 764-7126

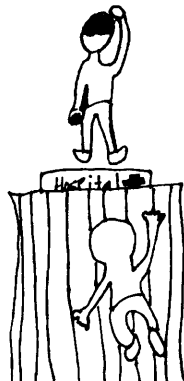
Fax: (313) 936-8520

## FEATURE STORY

# Holding My Breath



*This is how I feel*



*This is me breaking out*



*This is where I want to be*

That month began like any other. My son's stomach ache on Sunday must have been too much pizza at his sister's birthday party. Back to the doctor a few times when his stomach appeared distended, and he appeared pale and sweaty with veins showing through his chest. Each time we were told it was the flu. Trips to a hospital walk-in clinic and emergency left me exhausted. I was told I was an over-anxious mother, and dismissed.

I called another hospital. After he had been X-rayed, things began to happen. It was confirmed that he had fluid in his abdomen.

That Saturday night and Sunday were two of the worst days to be endured. Hooked to an IV he was so distended he could not lie down, walk, sleep, or drink.

The CT scan showed a mass in the abdomen. It was a large tumor. Surgery; a biopsy, spinal fluid and bone marrow samples followed. He was in ICU with a collapsed lung, and renal failure due to the amount of fluid and pressure and strain on his organs.

The cancer, classified as a Stage 3 in severity, had spread over the lining of all the organs in the area. The good news was it might be contained below the diaphragm and not involve the bowels. His bone marrow was negative. We began a very aggressive and highly successful protocol for this type of cancer.

*We slowly learned that the  
body and mind are more  
powerful than we are aware.*

I will always remember the moment I had to tell my son "the whole truth". His immediate response was shock, despair and anger. He wanted to know if he was going to die and I had to tell him that I did not know. He slept for almost a whole day. When he woke, he asked me some very direct questions and told me he was ready to fight. He had a lot of things to do and he was going to do them all. That was the turning point for my son.

Those days are mostly a blur, but I can recall the grim faces of the doctors warning us not to have much hope. I know that

was their duty, and perhaps it was fortuitous that their words never really totally 'sunk in', because it was unfathomable for me to have anything but hope. He was my son.

He was placed on continual dialysis, a fairly new procedure for cancer patients, and it had only been available for a year-and-a-half; this was a very positive reminder that this is a time when there are new ideas, new approaches, new procedures and new drugs every day, **a time when miracles happen.**

It was decided that the chemotherapy, although urgent to stop the cancer, had to be delayed and reduced from the original protocol. With fluid still trapped in the abdomen, and the kidneys and lungs not at full function, the drugs would have killed him. His treatment was halted many times while he regained strength. We slowly learned that the body and mind are more powerful than we are aware.

There were problems with everything. Decisions to let him drink or eat changed from day to day, often hour to hour. The catheter, transfusions, IV tubes, spinal taps, out-of-control fevers, endless x-rays and tests, collapsing veins, drug reactions, more drugs to combat the reactions, and the noise and lights 24 hours a day in ICU!!!

Over the next five months of intense treatment, moments of true elation, the peaks... the first signs of kidney function; the signs that the lung was improving; his first time sitting on the edge of the bed, moving out of the ICU... these were moments of joy in the midst of chaos.

From the moment my son entered ICU, I started a daily log. Every medication, every reaction was noted. I could help my son by learning and knowing exactly what was happening and why. This was very important to both of us. We had entered foreign territory—the language, routines, procedures—all new and potentially frightening.

Ten days in ICU were an eternity. The most difficult is that when my son needed me to hold him, or perhaps when I needed to hold him, to comfort him, I couldn't. The tubes, equipment, needles, oxygen, wires and sore spots, made it impossible, and that hurt.

The insidious mouth sores that my son endured cannot be understood by anyone who has not experienced them. The vomiting, the weakness, the nose bleeds, hair loss, tests, tests, and more tests. He suffered.

Then there were all the additional drugs to combat the side effects of the chemotherapy, and the infections, and ensuing pneumonia. I had raised my children holistically, with natures their whole lives, and here I was, happy that he was being pumped full of drugs, requesting that the morphine should be increased so that my son wouldn't suffer.

My son had to deal with the harsh reality that just when he seemed to have survived the first phase of the chemotherapy, and began to feel a bit better, the cycle was to begin again. The treatment is very intense with two weeks between five-day treatments.

My son has always been very expressive in his writing, music and art. One very 'blue' day, I encouraged him to leave his room and venture into the playroom. He could not yet leave the floor. I took some paper and asked him to draw how he saw himself. He drew a bony, hairless, scarred, frightened boy in a cell with bars, a ball and chain on his leg. I then asked him to draw where he wanted to be. The next frame showed a silhouette of that boy breaking through the cell wall, running. Then I asked him to picture himself doing all the things he loved. He quickly drew pictures of him playing basketball, playing piano, sitting on the sofa at home relaxing, with his sister and me, our dog, two cats and hamster. He felt better. I felt better. These drawings (and we kept adding all the things he pictured himself doing) soon decorated all the walls. These were catalysts for hope. They served as small goals to reach. He began to picture himself breaking through that wall.

One long month later, my son went home for the first time! Another triumph! We were home for almost 6 days before returning to the hospital.

*Look for that strand of hope,  
that almost nonexistent  
crumb... Don't give up.*

Later that month, a window opened. In devouring all the literature I was given, I came across a support group for neutropenia. As he had suffered from severe neutropenia with every chemo phase, I felt I should learn as much about it as possible. The voice on the other end of the phone was a hopeful and informed one. It came at a time when the doctors felt he needed some help with his severe neutropenia and side effects from the chemotherapy.

Through Lorna Stevens, I learned that there was an approved drug, and one with virtually no side effects. I thought it would be easy to obtain this G-CSF, and it was stocked in the hospital!

However, the hospital did not have the funds for the approved drug. The hospital often settled for the experimental one, because it was free. As a mother, I wanted the very best for my son.

The support and information I received from Lorna enabled me to intelligently discuss the benefits with the doctors, encouraging them to read the literature, watch the video, and realize that Neupogen (G-CSF) really was the best choice.

It was through our Staff doctor on the floor, who, after reading the literature, agreed and signed the order for G-CSF.

After a bumpy start we began the G-CSF on the fifth day of each phase of the protocol. It worked quite well on one of the two phases of chemo in each session. It lessened and sometimes eliminated the mouth sores to a very tolerable level and my son did not go through the floor in between treatments. There were times when he did not have to face the anticipated infections. That was a big deal. Not only did the infections drain his energy, but they always led to a myriad of drugs in the attempt to curb the fever, and they rarely made much of a difference. Infections and fevers also delayed the treatments.

The fevers were almost eliminated in one phase and reduced to the extent that his stays at home were more extended and more enjoyable. Neupogen gave my son options and the strength to see it through. It allowed him to stay home a little longer and he even made it to school for a couple of hours! He was able to feel better when visitors dropped by. All these things gave my son hope and confidence that he could deal with some of the awful things that chemotherapy can do, while terminating a disease. It helped him to picture himself beyond his illness.

The next few months were a series of very few highs and several lows. We could never tell how things were really going and oncologists are reluctant to commit to any kind of direct answers to the many questions I always had. There were setbacks, two of which resulted in major surgery when CT scans indicated more tumor. Thankfully there was no tumor. Children on our floor who didn't make it left us devastated. We became very close to one little boy, and his death was almost too much.

It is many months later. **Today is a milestone...** my son had his porte removed and next week we reach the half-way point at our sixth clinic appointment. As I listen to him playing his guitar in his room, and marvel at his bravery, his talents, and think about his sister, who is once again finding reasons to laugh, I too am finding reasons to rejoice. My son has said that having cancer and having been through the treatment, finishing it, and waiting through each checkpoint is like 'holding your breath and not being able to exhale'. We are just now beginning to breathe.

Illness affects each and every member of a family. Siblings often suffer feelings of abandonment, fear, isolation, jealousy, and anger, and seldom receive the attention they require. It is a tribute to the love and support that surrounded us and the will of my son and my daughter that I gratefully and thankfully write these words today, with hope in my heart and the confidence that he will be fine, and that we all will heal. We never really know our endurance levels, our true strength. No one, especially a child, should ever have to be tested like this to find out. But to you out there who are being tested and taken to the very edge of what you might imagine to be your limits, take heart. Look for that one strand of hope, that tiny almost nonexistent crumb, and try to find a window in your mind to a place without pain and suffering. **Don't give up. ■**



## You too "Can" Help!

THANKS TO **Jim and Janis Benzelock** for idea, **Shirley Cox** for 200 cans (more available on request), **Mike Carlson** for labels.

### Now we need your help!

- Donation cans will be available at Fashion Show Luncheon
- Write or call 1-800-6-NEUTRO to arrange for your store, bank, local establishment
- Donate funds for neutropenia projects in your province or state!

## Recommended Reading!

### FILGRASTIM (r-metHuG-CSF) IN CLINICAL PRACTICE

edited by George Morstyn, T. Michael Dexter

**To Order:** Write to Marcel Dekker Inc. 270 Madison Avenue, New York, N.Y., U.S.A. 10016

or call: 1-800-228-1160

\$125.00 (U.S.) a book



Special volunteers Shirley Cox, Lorna Stevens Mike Carlson, Janis Benzelock presented with plaque "In appreciation".

## Helpful Tips

- One-shot pneumonia prevention.

This simple life saving injection helps in preventing serious pneumococcal diseases. Ask your physician about this vaccination.

- A helpful way to give liquid during those severe mouth sore episodes: Give liquids through a very large 20cc syringe to get liquid to the back of the throat. (Tip from Mimi Dechabert, West Palm Beach, Florida)

- Rotate your shots to prevent sluggish absorption of the G-CSF (Neupogen), i.e. arm, arm, stomach, stomach, leg, leg. (Tip from Dr. Melvin Freedman, Hospital for Sick Children in Toronto, Ontario, Canada)

We welcome your tips! ■

*The Neutropenia Support Association Inc.*

*has gratefully received many*

*"In Memory of" donations.*

*May the knowledge that this gift will*

*aid others be of comfort.*

*The families have received acknowledgements*

*of the generous donations.*

*We continue our efforts with help from your tax*

*deductible donations.*

***Thank You!***

CANADIAN PUBLISHERS PRINTED SEPT. 1994

# Neutropenia Association offers information, support

Brenda Fleming  
Metro Writer

When Lorna Stevens talks about the people she knows through the Neutropenia Support Association, one gets the feeling she's talking about family.

She refers to everyone on a first-name basis and knows their stories and phone numbers by heart. For Stevens, neutropenia is a topic that certainly is close to her heart. Her son Lindsey was born with neutropenia, a rare blood disorder.

After discovering that her son had neutropenia, the River Heights resident embarked on a relentless search for information. She also wanted to share what she had learned with others, as well as bring together people affected by the disease together. To do that, Stevens founded the Neutropenia Support Association Inc. in 1989, a registered charity designed to increase awareness and understanding of neutropenia.

## Information Line

The association provides information about neutropenia through a newsletter and information line.

While Stevens' son Lindsey was born with neutropenia, Stevens knows people who have developed it after a viral infection, as a side effect from a drug, exposure to poisons or when being treated for cancer with chemotherapy drugs.

A potentially fatal disorder, signs of neutropenia can range from chronic ear infection to painful mouth ulcers and gum infections.

Stevens says her son has been fortunate, and hasn't had to face some of the difficulties others with neutropenia have had to face.

New drugs have become available which have shown promise in treating neutropenia and giving those affected relief from the often painful symptoms, Stevens said.

## Reinforcement

Constant reinforcement from families

who have contacted the association and realize they are not alone in the fight against neutropenia, as well as encouragement from the medical community has shown Stevens getting information out about neutropenia is important.

"There's such an incredible need. You don't really think about why you do it, you just know something's got to be done."

Those who want information about neutropenia can contact the Neutropenia Support Association Inc. at 489-8454.

The association has planned its major fund raiser of the year for Oct. 30 at the Radisson Hotel.

The event will feature a fashion show as well as an escape by Winnipeg escape artist Dean Gunnarson, who is a survivor of childhood leukemia and can identify with the challenges faced by those undergoing chemotherapy, said Stevens.

The event will also be an important opportunity to find out more about neutropenia, she said.

The event's guest speaker will be cancer researcher Dr. Laurence Boxer.

Tickets for the event are \$25 with proceeds going to the University of Manitoba's cell biology program, research and toward helping the association provide information about neutropenia. ■

## THE KEYS TO OPPORTUNITY

*"Some people see a closed door and turn away,*

*Others see a closed door, try the knob, if it doesn't open... they turn away.*

*Still others see a closed door, try the knob, if it doesn't open... they find a key. If the key doesn't fit... they turn away.*

*A rare few see a closed door, try the knob, if it doesn't open... they find a key. If the key doesn't fit...*

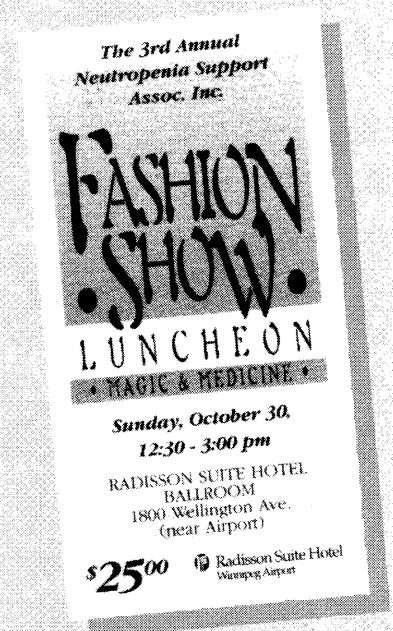
*they try a new one."*

AUTHOR UNKNOWN

*Thank you for always trying!*

*The Neutropenia Support Assoc. Inc.*

Please  
come and  
join us  
October  
30th!



## TICKETS AVAILABLE FROM:

Irene Zakala 668-8779;

Mike Carlson 253-9948;

Brian Gamley 663-6964;

Janis Benzelock 667-0324;

Lorna Stevens 989-5000;

Radisson Suite Hotel 783-1700.

# SCN Registry in Canada

**Re: Canadian SCN disease registry.** Registration is facilitated by the two Canadian registry physician contacts, Dr. Melvin Freedman, Toronto Sick Children's Hospital (ph: 416-813-6152 fax: 416-813-5327), and Dr. Bonnie Cham, Manitoba Cancer Treatment & Research Foundation (Ed. Note: Dr. Bonnie Cham is on maternity leave (It's a boy! Jonathan. Congrats!) until March, so please contact Dr. Freedman until then.)

Registration forms will be provided to the referring physician. Call your physician today to begin this process. Information on reimbursement possibilities will be outlined by Dr. Freedman.



## INFORMATION ORDER FORM

### SEND TO:

### THE NEUTROPENIA SUPPORT ASSOCIATION INC.

P.O. BOX 243, 905 CORYDON AVENUE, WINNIPEG, MANITOBA, CANADA R3M 3S7

TELEPHONE: (IN WINNIPEG) 489-8454 OR (CANADAWIDE) 1-800-663-8876

Please Forward:

- ☐ copies of "Neutropenia – Causes, Consequences and Care" (English)
- ☐ copies of "Neutropenia – Causes, Consequences and Care" (French)
- ☐ copies of the Neutropenia Support Association Newsletter and back issues (as available)
- ☐ copies of Chemotherapy and Neutropenia (English)
- ☐ Video tape — Physician Presentations
- ☐ Video tape — Physician presentations "in layman's terms" and N.S.A.I. general information
- ☐ Update mailing information only

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