



# Neutropenia Support Assoc. Inc.

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Local Winnipeg # 489-8454 Toll Free # 1-800-6-NEUTRO (663-8876)

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## What is Neutropenia ?

The following are excerpts under review from a professionally prepared information booklet we are in the process of developing, copies will be made available and distributed when completed. This Brochure is produced by the Neutropenia Support Association Inc. under a grant from Amgen Canada Inc. We are Thankful for their sponsorship.

Neutropenia is a blood disorder you don't often hear about, but can affect anyone. There are a number of causes. Some people are born with it. Others get it for no known reason, or develop it after a viral infection. In some cases, the cause can be a side effect of a drug, or exposure to certain poisons. And some people get it when treated for cancer with chemotherapy drugs.

Every person at one time or another has been sick with an infection. That's because it's easy for bacteria which cause infections to get inside the body. Healthy people don't often get infections, even though bacteria are all around us; even in the air we breathe.

The body protects itself against the constant risk of infection by making lots of neutrophils. They are your primary defense against infections. You might think of them as the soldiers who fight the bacteria that cause infections.

Neutropenia (NEW TROH PEE NEE AH) exists when the number of neutrophils in the blood falls to a dangerously low level. It's easy to see how not having enough soldiers to battle invading bacteria is an unhealthy situation.

People with neutropenia get infections easily and often. Most of the infections occur in the lungs, mouth and throat, sinuses and skin. Painful mouth ulcers, gum infections, ear infections, and periodical disease are frequent. Severe, life-threatening infections are not uncommon, and often the

patient must be hospitalized.

Your doctor uses blood tests to find out whether you have enough neutrophils.

New drugs have recently become available which stimulate the bone marrow to produce neutrophils, and help restore the body's defense against infection. Through their use, the number of neutrophils in the blood can be kept above the danger level all or most of the time. The less time the neutrophil count is low, then the less of a chance there is of developing fever or infection.

These drugs hold the promise of dramatically improving the lives of patients with neutropenia, lessening the number and severity of neutropenia-related infections and reducing hospitalizations.

## The Support Group

The Neutropenia Support Association Inc., a registered charitable organization, was formed in 1989 to increase awareness and understanding of neutropenia, to provide assistance to patients with neutropenia and their families. They continue to raise money for research and education.

The Neutropenia Support Association has been very effective in providing moral and political support to children and families of children who have Neutropenia. Since Neutropenia also occurs in children and adults receiving chemotherapy for cancer, they have recently been involved in efforts to assist these patients. The net result of this effort is a heightened awareness of Neutropenia and much improved treatment and understanding of this condition. They have been involved with families not only in Manitoba, but across Canada, and the organization has provided a vitally important support network where none existed previously. This is the only such support group in the world.

The Association has assembled an extensive collection of articles on neutropenia and its treatment. As well, a neutropenia information library has been established at the Health Sciences Centre/Children's Hospital in Winnipeg. With these resources, the Association is able to answer

many questions from patients, their families and the Medical community. The Association also publishes a regular newsletter.

Regardless of the type of neutropenia or treatment being received, there are several tips for patients to help lessen their chance of developing an infection. Since each person's needs may vary, it is important to consult with your doctor. Other members of the healthcare team also have an important role to play, including nurses, social workers and nutritionists/dietitians. Patients with neutropenia are recommended to take the following precautions.

- Wash hands frequently with an antibacterial soap.
- Avoid people with colds, flu or any type of infection or open sore.
- Avoid enclosed public areas where there are crowds of people.
- Be careful with personal grooming e.g., cutting nails.
- Use an electric razor instead of a blade.
- Use gloves when doing any physical work, avoid damaging the skin,
- Avoid dental work or cleaning when neutrophil counts are low.
- Always use a soft tooth brush.
- Make sure food is adequately cooked.
- Avoid constipation and follow a diet with plenty of fiber.
- Never use rectal thermometers.
- Avoid contact with animal stool or urine.
- Exercise regularly, and get plenty of rest.
- A proper diet is important, especially one that's low in sugar.
- Have everyone remove their street shoes when entering your house.
- Clean the furnace and ducts once or twice a year as required.
- The patient's outerwear should be dry-cleaned regularly.
- Clean children's toys periodically with a hospital-grade antibacterial soap. Antibiotic treatment is also recommended before and after any dental work or cleaning.
- Learn to manage stress. The Social worker can provide helpful tips.

Experience in treating neutropenia using granulocyte colony-stimulating factors suggests that children and adults can have a normal life with less need for precaution once their low neutrophil counts return to and remain normal.

*We are pleased to announce The 2nd Annual Neutropenia Support Assoc. Inc.*

## **FASHION SHOW LUNCHEON**

Sunday April 25th, 12:30 - 2:30 pm

**Radisson Suite Hotel Ballroom**

1800 Wellington Ave. (near airport)

**Returning After Rave Reviews !**

## **THE CALENDAR FIREFIGHTERS**

*Also Featuring :*

- \* **Danali** men's wear
- \* **Peepers** "Fun in the SUN Fashions"
- \* **Just Maggie's**
- \* **Addition - elle**
- \* **Teri's Furs**
- \* **Tom Q Milroy** " The Morning Man " Q 94 FM

*Guest Speaker*

Internationally Renowned Haematologist Oncologist

\* **Dr. Nathan Kobrinsky**

Returning to Winnipeg and reporting on Recent developments

\* **Fabulous Gourmet Luncheon**

\* **Exciting Door Prizes :**

- Courtesy of CJOB 68/97.5 FM
- Radisson Romantic Adventure
- Shorney's Optical
- 42nd St. Hair Co. & Golden Tan Sun Tan Studios
- Silent Sam Vodka
- Ready Foods Limited
- Mackie By Riviera Concepts
- Ormiston's Florist
- DELBRO Real Estate
- S.C. Johnson Homecare Products
- Eyelet Dove


and much much more !!

**Tickets Available :**

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

(major credit cards accepted)

**\$25<sup>00</sup>**

 **Radisson Suite Hotel**  
Winnipeg Airport

Proceeds to U of M Neutrophil Lab

Any contribution you could make for door prizes or a Chinese Auction would be most appreciated.

We will have a "Donators Board" in the ballroom, media coverage is expected and we will list your contribution on the program agenda.

Please call us and we will make arrangements to pick up your donation.

Lorna Stevens	989-5000 (Work)
Lorna & Lorne Stevens	489-2487 (Home)
Jim or Janis Benzelock	667-0324 (Home)
Brian Gamley	663-6964 (Home)
Mike Carlson	253-9948 (Home)

## **News Letter goes International**

Sent multiple copies to the U.S., U.K., Europe and Australia.

Copies given to biopharmaceutical specialists for distribution at Oncology centres.

Copies given to Cancer Drug Information centres which focuses on patient information.

## **We Now have a Toll Free Number**

The following is a Press Release issued Canada wide to announce the toll free number.

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Infection can be a matter of life and death for patients with neutropenia. Neutropenia is a potentially life-threatening condition resulting from a dangerously low level of white blood cells called neutrophils, which comprise about 70 per cent of white blood cells that fight Infection. Neutropenia occurs most frequently in cancer patients undergoing chemotherapy. Chemotherapy attacks both healthy and cancerous cells, including neutrophils, the important white blood cells that are the body's primary defense against Infection.

"Many patients undergoing chemotherapy are left with a dangerously low level of neutrophils," says Dr. Jon Gerrard, a Winnipeg pediatric oncologist "Their bodies can't combat invading bacteria and fungi, and a potentially life-threatening condition known as neutropenia results."

Dr. Gerrard, a neutropenia specialist, says infections are one of the most common and the most serious side effects for the 50,000 Canadians who undergo chemotherapy annually.

"Patients with neutropenia are susceptible to severe, life-threatening infections. Often, further chemotherapy must be delayed or reduced to allow time to rebuild the body's neutrophil supply," Dr. Gerrard says. Even with good clinical management of neutropenia, including hospitalization of the patient and intravenous antibiotics to treat the suspected infection, death from infection can

occur.

While neutropenia occurs most frequently in cancer chemotherapy patients, it can also occur as the result of a genetic defect. "Patients with congenital neutropenia battle infection throughout their lives because their bodies are unable to combat bacteria," notes Dr. Gerrard.

Chronic congenital neutropenia is most often diagnosed in children. Because the body cannot produce enough neutrophils to fight infection, a small scrape can lead to a blood infection, a cold can easily develop into pneumonia and painful mouth sores can be part of daily life. Two-year-old Allison Riley was diagnosed with neutropenia at birth. The Waterloo, Ontario toddler had endured recurring mouth ulcers, swollen and bleeding gums, and repeated hospitalization.

"Infection can begin easily from something as small as a scratch and lead to serious problems," says Cathy Riley, Allison's mother. "I have to be careful where she goes and who she is in contact with and take every precaution I can to decrease the transmission of germs."

"Congenital neutropenia is very serious because over time, the micro-organisms in the patient's body may become resistant to antibiotics," says Dr. Gerrard. "Secondary fungal infection can become a severe problem, putting the patient's life at risk."

The Neutropenia Support Association, based In Winnipeg, is the only known group in the world devoted to providing support and information to neutropenia patients and their families. The group is also involved in fund-raising, to support on going research into cell biology.

"We provide information both to the public and the medical community," says Lorna Stevens, founder of the neutropenia Support Association. "Neutropenia is a disease that is not well known, and effective treatment has only been recently identified. The more information we can provide to physicians, nurses and pharmacists about new treatment options, the better informed everyone will be."

Study into the science of genetic engineering has recently led to the discovery of one of the newest treatments for neutropenia.

In the 1980s, scientists began studying a family of hormones that regulate the production of blood cells. Through DNA technology (cloning), they were able to produce these hormones, known as colony stimulating factors (CSF), in sufficient quantities to be used clinically.

Colony stimulating factors stimulate bone marrow to produce more blood cells. One of the most important colony stimulating factors is G-CSF, which stimulates bone marrow to produce infection-fighting neutrophils. For patients with neutropenia, the drug is a lifeline.

In clinical trials G-CSF was shown to be effective in

reducing by 50 per cent the incidence of potentially life-threatening infections in cancer patients treated with chemotherapy. More recent trials carried out at the University of Michigan Cancer Centre have also found the drug to be nearly 100 per cent effective in patients suffering from the congenital form of neutropenia. The results of a study involving 130 patients, mostly children under 10 and some adults, were described as "phenomenal" by Dr. Laurence Boxer, who conducted the investigation. "Without G-CSF many of the children in the study would have died from overwhelming infection," he noted. "It's not often in medicine that you can completely turn around a patient's life."

Now trials are also underway into other blood disorders and cancers where colony stimulating factors may play a role in treatment.

Meanwhile, the Neutropenia Support Association continues to promote awareness of neutropenia in Canada, and collect new case studies and literature pertaining to the disease. They've developed a neutropenia "library," which is housed at the Children's Hospital of the Health Sciences Centre in Winnipeg, they also offer patient support and information through a newsletter and toll free help-line number, **1-800-6-NEUTRO (1-800-663-8876)**.

"Many of our members came to realize that they or a loved one was suffering from neutropenia by hearing about it in the media and going to their doctor for confirmation," says Stevens. "Our hope is that we can use the information library that we've established to pass the information along to Canadians right across the country."

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## **Lorna Receives Canada 125 Anniversary Medal**

On December 12th, 1992, Lorna Stevens, a DELBRO, Real Estate Agent for the Corydon office, received a Canada 125 medal to honor her significant contributions to her community and to Canadian society as a whole.

Lorna earned her prestigious award for her efforts, in founding the Neutropenia Support Association Inc., a Canadian charity and the only such support group in the world that promotes awareness of congenital neutropenia and rare blood disorders and provides patient support and information.

Lorna, who's own child suffers from neutropenia, started the Neutropenia Support Association during "extra time" while on her 1989-90 maternity break. By rallying the support and interest of parents of neutropenia patients and other interested parties, the Association, which was

registered as a Canadian charity January 1990, is now achieving international recognition.

Dr. Jon Gerrard, a Winnipeg pediatric oncologist with whom Lorna works closely, describes Neutropenia as a potentially life-threatening condition resulting from a dangerously low level of white blood cells called neutrophils, which comprise about 70 per cent of the white blood cells that fight infection.

While neutropenia occurs most frequently in cancer chemotherapy patients (chemotherapy attacks both healthy and cancerous cells, including neutrophils), it can also occur as the result of a genetic defect. Dr. Gerrard, explains that patients with congenital neutropenia battle infection throughout their lives because their bodies are unable to combat bacteria. Lorna recently received additional appreciation by being invited as a guest speaker to the National Children's Cancer Conference to be held July 30th in Kingston, Ontario. Congratulations, Lorna.

## **Comments From Lorna Stevens**

This recognition is appreciated and in its way, also helps to promote awareness of Neutropenia. This is an award to be shared with all the Winnipeg families, the medical community that advise and help us, and the public at large supporting and encouraging our endeavors.

Our executive:

Many of our members are developing skills and sharing abilities to aid our growth. Brian Gamley, our Vice-President, through Toastmasters is honing his public speaking skills, has been a very successful fund-raising leader and is available for Speaking engagements. He can be contacted at 663 6964. He assists with the Chinese Auction and Ticket sales for our major yearly fund-raiser. Brian has neutropenia, is on GCSF and has two boys diagnosed with neutropenia.

Mike Carlson, our Newsletter editor spends many hours on the computer setting up the Newsletters. He assists with the treasury responsibilities, ticket sales and Chinese Auction section of the Fashion Show Luncheon. He has cyclic neutropenia presently managed on antibiotics.

Janis and Jim Benzelock are very active with all aspects of the Fashion Show Luncheon our major Research Fund-raiser, from ticket sales and media promotion to feature preparation. Janis will assist with the development of the Ontario Neutropenia Support Association Incorporation July 30 -August 1, 1993 in Kingston, Ontario. Their son Jamie is part of the Ann Arbor, Michigan, Amgen Study.

Lorne Stevens is a full time respiratory therapy student for 3 years, so I have taken on extra duties until he has completed his studies.

We have many other families giving of their time and

energy as their circumstances permit. We all share common goals and this very strong desire to promote awareness, educate, support research and be advocates for families and all those needing our help.

## **Thanks for Your Support**

We have been chosen by the Worthy Matron of Jubilee Chapter #27 Order of the Eastern Star for her Special Project of 1993. She and her husband who is the Worthy Patron of this Chapter will be attending our fashion show and their donation will be presented at this time.

We are Truly grateful for this significant honor and support.

We again received a most generous donation from the Lion's Club Alexander Manitoba. Their generous support helps us to carry on our activities.

We are grateful to the many and generous "In Memory of Brin Brown " donations our charity received. Our sympathy is extended to Lorna Stevens and family.

## **Dr. Jon Gerrard Receives Researcher Award**

The Children's Hospital Research Foundation 11th annual Teddy Awards April 18th, 1993. Dr. Jon Gerrard is receiving the Researcher Award. Internationally known for his research into blood disorders and cancer. He served on the Foundation's executive and chaired the Foundation's Medical Advisory Committee for over 7 years. Due to his vision and foresight the Foundation used its growing resources to build up teams of Top Notch medical researchers in Manitoba. Dr. Gerrard, Sincere Congratulations from all of us!



***Dr. Jon Gerrard***

## **Comments from Dr. Jon Gerrard**

Neutropenia occurs on an inherited basis in a relatively small number of children. For these children, however, the results of this condition are major problems with infections. These children have frequent fevers, mouth sores, ear infections, pneumonias and sometimes rectal sores and abscesses as well as other infectious problems. They frequently miss significant amounts of school and are unable to participate fully in sports and other activities. Over the last several years a drug has been developed which has been remarkably successful in treating many of these children.

The Neutropenia Support Association has been very effective in providing moral and political support to Children and families of children who have Neutropenia. Since Neutropenia also occurs in children and adults receiving chemotherapy for cancer, the Association has recently been involved in efforts to assist these patients. The net result of this efforts a heightened awareness of Neutropenia and much improved treatment and understanding of this condition. The Association has also been involved with families not only in Manitoba, but across Canada, and the organization has provided a vitally important support network where none existed previously.

## **Thanks Dr. Gerrard**

Dr. Jon Gerrard has helped our association immensely. We are truly Thankful for his special interest and assistance.

## **Dr. Bonnie Cham also an Award Recipient**

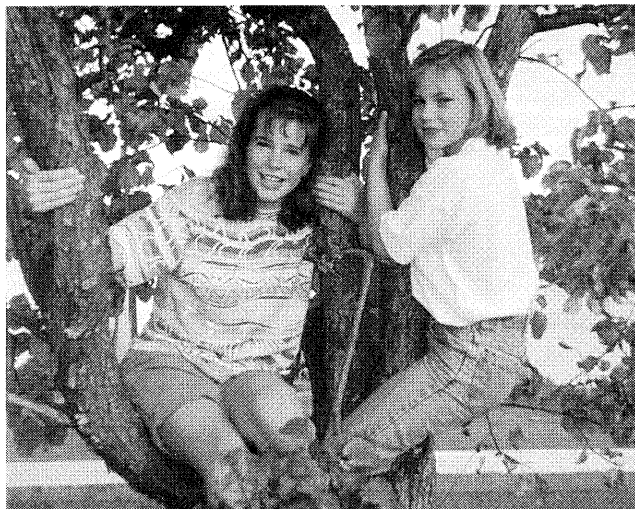


## ***Dr. Bonnie Cham***

The Children's Hospital Research Foundation awarded five major annual personnel awards which will support physician/researchers at Children's Hospital who are investigating a wide range of childhood diseases.

Dr. Bonnie Cham is the recipient of the Foundation's three-year scholarship. This will enable her to continue her studies of neutrophils, white blood cells which search out infections and kill bacteria. Neutrophils are particularly important to children with cancer because chemotherapy can decrease the number of neutrophils and lead to infections.

### **Pretty Picture not always Picture of Health**



*Cousins Carla Warford and Krista Cooper look like pictures of health, but pictures are not always the way they appear. Thirteen-year old Krista suffers from Neutropenia*

The following article was written by Karen Parmiter and was a special to the Advertiser, Newfoundland

Both of these girls look healthy and strong; however for years, one of them has faced one climb after another, struggling with a rare blood disorder. Krista Cooper of Point Leamington has Neutropenia. She is the first person in Newfoundland to be diagnosed with the disease. Neutropenia prevents the production of neutrophils, white blood fighter cells which combat bacterial infections.

Krista's problems started when she was two weeks old. Now 13, she had an infection in her umbilical cord. "We almost lost her," said her mother, Diane.

Since then, it's been one infection after another her lungs, throat, mouth, ears, and so on."

Krista has always had a constant sore throat and gums. A common cold could turn to pneumonia in a matter of hours. A mild fever could reach convulsion stages in a short time. A small splinter could infect her arm to the elbow within an hour. Krista's energy levels have been lower than average for a child her age.

Although Krista's is the only known case of its kind in Newfoundland, there could be others on the island and throughout Canada. The Neutropenia Support Group in Winnipeg reports that 28 known cases have been discovered so far, ranging in age from 24 months to 64 years. The

degree to which each individual is affected varies, and some patients have died as a result of the disease.

In a healthy person, when an infection occurs, over 5,000 neutrophils double themselves to engulf the infected area. In Krista's case, her neutrophil count has always been less than 500. Responding to any treatment always took eight to 12 days.

"For years, we lived in a nightmare," said John, Krista's dad. "We kept our vehicles full of gas and parked by the door, in fear of having to rush Krista to the hospital, 45 minutes away. We were on alert all hours of the night."

In 1992, a drug called Neupogen was approved for use in Canada. Neupogen reduces the chance of infection by 50 per cent. The same day the drug was approved, it was flown to St. John's for Krista. She underwent an eight day trial, supervised and documented by Dr. Ingram, at the Janeway Children's Hospital. "The results were phenomenal," said Mrs. Cooper. "For the first time in her life, Krista lived free of pain."

The Coopers felt Neupogen was a miracle drug, and wanted to put Krista on the drug right away. But there were financial complications. The drug would cost them \$20,000 a year, for the rest of Krista's life. John is a seasonal worker and Diane is a part time hair dresser. Putting aside \$20,000 a year from their income would be next to impossible.

But the Coopers didn't stop there. With the assistance of their doctors, the Department of Health, and other professionals, mountains began to move. In October, the Coopers received a phone call. The cost of Neupogen had been approved for Krista! It was like a dream come true.

On Nov. 30, Krista received her first daily injection of Neupogen, administered by her mom and dad.

"We're happy that Krista can finally lead a normal life," said Mrs. Cooper. "She's doing so much better now to date, she hasn't had problems with sickness of any kind."

Although there are no side effects of the drug, the Coopers are concerned about what will happen to Krista's neutrophil count if an infection does occur.

"Right now, the main thing is Krista has neutrophils," says Mr. Cooper. "We'll just have to keep praying, and hope for the best."

The Coopers are thankful to Dr. Ingram, Dr. Kelland, Krista's dentist Dr. Musseau, Lorna Stevens of the Neutropenia Support Group, Exploits MHA Roger Grimes, and their family and friends who's consistent efforts helped to obtain Neupogen for Krista."... "But most of all," says Mrs. Cooper, "we have to thank God."

The Coopers are heading up a local Neutropenia Support Group for Newfoundland. If you have any questions, concerns, or would like more information on Neutropenia, call (709) 484-3592.

Karen Parmiter is a freelance broadcaster and writer.

We received a nice letter of thanks from the Cooper Family in Newfoundland. This poem was enclosed for us to share with our readership. This poem is featured at their medical centre

## Words of Wisdom

And a woman who held a babe against her bosom said,

### "SPEAK TO US OF CHILDREN"

Your children are not your children,  
They are the sons and daughters of life longing  
for itself.  
They come through you but not from you,  
And though they are with you, yet they belong  
not to you.  
You may give them love, but not their thoughts  
For they have their own thoughts.  
You may house their bodies but not their souls  
For their souls may dwell in the house of  
tomorrow  
Which you cannot visit even in your dreams.  
You may strive to be like them,  
But seek not to make them like you.  
For life goes not backwards  
Nor tarries with yesterday.  
You are the bows from which your children  
living arrows are sent forth.  
The Archer sees the mark upon the path of the  
infinite.  
And he bestows you with his might  
That his arrows might go swift and far.  
Let your bending in the Archers hand be for  
gladness.  
For even as he loses the arrow that flies  
So he loves also the bow that is stable.

## Patience and Perseverance Pays off

A letter from the Cox Family, Everett, Ontario.

I'm just jotting down a few of the problems we have had in trying to get the ball rolling in the right direction at this end. When the original application was submitted November 23, 1992 there was absolutely no direction given to me in regard to what would happen next or what the procedure would be, except that the process would take 8-10 weeks to process. So we waited. After being very patient and giving everybody the benefit of the doubt that they are efficient, I finally called our Doctor's office to see if there was any word. The Doctor's office was told that the documents

would go no further unless a drug card was issued. No further instruction - it was only because of our experience with the children that I know where to start. I started with Handicapped Children's Benefit Social Worker and asked what the adult equivalent was. When I called, the service (now I cannot remember) said that if he was employed and not mentally handicapped, no way.

I called my pharmacist to ask where drug cards came from -he said welfare. Well, no less than 10-15 calls later and after explaining our situation and the costs, I finally found somebody who seemed to understand the dilemma and was willing to do something. Coincidence had it that 2 days later was the social workers day in my area, and after filling out the application for Welfare and being "audited" for every cent we and the children have, and the seriousness of the problem being explained, the application was issued as a "rush". A Doctor's certificate had to accompany this application along with a letter from the pharmacist itemizing the daily dose cost. That also initiated calls to the Doctors office to have dosage estimates relayed to the pharmacy.

Our social worker was wonderful and took in the application on her day off for special "Rush" approval after I faxed her the Doctors and Pharmacists documents and after approximately a week, called to say it was out of their area but would issue an emergency card month by month - until the Ministry had set up what exactly had to be set up and a permanent card could be issued. Approval numbers were telephoned to our drug store so the drug could be ordered.

Once I had these numbers or knowledge that they existed, I called (on approximately January 25) Julie Faubert to tell her we had a drug card and who to talk to in order to get numbers, etc. and that she could now process the application. she told me they had gone ahead and processed the application anyway, and the letter would be sent to our District office that afternoon so we could get everything going. I called you and you got the same information. All I had left was to see the Doctor for final instruction and to pick up the prescription and approval letter for the Pharmacist to use for billing purposes. We eagerly awaited the appointment. We had to hire my father to run the shop all day, pay for the gas, parking, lunch - only to get to the office to find that the letter had arrived a couple of days earlier dated December 21, 1992. This was February 9, 1993 and it was a denial letter with option to appeal. Totally infuriated, I started calling Julie Faubert, her supervisor Mr Inoue and Kathleen Jacobs who is a trouble shooter, were either off for the day, totally knowledgeable or Kathleen was in a meeting. Then I called you. After spending almost \$200.00 just to go to Toronto for the appointment, we were hostile to say the least, that somebody at whatever level had



once again managed to prolong this application. Typical as it is in the Government that the left doesn't know what the right is doing and they are all blaming each other for lost and misplaced documents all wasting both theirs and our time while we processed the appeal.

Not only is there serious problems all the way up the line to what services are implemented, I have spent without a doubt, 15 hours on the phone trying to get things on track, checking up on people to make sure they have done what I wanted or what they said they would do, only to be deceived and lied to. People do not take this disorder or the element of risk seriously when handling these requests. And if during all this shamble, Michael succumbed to something the only people who care are you, and I, as it will just be less work for them. Things would change fast if it was for their own loved ones.

Along with our data, we will resubmit all the information previously provided already including extra documentation.

I honestly don't know what we would have done without you or the support group as you are already a pillar of strength and always ready to act on our behalf when we cannot find the strength to go any further. We respect your advice to hold off on media coverage for the time being, but when you are dealing with a life and death situation, time is of the essence and patience is for the healthy. Thank you again so very much for your guidance, understanding and total commitment to this worthy cause. You and the support group truly are saving lives. If Neutropenics had to do it on their own, they would probably give up before they got results.

This brief outline of what I've gone through is so others can start at the right place and finish with a positive outcome.

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The Neutropenia Support Assoc. Inc. was asked in the 10th week of their frustration to assist with the application process.

## **Letter from Michael Cox**

I am writing this brief outline of my medical ordeal as very few people seem to truly understand the difficulties and hardships caused by this horrific blood disorder. I was diagnosed at age two and was not expected to live past the age of five. I have been seen by numerous general practitioners, interns, surgeons, dermatologists, immunologists, haematologists, dentists and denturists. Fever, infections, pain and discomfort are an every day part of my life, infections so severe they would have to be operated on, ear infection after ear infection resulting in a mastoidotomy operation. Bleeding, sore and swollen infected

gums eventually led to the removal of all of my teeth. Denture rub causes discomfort and leads to bacterial and fungal infection which causes difficulties eating which leads to dangerous weight loss. Major skin infections can result from paper cuts. These infections can lead to blood poisoning which, in itself, has numerous complications. Breathing is life threatening because of airborne viruses.

During school years, sick days were many and the frequency of illness increased due to the increase in human contact and exposure. I was unable to complete secondary school because of frequent lengthy illnesses and not having the energy or ability to keep up. Warm weather caused sweating and led to infections. Cold led to pneumonia or plaurisy which caused massive scarring on both of my lungs. Pneumonia occurred as frequently as twelve episodes in a year. Painful mouth sores developed one to ten at a time. Infections can develop at blood test sites. My entire body is scarred by boils and skin infections. My spleen is frequently enlarged and is a source of pain and constant discomfort. I have endured testing, experimentation and operations including the removal of a gangrenous bowel. I live life day to day with dread and in fear of what will happen next. I had resigned myself to the fact that I would never live free of pain, that I will always have a severe potential for numerous hospital admissions and frequent life threatening, overwhelming infections and to the fact that things will only get worse. My condition has been reviewed throughout my life by various doctors and up to now no treatment has been of value.

Stress is tremendous as each day I survive is truly miraculous. Any jobs I did manage to obtain were also a source of stress and resentment as I was either let go because of some drummed up excuse or was constantly passed by for promotion. Up until July 1992, I had been unemployed for more than a two and a half year stretch, at which time the only route to ensure permanent employment and a modest income before taxes was to purchase my father's business.

We rely very heavily on family and mostly on my father (who has just been diagnosed with cancer) to be available any day to run the shop for stretches for sometimes weeks at a time while I am sick. If my father can no longer be available at any time to aid me when I am ill and I do not receive financial assistance for the drug Neupogen, I will, without a doubt, lose my business and be forced to consider uprooting my wife and children and moving to a province where the drug is covered for my sons and I and where I can obtain gainful employment to support my family.

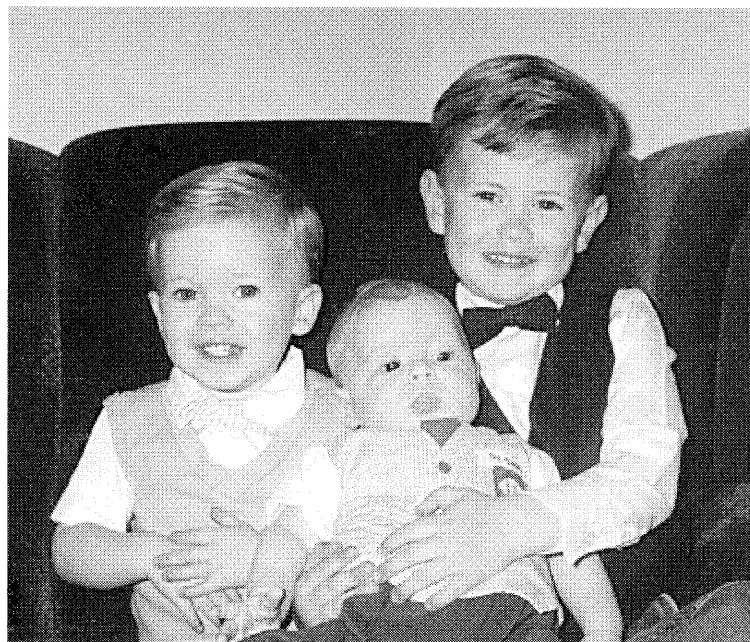
Affected individuals can lead productive lives and cost analysis studies have shown that such therapy is appropriate not only from the emotional and medical point of view but also from a financial point of view as well.



This illness has caused myself and my family great tragedy, sadness and sorrow beyond explanation. I look forward to a relatively healthy lifestyle, one that most people take for granted. Neupogen is a life saving drug for my sons and I and a few other Canadians who have to endure Neutropenia and all the hardships, pain and suffering that it brings with it. Please make Neupogen financially available for those of us who so desperately need it.

**The Good News..** 9:23 am Feb. 22, 1993. Michael Cox received "The Go Ahead" on coverage for treatment. This treatment commences the first week of March 1993.

Good Luck Michael !



*Picture of Travis and Spencer Cox Both granted coverage for G-CSF, Both doing well.*

## **Two of the Letters sent in support of the Michael Cox Application**

### **Excerpts of first letter. From Brian Gamley**

It is with the care and consideration of many groups, Doctors and individuals that this second chance has been given to me. It's now my turn to help someone else and I can hopefully help many others. Only a fellow sufferer can understand what he's gone through and will continue to go through. Only I can understand the frustration of knowing there's a possible solution in a revolutionary drug that simply costs too much for the average man.

I was born and raised in Canada and in my many trips to the United States have always been proud to say I'm a Canadian. It used to be that as a Canadian you could always be told by visitors, "how lucky we were to have the medicare system that we have". From all the shuffling I have been through and I know others are going through right

now, I think it's time that the Government of Canada, be it either Provincial or Federal, step forward and show that we do indeed have the best medicare system going.

In closing, I would like to offer my services to attend or answer any questions regarding the life threatening disease, Neutropenia, the new drug neupogen, or the, in my opinion, the ridiculous alternative, the life long use of prednisone. This would be from a first hand sufferer who has been through the highs and lows of not only dealing with the disease but all the other obstacles one must face.

Brian will be available for Speaking engagements. He is a guest speaker on April 21, 1993, in Minnedosa Manitoba at the Central Regional Health Auxiliaries.

### **Second letter. From Bill Plomp, Alberta**

My name is Bill Plomp. I am a 52-year old Police Officer in Lethbridge, Alberta.

In June of 1986, I began to feel the effects of ill health which, after multiples of processes, procedures, hospitals and Doctors was finally diagnosed by the Mayo Clinic, Rochester, Minnesota as "Auto-immune Neutropenia". Prior to this time I was, what I believed to be, in excellent health.

By now my deteriorating health had resulted in the surgical removal of the lower lobe of my left lung. I continued on a sharp "down hill" decline and in December of 1986 was put on a steroid treatment program which did improve my health, but not without a price.

The day to day struggles of coping with the illnesses relating to neutropenia necessitated the involvement of Doctors, hospitals, procedures far to numerous to recall. The continuing use of antibiotics to ward off and fight infections also did not come without a price. A heart blockage, as a result of medications I believe, the rising blood pressure, etc. etc., one could go on as to the problems caused by or associated to neutropenia regardless of its origin. However, let me say that the big factors in overall health, also a factor brought on by neutropenia is the psychological stress, that constant worry of what will be next and when, takes a drastic toll on the quality of life as well as the fact of being constantly sick.

Loss of work, about 18 months since August, 1986 is also a "side effect" of neutropenia which is in itself very destructive.

Then NEUPOGEN. September 18, 1992 I took my first injection of Neupogen and in six days of daily injection, my absolute neutrophil count went from 51 to 9600—WOW—A Miracle????? I believe so, but best of all my general health followed the same sharp upward climb.

No more steroids, no more antibiotics, NO MORE SICK, NO MORE WORRY, no more neutropenia induced

stress. When judged on a scale of 1-10, my quality of life now sits at 9.999 compared to a 2 four short months ago.

NEUPOGEN is a powerful drug in more ways than one. Realizing that the individual body responds differently in all cases, I do wish to point out that in starting at 1.6ml of Neupogen per day, I am now reduced to a 1.6ml vial of Neupogen once every five days. I repeat, a miracle, Neupogen has given me a new lease on life, a new hope for a tomorrow to enjoy.

What more can I say. I am now and will forever to indebted to and thankful to all those who assisted me in my bid for Neupogen, for that second chance. As such, I too wish to share with and assist any fellow sufferer of neutropenia in any way which I can, because, I do understand, I have been there.

My thanks to the Alberta Government for understanding, for caring about me, to make NEUPOGEN not only available but financially accessible to me.



*Marie & Bill Plomp with Lorna Stevens, after the Alberta Health Presentation*

## **Winnipeg Welcomes Dr. David Dale**

The following is an article from the Winnipeg Free Press October 30th, 1992, By Alexandra Paul

### **What Helps him also Hurts**

Potentially life-threatening side-effects of chemotherapy are close companions for six-year old cancer patient Brett Cook. "He probably knows more about doctors, nurses and hospitals than he does about hockey or swimming," his father Darrin Cook said.

Cook, stricken with a rare form of cancer known as Burkitt's Lymphoma, relies on the power of chemotherapy to stay alive.

But more than once he's been brought virtually to death's door by the same drugs.

"The first day they gave him chemotherapy it actually

stopped his heart," Cook recalls.

But a more insidious side-effect is a condition known as neutropenia, a blood disorder caused by the destruction of neutrophils, infection-fighting white blood cells made in the bone marrow.

Neutropenia affects as many as one in three chemotherapy patients and one in a million others born with congenital blood disorders.

Eleven of the identified 28 patients in Canada whose children suffer chronic neutropenia live in Manitoba.

But Cook says doctors tell him Brett's bouts are among the worse they've seen.

"Over the past year, he would be treated once every four weeks with chemotherapy and he would spend up to 10 days in hospital every month," Cook said.

Doctors say they can fight neutropenia infections with antibiotics but the condition also acts as a major obstacle to timely cancer treatment, often delaying the frequency of chemotherapy.

"We have a child for instance in the Intensive Care Unit at the moment who has a severe infection from a low neutrophil count," Health Sciences Centre specialist Dr. Jon Gerrard said.

Not a month goes by without at least one child in hospital fighting infection related to chemotherapy side-effects, he said.

Dr. David Dale, former U.S. National Institutes of Health Infectious Disease Specialist, said there's a promising new drug called Neupogen that doctors can use to lessen the severity of neutropenia-related infection and the lengthy hospital stays. "We can cite instances where this drug saves lives," said Dale, in Winnipeg this week to brief doctors on the condition, its causes and treatments.

Cook said the drug pushed his son's white blood cell count up to normal in three days.

Many of us gained immeasurably from "A Day with Dr. David Dale" October 29th, 1992 in Winnipeg. This session was Taped and copies are available.

Our Taped Topics:

1. Growth Factors in the Treatment of Chemo-Therapy Induced Neutropenia.
2. Neutropenia - It's Causes, Consequences and Treatments

### **A Letter of Thanks from Dr. David Dale**

Thank you very much for your warm hospitality and the interesting evening with the Neutropenia Support Association. I was most impressed by all that you have accomplished and the interest and enthusiasm of the group. It was a very stimulating evening for me.

I appreciate also so very much the beautiful gardening

book you gave me. I have already read most of it and am looking forward to using some of the ideas I found there for my vegetable and flower gardening adventures next year. The book is beautiful and I appreciate it and all that it means so very much.



*Dr. David Dale*

*Top Right Picture:*

*Our President: Lorne Stevens*

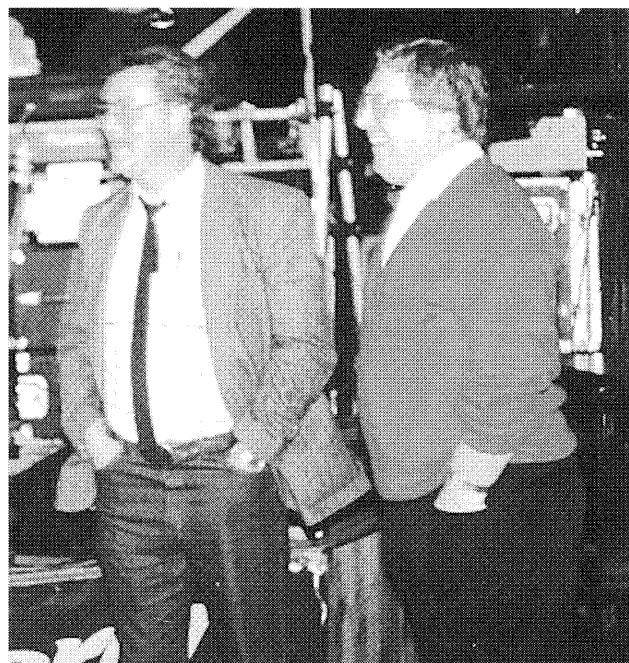
*Bottom Right:*

*Our Talented Vice-President:*

*Brian Gamley*

*along with one of our Directors:*

*Jim Benzelock*



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