



Neutropenia Support Assoc. Inc.

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UNITED STATES "KICK-OFF"!!

Amgen Helps Create SCN Support Group

By David Kaye, Thousand Oaks

Most of us are familiar with global patient organizations such as the Leukemia Foundation and the American Cancer Society, but on a cool weekend in January, four Amgen employees had the unique opportunity of helping to create a support network for people who have a disease with which fewer than a thousand patients have been diagnosed worldwide.

The National Neutropenia Network (NNN) was created on January 9th by nine people who have family members with severe chronic neutropenia (SCN), along with two Neupogen (Filgrastim) clinical investigators, Dr. Laurence Boxer, Dr. David Dale and Lorna Stevens (Neutropenia Support Assoc. Inc. Canada) to "promote awareness, education and research about SCN and provide a support system for patients with neutropenia and their families through a national resource network".

The group named Robin Murphy of San Angelo, Texas, as its first U.S. leader. Robin's daughter Brittany, 8, was diagnosed with SCN when she was three months old and has been receiving Neupogen for five years.

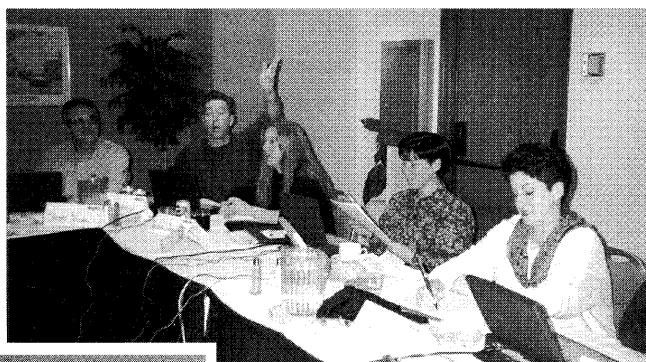
"The ideas and energy displayed over the week-end are the real fuel that will make the National Neutropenia Network a success in the future," commented Neupogen Product Manager Dave Boyden. "Amgen was pleased to sponsor the meeting and bring together a group of families that have lived for many years with SCN. We hope this meeting will serve as a useful kickoff to

the creation of a bona fide network of families and patients impacted by this heart-breaking disorder."

Participants in addition to Dave and myself, were Linda Erlich,



(above) Beth Jacobs, Robin Murphy, Sonja Cary, Lee Reeves, Silke Deeley, Alexander Johns



(left) Edward Nicola, Stephen Johnson, Barbara Johnson, Beth Jacobs, Robin Murphy



Dr. Boxer, Garry Ann Nicola

Clinical Support Specialist in Neupogen Marketing, and Carol Fier, Project Manager, International Clinical Safety, and a professional facilitator Alexander Johns, Quality Directions Inc.

SCN is a rare, potentially life-threatening blood disorder in which the body fails to manufacture sufficient infection-fighting white blood cells or neutrophils. Before Neupogen, people with the disorder typically were treated chronically with antibiotics, often requiring hospitalization. Patients treated with Neupogen showed a reduction in both the number and length of infections, as well as a reduction in antibiotic use. Prior to Neupogen, no predictably effective treatment was available.

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"This is truly remarkable," said Lee Reeves of Pinckney, Michigan, of the meeting. "We have gone from talking about issues of illness to issues of wellness." Lee's daughter, Leta, now 17, was diagnosed with SCN shortly after birth.

The NNN has identified the following as priority initiatives for its first year:

- Newsletter
- Hotline
- SCN management handbook
- Brochure
- Patient Directory
- A "buddy system" to provide individual support
- Investigator directory
- Publicity packet ■

Presentation – L.A. Meeting Jan. 8, 1994

By Lorna Stevens, Winnipeg, Manitoba, Canada

Our group's members send their best wishes. They remember the exciting beginnings of our support group. One specific comment was, "Don't be overwhelmed by all you hear, we learned to walk before we ran, and took small steps along the way. Over time, it's amazing how much you will all accomplish."

How did we start? We found ourselves in very similar circumstances to what you are in right now. We were brought together by a physician, all strangers with the common link being our children's neutropenia, and we were very excited with the opportunity to speak with others who understood our experiences. We were strongly encouraged to create a formal organization.

The advantages have been:

- 1) Public Awareness
- 2) Media Interest (radio, T.V. and newspaper)
- 3) Credibility in areas of fundraising

In the beginning, our main objective was to promote the awareness of SCN and accelerate in any way possible the approval process of Neupogen since some of our members were participating in the same study as yourselves. Our first radio and national T.V. coverage pertaining to this was in November of 1989. There has been ongoing media interest ever since. This helps to identify more and more families.

When Neupogen was approved in Canada for cancer patients in 1992, we shifted some of our attention to helping chemotherapy induced neutropenia patients obtain information. This introduced us to other support groups such as Candlelighters and Jeffrey's Folks Support Groups for families of children touched with cancer. We continue to gain leadership direction and encouragement from these associations.

On October 28th, 1993, the H.P.B. Canada approved Neupogen for long term use in the treatment of patients with SCN (cyclic, congenital, idiopathic).

The focus on SCN awareness continues through various presentations in different provinces helping patients with severe chronic neutropenia access treatment and financial coverage. We also do our best to inform governments, medical support staff, and the general public through presentations, and speaking engagements.

We further inform by way of hospital/patient/physician information libraries, our periodic newsletters, Canada wide toll-free number,

and our information booklet, "Neutropenia: Causes, Consequences, and Care".

Our second booklet, "Chemotherapy and Neutropenia" will be available in March, 1994.

Our newsletter keeps us informed coast to coast from British Columbia to Newfoundland. Also, International distribution is progressing as each country's support group develops a newsletter that will focus on their own issues and needs.

Our editor, Michael Carlson has offered to share his newsletter expertise. Mike came to us after hearing us on a radio broadcast and has recently started on Neupogen. Mike and his Mom are outstanding volunteers.

Our support group continues to grow with each media story. I can't emphasize enough how important the media has been. With each and every story presented, we discover new families, or I should say; they discover us.

For example, a newspaper article December/93 (Winnipeg) brought forward 5 new families wanting much needed information. We are continually motivated by this overwhelming need for information and understanding.

Since our primary mandate has been and always will be to help support neutropenia patients and their families, we also further educate in this field by way of featuring renowned speakers such as Dr. David Dale, the Honourable Dr. Jon Gerrard, Dr. Melvin Freedman, Dr. Nathan Kobrinsky, Dr. Bonnie Cham and others.

Dr. Laurence Boxer will be our guest this April to speak to our group as well as share his knowledge with the Manitoba Cancer Treatment and Research Foundation. We look forward to his visit.

EDITOR'S NOTE:

April 14th, Thursday, 7:30 p.m.

ALL WELCOME!

Speaker: Dr. Laurence Boxer (from Ann Arbor, Michigan)

ANNIE BOND ROOM (Community Services Bldg.)

685 William Avenue, Winnipeg, Manitoba

We extend a special invitation to Jeffery's Folks members and other interested groups.

No Charge — Refreshments Served

Our membership, in promoting awareness, has had the opportunity to share information and gain valuable insight with other very successful and knowledgeable support groups.

We participated in the 1993 National Children's Cancer Conference and will be participating in the National Candlelighters Conference this summer. A number of physicians will speak specifically about congenital neutropenia and chemotherapy induced neutropenia.

A number of American families on the East Coast will be invited to attend the Halifax, Nova Scotia conference and maybe this will bring forward more families for your support group.

Supporting research has always been a key element for our group. We have been fortunate to have the Winnipeg, Manitoba Children's Hospital Research Foundation 1993 Top Researcher Award Winner, Dr. Jon Gerrard as one of our medical advisors. He is now the Secretary of State; Science, Research, and Development.

Dr. Cham, also our medical advisor, is a research award winner as well and is a key facilitator of the Canadian Neutropenia Registry. We

support her team's neutropenia related research projects (Winnipeg).

In addition, we have a special relationship with Dr. Melvin Freedman, Chief Haematologist, the Hospital for Sick Children, Toronto, Ontario and recently began supporting his team's neutropenia research.

There are many others that feel that the net result of these efforts, however small, will improve the further treatment and understanding of this disease.

I should mention our present mandate is to donate 100% of money we receive from the general public for research and education related endeavours.

We accept all types and sizes of donations and properly acknowledge them. We include a tax deductible receipt. Since we are all volunteers, our expenses are directly associated with achieving our goals and objectives.

At first there were many small fund raising projects such as selling cash calendars and raffle tickets. They were a big effort for a small gain. We always sold out, but our group was too limited.

So we put our heads together and came up with the idea of a lady's and men's fashion show luncheon featuring many sponsors. The Calendar Firefighters were our main attraction. In our second annual show, we added the Panache Models and others. Ours is a fun production and attendance has exceeded our expectations!

Janis and Jim Benzelock's son Jamie participates in Dr. Boxer's study. They are our special event co-ordinators. It is because of volunteers like them that this fundraiser is such a roaring success.

We found out recently that the Winnipeg Blue Bombers of the Canadian Football League may be added to this year's excitement. We also feature a guest speaker at this event, again always educating the public and our membership.

We now want to accept a greater challenge and invest some of our on-hand funds to develop a major ongoing fundraiser in partnership with a number of haematologists and oncologists.

We want to promote art by children in hospital touched by serious illness. We will reprint this art on greeting cards, and again educate by way of a brief message about severe chronic neutropenia and chemotherapy induced neutropenia on the back of the card.

This could be a common fundraiser for all neutropenia chapters and also encourages a partnership with other interested groups. We have other ideas that we will develop over time and welcome your input.

Another future goal is to develop a workbook for children that have neutropenia to help take the fear away of procedures and injections. We hope this will be developed with the aid of the Manitoba Cancer Treatment and Research Foundation Child Life Department.

Ultimately, we would like to fund a social worker specializing in neutropenia family needs. Many adults too have lived with difficult times affecting their total outlook on life as they battle their disease.

Anyway, all these efforts are summed up in helping each other, sharing concerns, answering questions and being a vehicle to connect people with one another. We try to work on a buddy system so families isolated know they have someone they can turn to that understands their fears and offers hope.

Refer to The Support Group Way Handout (Volume 5 Newsletter)

We are constantly reminded as to why our volunteer work is important and receive sincere cards and letters because of these efforts.

Our recently formed Ontario N.S.A.I. Chapter Leader, Shirley

Cox, wrote this poem and gave it to me in 1992 when we met for the first time in Toronto. ■

Moving Mountains

by Shirley Cox, (first printed in Support Newsletter No. 5)

My babies are so sick. To look you would not know. Their sweet and lovely faces. Full of smiles and all aglow.

My babies, they are dying. We've been told, things just aren't right. So we watch them every moment. In total fear and fright.

When I tuck my babies in their bed and kiss them on their cheeks, I hug and kiss them one more time. As tears stream to my feet.

Our Stacey left us years ago. Her picture's all we have. Her hopes and dreams and love of life. Are memories of the past.

I know the boys would love her. If they'd ever met. As she touched so many hearts. In her life before she left.

She did not mean to hurt us. Break our hearts and crush our dreams. But she was called to Heaven. And we couldn't intervene.

Now Stacey looks from Heaven. And keeps us safe and sound. I think she lent her little hand. For this cure to be finally found.

We know she helped and guided them. We know she knew our pain. The tragic loss of a precious child. We couldn't endure again.

Our babies they are healthy now. The sickness gone for good. They laugh, they grow, they jump and sing. I wish they understood.

As parents of sick children. We hope you keep in mind. The faith and promise in our hearts. For the cures we hope you'll find.

For us there's now bright sunlight. For others the darkness looms. But maybe today you'll discover a way. To move mountains and watch flowers bloom.

This poem is a constant reminder of the needs of others. I can never read this poem without crying since it conveys the message so clearly.

Now I carry a picture of Stacey Cox as a reminder of how fortunate we all are that our children were born while research miracles were happening. They have benefitted from extraordinary medical care and recent treatment advances.

Stacey Cox died at the age of 5 in 1985 before Neupogen was available.

Shirley Cox's sons, ages 23 months and 3 years, as well as her husband now receive Neupogen and are all doing very well.

We've all been there, but possibly after years of successful treatment, the stresses lessen. It is important to remember how it was before the study and treatment was available to us all.

The efforts you are making this week-end and over the years will, yes, help yourselves, and also as one mom recently put it, affect others directly and profoundly by improving the lives of many as you share awareness and understanding.

Speaking for all of us in our group, I wish to say we will always

be there to help you in any way that we can, and we wish you every success as you grow and reach out to embrace a healthy, happy and long life for every baby born with neutropenia.

These "Stories" have been sent by the families I got to know in L.A. They are very wonderful people accepting an extraordinary challenge! Best wishes!! LORNA STEVENS



Matthew (5), Jacqueline* (9)

"Dorothy"

By Beth Jacobs, Randolph,
New Jersey

Our daughter Jacqueline (Dorothy, you'll see!) was diagnosed with SCN when she was a little under 2 years old. Remembering when Jacque was selected to participate in Dr. Boxer's University of Michigan study is special to us! We all laugh at some of

the events which took place the 6 weeks that Jacque, her brother Matthew and I lived at the Med Inn.

We drove to Michigan from New Jersey. Our car was full of every luxury we *thought* we needed—clothes, food (mostly dry goods to just heat in the microwave), a baby monitor, a VCR (lifesaver!) and many other things.

I especially remember these few things:

Matthew was at a stage in his life when he still took a very long nap in the mid-afternoon. The room was such that there was a large, wheelchair accessible bathroom which during the nap-time of the day, was his "bedroom". It was so dark in there that Matthew slept for hours! During this time, Jacque and I were doing her daily bloodwork and other required tests. The cleaning ladies on the floor became my friends. I remember how they looked after Matthew for me and "took care of him" during the nap while we were gone. They were wonderful, caring women.

During our stay, it was flu season and both children got the flu badly. How I loved being in a hotel to change those sheets that week at least 2 or 3 times per day! It was great to be able to care for two with the flu without doing the wash. And I never came down with any symptoms!

The VCR was a lifesaver! There were two tapes which the children grew to love and they were eventually played exclusively. We must have watched those tapes 4 to 6 times per day for 4 weeks straight! One was a "My Little Pony" tape called "Mishmash Melee" and "Baby, It's Cold Outside". The other was "The Wizard of Oz". Jacqueline was particularly fond of "The Wizard of Oz". She literally became Dorothy. Jacqueline dressed like Dorothy, acted like Dorothy, carried "Toto" in a basket, sang Wizard songs, and her new name *became* Dorothy! She would only respond to Dorothy! It was easy for "Dorothy" to get all her tests done, even bloodwork. The characters were her imaginary friends. I was Glenda, of course! Matthew was Toto! ■

The National Neutropenia Network telephone number is 1-800-NEUTRO-8. Beth Jacobs has volunteered to return messages left on the answering machine. She invites your calls!

*denotes Neutropenia patient

"Four Leaf Clover"

By Sonja Cary, Santa Ana, California

Greetings from Southern California. I had the pleasure of participating in the start up meeting for the National Neutropenia Network last month. Coraline and I have been together for the past nine years. She's the one with Cyclic Neutropenia. Since 1988, she's been injecting G-CSF. We received a call out of the blue from Dr. Dale's office in Seattle asking us to participate in his study. I was just finishing up my degree in Amherst, Mass. so we decided to participate. At the end of the semester, we sent most of our belongings in a moving van to Coraline's mother. Our cats and whatever else fit in our Toyota headed west for Seattle.

We didn't think much of how Coraline's health and her lifestyle might be changed by this study. Up until then, she tried to be as active as the next person, but low neutrophils tripped her up a few times. By the sixth grade, she had spent enough time in bed to have read all the classics. She played basketball and swam at Santa Barbara High School, and at the same time, monthly illnesses gave her plenty of opportunities to move on to modern authors. She enrolled at West Point but spent too much time in the hospital to keep up with her classwork. In college at William and Mary, she made the most of her periods of health. She even crawled to enough classes to earn Phi Beta Kappa.

In January 1988, on our trek to Seattle, we encountered some bad weather. To beat a storm threatening to close Snoqualmie Pass, we drove into the night to reach Seattle. Early the next morning, with the car still packed, we showed up at the University Hospital to meet Dr. Dale and find out what to expect for the next few months. Since Coraline had become an expert at managing her illness, and we didn't want to get our hopes up, we didn't speculate on the success of this new experimental treatment that worked on Grey Collies and a kid named Matt.

As we arrived at the hospital, Coraline looked down at the green grass with the winter weary eyes of an Easterner. "Hey, a four-leafed clover." Coraline snapped it up and ran in to meet her new friends on Seven South.

Now, after completing a Master's Degree at Berkeley, Coraline coaches basketball and teaches weight training and frisbee at Chapman University. She still tries to make the most of her health and energy as if it might not be there tomorrow. She frequently tells her friends, "You don't know what it's like to be healthy." The dramatic turnaround in Coraline's health is attributed to G-CSF. We think it's really the luck of the Irish!

We would be happy to share our experiences with others. Give us a call at 714-834-1969. Sonja Cary and Coraline Glerum, 617 East Bishop, Santa Ana, CA 92701. ■

Sonja Cary has volunteered to be the data base, co-ordinator, vice chair, Rare disease liason with other self-help groups. E Mail address: NEUTRO-1@AOI COM

The Nicola's Story

By Garry Ann and Edward Nicola, Whittier, California

DOCTORS, NURSES, HOSPITALS, CLINICS, INSURANCE COMPANIES, EMPLOYEE BENEFITS, LABORATORIES, PHLEBOTOMISTS, RADIOLOGISTS, JUDGES, ATTORNEYS, AND THE IRS, we've dealt with them all.

Our three daughters, D'Arcy, Diane and Danielle, and their father all have Severe Chronic Neutropenia (SCN). Participating in Amgen's

G-CSF study through the University of Washington Hospital has improved our quality of life and drastically reduced our dealings with these various agencies.

Diane nearly died in 1972 when she was eight months old. It was at this time that we learned about our family's hereditary condition



D'Arcy (23), Danielle* (19), Diane* (22)*

called cyclic-neutropenia. To date, we have identified nineteen family members, four generations, with cyclic-neutropenia.

Our first daughter (D'Arcy) was born in July of 1970. Looking back, symptoms of her neutropenia began immediately. Even as a baby, she saw the doctor several times each month. When I said this isn't normal, he would say, "D'Arcy is prone to viral infections," and prescribed more antibiotics. The neutropenia *could* have shown up in a blood test during one of the many illnesses.

Diane was born in December 1971 and began the same pattern of sickness and doctor visits. When one was ill the other was well. They took turns at the doctor's but now he said, "Both your children are *very* prone to viral infections." Again, no blood tests were ever done.

Diane was due for her eight month 'well-baby' checkup. She was sick again. "Bring her in anyway—it's OK," they said. She was at the doctor's each of the next four days, with new symptoms and new medication prescribed each time. He said, "I've never seen anything like this before." At her last visit she was given thorazine to stop projectile vomiting, and aspirin for her 104° fever.

When her doctor wasn't available the next evening, in desperation we went to the Emergency Room. The doctors there were alarmed and we were sent to the USC Medical Center Contagious Disease Ward. Once there, we were accused of abuse and threatened with police action. And the blood tests *finally* began. After many tests, and three days later, it was determined that Diane had a bacterial infection in her blood stream (pseudomonas), caused by over medication.

The infection had spread throughout her body and she had sores all over. The worst was what looked like a giant bruise, as a result of the infection spreading to the damaged tissue caused by the injection of thorazine she had gotten from the pediatrician the day before.

Once the problem had been diagnosed, and the proper treatment given, she recovered quickly, except for the damaged tissue from the injection. The treatment, at the USC Burn Clinic, to heal this sore was difficult and took over four months. Diane has had plastic surgery twice

to reduce the scarring.

During the seven weeks Diane was being treated, her blood was tested daily, and in detail (CBC with manual diff.). One of the doctors noticed that her neutrophils cycled (cyclic-neutropenia). She was diagnosed with cyclic-neutropenia. At that time what little information there was on cyclic-neutropenia indicated that it could be hereditary.

At the time, there were only forty or so cases recorded in the world. With Dr. Wilkinson we began checking our family for the condition. First he checked the parents (GarryAnn and Ed), and found that Ed has it. Then Ed's parents were tested, and found that it came from his mother. His sister and brother both were found to have it. Every member of the family that could be, was tested. To date nineteen family members with cyclic-neutropenia have been identified.

When our third daughter, Danielle, was born in August of 1974, she was tested for a year for the condition. She would have been the youngest cyclic-neutropenia patient ever discovered. She did not have it. However, at three and one half years old she was diagnosed with Acute Lymphocytic Leukemia (ALL).

The family began another ordeal. Danielle began chemotherapy, and remission was achieved. After two and a half years chemotherapy had to be stopped because of a severe case of Chicken Pox. Remission only lasted six months. She relapsed and chemotherapy was restarted and remission again achieved.

The option of a bone marrow transplant was presented as her best chance to live. Again we faced a life or death decision. A bone marrow transplant was done in July of 1981.

Daughter D'Arcy was the donor for the transplant. Before the transplant we were told that a diseased marrow was not usually transplanted. Since Danielle and D'Arcy's marrows were a very close match, the transplant was recommended. We decided that cyclic-neutropenia would be better than Leukemia and went ahead with the transplant.

This was a very emotional time for us all. Diane wished she could be the donor. D'Arcy worried about whether her marrow would work. We wondered how long we would be making these life and death decisions for our children. Danielle was in isolation for thirty-two days after the transplant. I spent nights and her mother spent days with Danielle in her hospital room. During one of those long nights I captured some of the emotions I was feeling in a poem.

As it turned out, the neutropenia was transplanted from D'Arcy to Danielle. This was published in the medical journals since it showed that cyclic-neutropenia is a condition associated with the stem cells.

Dr. Dale and Dr. Hammond at the University of Washington hospital had been doing neutropenia research. When they learned about our family from the journals they contacted us about possibly participating their study and testing of G-CSF.

D'Arcy was one of the first patients to join Dr. Dale's study, later Diane and I joined. Danielle also began taking G-CSF on a compassionate basis. We all began enjoying the benefits of the drug immediately, including fewer dealings with the many agencies associated with medical services.

This short version of our twenty plus years of dealing with our condition has been difficult, trying, and occasionally traumatic, but thanks to G-CSF the last few and hopefully the future years will be happy and healthy. ■

Edward Nicola has volunteered to be the liason with Amgen Inc. He sent this notice pertaining to U.S. families:

All new (non study) SCN patients who require NEUPOGEN should

be encouraged to contact the Amgen Safety Net program at 1-800-272-9376. They need to identify themselves as an SCN patient when they call Safety Net personnel will provide them with information about the registry and eligibility for NEUPOGEN reimbursement .

Of Snowflakes and Children

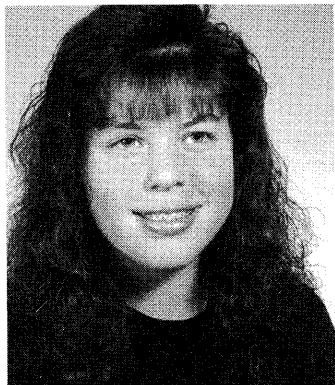
by Edward Nicola, Whittier, California

*God's creations of crystallin perfection,
Released from the heavens in every direction.
Floating to Earth on gentle breezes,
Reflecting the beauty of God and Jesus.
Snowflake on snowflake, one on another,
Joining together, like sister and brother.
Covering the world with a gift from above,
A blanket of innocence, and purity, and love.
Each tiny snowflake, and each child too,
Sent here from God, for me and for you.
To add to the beauty in all of our lives,
To add to the meaning of husbands and wives.
Sent down to Earth for us to behold,
Sent here to enjoy, to love, and to hold.
To hold for a moment, in amazement and wonder,
To revel in His work, to puzzle and ponder.
Then on they must go, as His will demands,
To their ultimate destiny, in His gentle hands.*

"God's Burdens"

By Silke E. Deeley, Chicago, Illinois

We have often heard that God never gives us a larger burden than we can carry. How often we had heard that, and even espoused that very phrase to friends and acquaintances who were going through difficult times. We never dreamed that someday it would pertain to us.



Alyssia* (15)

The year 1984 found us wondering why we were spending so much time in doctors' offices with our daughter Alyssia, who had just turned 6 in July. One infection after another, constant mouth sores, and bloody noses and the pediatrician was unable to determine a cause. "Perhaps this was just a phase and she would outgrow it in time," was what we heard, and because a "doctor" had said it, it must be true. Another 2 years went by and Alyssia became sicker and the infections became more serious, requiring terrifying bone marrows, hospitalizations, surgeries, and more specialists than we care to remember. None of them had any answers. Was it possible that in the entire medical community in the city of Chicago there wasn't a single physician who might diagnose the illness our daughter had? We had given them 2 1/2 years and subjected Alyssia to so many tests; how much more could we put her

through? How much more could we take?

We prayed for an answer because our next step was the Mayo Clinic, (which to date has only diagnosed 4 cases of Neutropenia). Our prayers were answered in the form of Dr. Jong Kwon, who came to Lutheran General Hospital in Park Ridge, Ill. from Sloan-Kettering in New York. Finally, in 1987 we had a diagnosis. Alyssia had Idiopathic Neutropenia, but there was no cure. Hospitalizations for 3 weeks at a time to receive intravenous antibiotics were going to be a way of life. Even though the constant hospitalizations took their toll, we found ourselves being grateful that Alyssia didn't have cancer like so many of the children we became so familiar with during these visits. We also clung to the hope that someone knew more about this disease and we would eventually find out who and where they were.

Doctor Laurence Boxer was that someone. Finding him proved to be a bit of a hunt, (he had moved), but thanks to Dr. Kwon, and many phone calls, we caught up with Dr. Boxer at the University of Michigan Hospital. The Spring of 1988 found us in Ann Arbor with Alyssia in hopes that she fit the protocol and would be chosen as a participant to receive a new drug called G-CSF. By the luck of the draw Alyssia was accepted but became ill during the waiting period, and the first two weeks of our 6 week stay had Alyssia in the hospital and me at the Ronald McDonald House. The anxiety and depression of having a sick child was beginning to take its toll on me, especially since my husband and I had found it necessary to divide the time required in Michigan and I found myself alone during this first two weeks. The Ronald McDonald House staff and other parents who found themselves in similar situations certainly helped to make this time easier. Talking to other parents whose children would eventually die, made us see our situation from a totally different perspective. We would eventually be able to take Alyssia home.

Once Alyssia was on drug and on the road to wellness, my husband Patrick spent the remaining weeks in Michigan. His stay with Alyssia certainly turned out to be much more enjoyable because G-CSF was working and hospital stays were going to be a thing of the past.

And so it has remained. Alyssia has been well for 5 years. She is no longer on a first name basis with hospital staff. Her classmates don't send monthly get-well cards. We no longer panic at every symptom of a possible illness. Sometimes, we even forget that she has an illness and sometimes she forgets too. But we do not take for granted how precious is the life she is able to have because of Amgen and G-CSF. ■

Silke Deeley has volunteered to be the U.S treasurer and maintain the central address: P.O. Box 205, National Neutropenia Network, Chicago, Illinois 60630

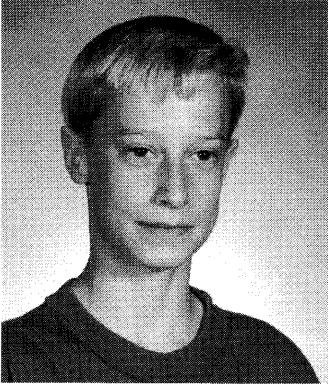
"The Military Connection"

By Stephen and Barbara Johnson, Oak Harbor, Washington

Hi! We are the Johnson family. We would like to introduce our family to yours and share some of our experiences of having a child with neutropenia.

Our names are Stephen and Barbara Johnson. We've been married 20 years. Stephen has been an Air Traffic Controller in the U.S. Navy for 18 years. I do volunteer work, and work as an Instructional Classroom Aid (Paraprofessional).

We have two children. Stephanie is our oldest. She is seventeen and a junior in high school, an authentic typical teenager. Stephen



Stephen "Adrian"* (14)

"Adrian" is fourteen years old and in the seventh grade.

Adrian has chronic neutropenia. His first hospital stay was at 4 weeks old for an infected tear duct. Adrian was diagnosed with neutropenia at ten months of age for an infected tear duct. After two abscesses on the side of his head could not be surgically treated, the true cause of his infection was discovered three weeks later. Over the years Adrian has suffered from over 30 different cases of

otitis media (ear infections), numerous oral infections; the worst is bone loss, and ulcers. Adrian contracted an infection in his lungs at age six; aggressive antibiotic treatments had no effect and an abscess developed on the upper right lobe of his lung and the entire upper right lobe had to be removed. This was the scariest time we had to face as we almost lost him. Since then it seems one can condition oneself to handle almost any situation as y'all (that's Texan for 'you guys') probably have realized. At nine and one half (9 1/2) he was hospitalized for a blood infection from what started as a paper cut. That turned into yet another hospital stay.

Through the years we lost count of the hospital stays. My husband's Navy career has taken us many different places and fortunately one of them was San Diego, California, in 1988. While stationed there we learned about the G-CSF program. On January 5, 1989, Adrian was placed on the protocol program. Those of you on the G-CSF program know the results. Those that are unable to obtain the drug we hope and pray that you will be able to get it soon. Since his acceptance, Adrian has not suffered a single illness, or hospitalization. His dental problems have reversed and tooth extraction may not be necessary, with aggressive treatment.

We appreciate you allowing us into your family with our story. We have gone through many crises and they never seem to end. If you have any questions—no limits; anything from sibling rivalry, to teenage blues, to medical, and dental, please call us at 206-675-7142 collect.

Again, thanks for listening. Hope to hear from y'all. ■

Barbara Johnson has volunteered to be Secretary. Stephen Johnson has volunteered to be Newsletter Editor. The first U.S. issue will develop as funding is confirmed. In the meantime we will assist with the N.S.A.I. newsletter. "There are no borders for SCN families worldwide. We want to help each other, eh?" (That's Canadian for OK?)

"Are There Two Dr. Boxers?"

By Lee Reeves, Howell, Michigan

"This is the meanest umbilical infection I have ever seen", scolded the young resident as he admitted my ten day old daughter to the hospital. "No, you can't breastfeed her. We don't want to increase the risk of infection." No, you can't stay overnight; it's against hospital policy."

The intimidating words of the self-assured resident reflect the

tone of hospital pediatric wards in 1976. His comment on my daughter's condition illustrates the ravaging power of an army of bacteria in the defenseless system of a neutropenic child.

Following our two week hospital stay, my husband, Louis, and I enjoyed a few short weeks of normalcy with our new baby. But soon our lives would be dominated by countless visits to baffled pediatricians, mysterious fevers, and endless array of antibiotics, blood tests, x-rays, and special diets and vitamins.

Eventually a liver abscess was discovered, and soon Leta's pain was given the exotic name congenital agranulocytosis. We were told her condition was extremely rare, and that she probably would not live to be an adult. The quality of her life would be compromised by recurrent life-threatening infections.

I launched a personal campaign to educate myself on this rare disease. I learned about stem cells and their stunted proliferation in neutropenic patients, and although there was a liturgy of names for this disease, very little seemed to be known about it.

After reading all of the medical journal articles I could locate, I decided to call Doctor Laurence Boxer whose name appeared frequently in the medical literature on Neutropenia. Just days after my first phone call to Riley Children's Hospital in Indianapolis, Indiana, Leta and I were on a plane to meet doctor Boxer in hopes of a treatment unknown to our Michigan physician.

Doctor Boxer confirmed the diagnosis and tried several of the treatments being explored to help neutropenic patients. My hopes faded with the unchanging test results. I learned that my daughter's stem cell activity diminished after the second of five stages of proliferation. No internal predator could be detected; the conclusion was that the stem cell, though normal in appearance, was just unable to provide the first line of bodily defense for which it was destined.

Although the news in Indiana was disappointing, I felt more secure after meeting Doctor Boxer. At least my daughter had a champion, one who was knowledgeable and actively investigating her disease. I knew Doctor Boxer would welcome calls from my doctors when they were unsure of the best course of treatment.

As the years passed, we learned to live with hospitals, antibiotics, needles and anxiety. We learned to value the good times and make the best of life in what was to become our second home, the hospital.

Our calls to Doctor Boxer became infrequent, but I thought about him often, hoping that some research would identify a catalyst that would jump-start the lazy neutrophils in Leta's bone marrow.

After five years our family, which now included a healthy one year old boy, Skyler, moved to the Ann Arbor area. I decided to visit the children's hospital to introduce myself. When I arrived at the pediatric hematology department and looked at the name plate on the director's door I was incredulous. "Are there two Doctor Boxers who are pediatric hematologists?" I asked the department secretary. She replied, "Doctor Boxer is our new department head;" I was pleased and surprised. She continued, "He just moved here from a hospital in Indiana."

In minutes, I was talking to my old friend. He called our meeting "fortuitous," and asked me if I could take a few minutes to meet someone special. Leta, who was five and feeling healthy was always enthused at the prospect of meeting new people.

We followed Doctor Boxer to one of the dreaded treatment rooms where we were introduced to an anxious mom with a sad eyed, frail young boy. Doctor Boxer didn't have to tell me the two year old boy had the same rare affliction as my daughter. I empathized with the

despair of this sad mother, and was glad to give her some hope in the encounter with my happy daughter.

Over the next eight years, the hope and optimism we shared at that moment was clouded by many difficult trials. Yet the hope we felt that day pales in comparison to the unparalleled joy experienced by our families when doctor Boxer called to let us know there was a new medication being tested for neutropenic patients, and the response had been promising. Normal white blood counts had been confirmed just days after taking this new drug.

As the heirs to an incredibly rare disease our children have always been unique. As the recipients of the elusive medical miracle brought to us by AmGen and years of tireless research, our children have a rare place in medical history, and as parents we are blessed...and grateful. ■

Lee Reeves has volunteered to guide N.N.N. through incorporation and apply for I.R.S. Charitable Status (U.S.). She also will help develop a handbook for neutropenic patients and their families. e.g. how to handle the hospital, sibling issues, dealing with educators, listing related resources.

The National Neutropenia Network Mission Statement:

To promote awareness, education & research, and provide a support system for patients with Neutropenia and their families through a national resource network.

Objectives:

- 1) To promote all general and clinical research related to Neutropenia.
- 2) To provide information to educate SCN families, the medical community and the general public which will allow SCN patients to manage their risks and needs.
- 3) To collect and distribute the latest medical data on SCN including long-term effects, inheritance, effect of other treatments, info resources, psychological and medical experts.
- 4) To provide information about working with hospitals, doctors & nurses, and other health care providers which will make the neutropenic patient's medical care as positive as possible and to give neutropenic families the skills to be effective.
- 5) To increase and support general public awareness.
- 6) To identify patients and families whose lives are affected by neutropenia.
- 7) Facilitate recognition of the psychological effects of dealing chronic illness and encourage the seeking of professional help for families.
- 8) To increase awareness and understanding of neutropenia within the medical community.
- 9) To act as an advocate for the registry. ■

Comments from Lorna Stevens

Winnipeg, Manitoba, Canada

"Such a wonderful experience. I can't express how exciting it was to participate in the development of the U.S. National Neutropenia Network. Truly a dream come true!"

Group Activity

- Expectations for meeting outcome
- Agreement on meeting objective
- Needs/issues for network to address
- Mission Statement and objectives
- Short term goals
- Priorize short and long term goals
- Volunteers to carry out objectives
- Then, one month later; conference call
- Progress Report; reconfirmed objectives
- Schedule monthly group communication

I highly recommend this format for all countries developing a support group. It works!

A small group was needed to develop realistic goals – "start simple and add later". The facilitator Alexander kept things controlled so there was a good exchange of information and participation from everyone with the use of computer groupware. The meeting was a starting point for action; free expression of ideas and personal experiences still continues by phone. All U.S. families are invited to join in by phoning the toll free U.S. number 1-800-NEUTRO-8.

The meeting was *so successful* for all of us because of the dedication displayed and information shared together with Dr. David Dale and Dr. Laurence Boxer — **THANK YOU**. The slide presentation was *incredible!*

Sincere appreciation is expressed to the organizers at AMGEN Inc. — Job well done! ■

There is no greater gift...

Originally in this newsletter we were sending our best wishes to Robin, Curtis, Brittany*, and Christopher announcing the safe and early arrival of Jon Vinson Murphy, 5 lbs., 11 oz.

Robin Murphy (San Angelo, Texas) had volunteered to chair the (U.S.) National Neutropenia Network. Now, understandably, she needs to relinquish this position as her daughter Brittany Rieger has recently been diagnosed with (A.M.L.) acute myelogenous leukemia.

Brittany will be treated at Cook Fort Worth Children's Medical Center, Texas.

We *sincerely* wish the family well and our *hearts* go out to them.

We strongly encourage all to consider bone marrow transplant donation. There is *no greater gift* than to help a child under these circumstances.



Lorna Stevens & Robin Murphy in Los Angeles N.N.N. (N³) "Kick-off"

Brittany* Rieger (8)

Ongoing bone marrow, chromosome testing, is necessary to monitor all SCN patients receiving long term G-CSF (Neupogen) treatment. Please consult with your physician.



INFORMATION ORDER FORM - National Neutropenia Network (N.N.N.)

NAME _____

ADDRESS _____ ZIP CODE _____

STATE _____ PHONE NUMBER _____

AREA OF INTEREST AS VOLUNTEER: _____

- ☐ Would like Neutropenia Registry information
- ☐ Would like to be on U.S. National Neutropenia Network mailing list
- ☐ Would like a U.S. National Neutropenia Network "buddy" or "penpal"

SEND TO:

OR CALL:

ADDRESS:
P.O. Box 205
National Neutropenia Network
Chicago, Illinois
U.S.A. 60630

TOLL FREE 1-800-NEUTRO-8

E-MAIL NEUTRO-1 @ AOL COM

CONTINUING IN CANADA

ONTARIO NEWS

Shirley Cox (Ontario N.S.A.I. Chapter) has diligently been sending out order forms across Canada and we have been thrilled with the response from hospitals, nursing centres and various medical groups. We now add "shipper-receiver" to our list of voluntary activities.

See page 16 for "tear off" order form.

Why Not?

Dr. Fred Saunders and I want to thank you for the generous donation for support of neutropenia research. We will be using the funds immediately for the study of bone marrow cells from a child with SCN that has not responded to G-CSF therapy. The research question in this case is... "why not"?

The Hospital for Sick Children
Toronto, Ontario

EDITOR'S NOTE: The Ontario Chapter and Head Office (Winnipeg) of the Neutropenia Support Association Inc. combined donation: \$2500.00

New Lease on Life

By Jan Soule

Reprinted with permission of The Barrie Examiner. (Corrections made with Jan Soule's and Shirley Cox's permission.) This story distributed by Thompson News Wire. Thank you to the Barrie Examiner. A number of Canadian families responded to this article for more information.

The thought of Tyler starting school frightened his parents.

If their blond-haired, blue-eyed pre-schooler brought back one germ it could have killed his entire family.

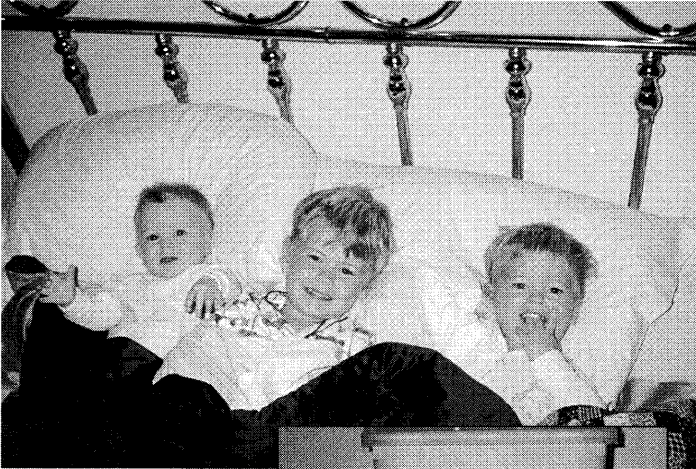
"He could have come home and wiped out the rest of the family," said his mother Shirley Cox.

Tyler's father Michael, 36, and his brothers Travis, 3, and Spencer, 19 months, all suffer from a rare blood disorder called neutropenia.

Neutropenics don't have enough neutrophils, white blood cells manufactured by the bone marrow. Neutrophils kill infections, without them the body has no defence against the daily barrage of bacteria and viruses.

A simple paper cut can lead to an infection extending up to the elbow within an hour.

Statistically, neutropenia affects one in every 100,000 people, which should translate into 270 cases across Canada. But, only 62 confirmed cases have been reported — 22 in Ontario. (Canada now reports



(Above) The "Cox kids"
morning cuddle.



(Right) This keeps
them well!

over 100 patients including those diagnosed with milder forms of neutropenia. ED.)

The Cox family members have been diagnosed with severe chronic neutropenia.

Tyler was able to start school this year, with his parents safe in the knowledge that he would not transmit some normally safe childhood disease to his brothers, because of Neupogen. This new drug has completely transformed the family's quality of life.

"We couldn't make plans. Our life revolved around keeping close to the hospital and following preventative measures to keep bacteria away from the family," said Cox.

The fear of catching infections was not an exaggerated one.

Eight years ago the family was devastated by the death of Stacey, their five-year-old daughter.

"Stacey only lasted three months in the school system before picking up a fatal infection," said Cox.

She died from an infection of the inner lining of the abdomen.

To maintain sufficient levels of neutrophils Michael, Travis and Spencer must receive daily needles.

"They cry, of course they cry; it hurts, but I try to make it as fun as possible.

"In the future we're hoping there won't be a needle, but in the meantime don't knock it!"

Not everyone can go on Neupogen because of the expense. Only the most extreme cases receive the financial help necessary from the government.

"I feel sorry for the people who aren't as severe (as her boys) and have to go through the hell we went through because they aren't sick enough (to receive the drug)," said Cox.

Fighting germ warfare

Neutropenia is a rare blood disorder which leaves those afflicted with an improperly-functioning immune system.

The disease is caused by a lack of neutrophils in the body. Neutrophils are white blood cells, produced in the bone marrow, which surround and destroy bacteria in the body.

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 periodontal disease are common. It can be difficult to diagnose. Many specialized blood tests may be needed for a haematologist to determine neutropenia.

Neutropenia can affect anyone.

Some people are born with it; it can happen after a viral infection or be a side effect to a drug or certain poisons.

A more common form of neutropenia affects as many as one in three cancer patients. Chemotherapy treatments are designed to kill quickly dividing cells often kill neutrophils along with the cancer cells.

A drug which allows neutropenics to live relatively normal lives — Neupogen — was originally developed to help cancer patients.

For more information call Shirley Cox, co-founder of the Ontario Chapter of the Neutropenia Support Association at 705-424-1285, or the Neutropenia Support Association in Winnipeg, 1-800-663-8876.

The Neutropenia Support Association is the only one in the world.

Information provided by the Neutropenia Support Association in their booklet, *Neutropenia: Causes, Consequences and Care*.

The medical bill for the three Cox family members is \$95-\$100 a day. That cost will increase because the dosage is prescribed by weight. As the boys grow so may their need for the drug. Their father Michael reacted extremely well to the drug and can maintain his health on a very low amount of Neupogen.

Spreading information on neutropenia is almost as important as Neupogen to Cox.

"If I can help one person that makes it all worthwhile," said Cox. ■

THE MARITIMES NEWS

Dianne Cooper's fundraising efforts in PT Leamington and other Maritime areas:

TOTAL TO DATE: \$1,166.58

for "isolation entertainment centre for kids in hospital".

Thanks especially to the PT Leamington men's dart league, ladies auxiliary, Fire department and many other caring citizens.

"Caring and Compassion"

We are sincerely grateful for the freely given commitment of time by Dr. Melvin Freedman and Dr. David Dale last summer.

Their presentations at the National Children's Cancer Conference, Kingston, Ontario, "Growth Factors in the Treatment of Chemotherapy Induced Neutropenia" were very well received by all in attendance.

The Candlelighters Childhood Cancer Foundation Conference "Childhood Cancer and the Family: Caring and Compassion" is July 8th to 10th, 1994, Halifax, Nova Scotia.

We shall, at this conference, feature a special session July 9th, 1994, "Chemotherapy and Neutropenia", "Neutropenia: Congenital and Chronic". We are immensely grateful that these physicians have agreed to be our speakers:

1. **Kaiser Ali, MB, BS, FAAP, FRCPC**
Saskatoon Cancer Centre
Saskatoon, Saskatchewan
(previously from Newfoundland)
2. **Lewis Ingram, MB, CHB, PHD, MRCP, FRCPC**
Dr. Charles Janeway Health Centre
St. John's, Newfoundland
3. **A 3rd physician will present (at this time unfirmed)**

We shall again take the opportunity to invite participation for support group development. Dianne Cooper, Co-ordinator for the Neutropenia Support Association Inc. Maritimes, will assist in this endeavor. She can be reached by calling: 1-709-484-3592

Please contact the N.S.A.I. (Head Office 1-800-6-NEUTRO) to discuss accommodation and meal plan reduced rates. We want as many families as possible to have the opportunity to attend.

We express our sincere gratitude to the organizers of the National Children's Cancer Conference and the Candlelighters Childhood Cancer Foundation for enabling these important sessions to be available on their programs. ■

MANITOBA NEWS

Meet and Greet

Sandra DeMarco, Arlene Ericson and Irene Zakala are working on a "MEET and GREET" for all local families to attend.

LOCATION:

Annie Bond Room (Community Service Bldg.)
685 William Ave. (across from H.S.C.)

269-7065 - Sandra (evenings); 261-0775 - Arlene;
668-8779 - Irene (days)

CHILDREN WELCOME!

Please call for further information.

The renowned
DR. LAURENCE BOXER
from Ann Arbor, Michigan

NEUTROPENIA PRESENTATION
The Role of Neutrophils in Host Defense;
Quantitative & Qualitative Abnormalities.

April 14th, 1994
7:30 P.M.

Annie Bond Room, Community Services Building
685 William Avenue (across from Health Sciences Centre)
Winnipeg, Manitoba

All are welcome.
Special invitations to Jeffery's Folks and the
medical community.

Complementary refreshments will be served.

Fundraiser: April 30th

We need your help

The Winnipeg Club Oldtimers Hockey Team is a non profit organization. Their main function and purpose other than playing hockey is to give something back to society by organizing various functions, and providing financial support for charities and persons who are in need.

The theme being, "GIVING IS REWARDING".

With the approval of the Neutropenia Support Association Inc. & Children's Wish Foundation of Canada, we are holding a social function which will consist of various contests such as Line Dancing, Karaoke, etc.

The social function featuring Celebrity Judges will be held

Saturday evening, April 30th, 8:00 pm til 1:00 am at the Red River Community College South Gym with the admission of \$8.00/person. We would appreciate your assistance in helping sell tickets for this event.

The Winnipeg Clubs will manage the function and give (100%) of the proceeds (profits) to the Neutropenia Support Association Inc. and Children's Wish Foundation of Canada.

If you have any questions or queries in regards to this fundraiser please contact Mr. Don Kuryk, 652 Foxgrove Avenue, Winnipeg, MB R2E 0A7 at home 669-3987 or at work 945-5827.

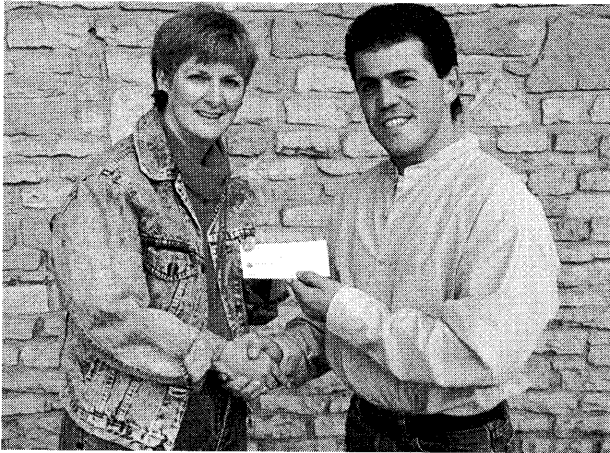
In anticipation of your support we advance our sincere thanks. ■

We are thrilled to hear of the potential support of many clubs, organizations and businesses.

We would be pleased to send further information or speak to you personally about our "Special Charity".

We are 100% volunteers and welcome your assistance.

Janis and Jim Benzelock are our "Special Events" co-ordinators. Call Jim at CJOB/97.5 FM (774-5577) or at home (667-0324)



Janis Benzelock and Kevin Neale presenting cheque for \$190.05 from golf tournament held at River Oakes Golf Course with City of Wpg. employees



Janis Benzelock and John Lemire, Boeing Baseball Tournament Recreational Club. Donation \$120.00.

Congratulations!! Dr. Agnes Bishop

Female MD first to head college

Excerpts from an article

by Kevin Duke, Wpg. Free Press Correspondent

A Manitoba doctor has become the first woman and the first pediatrician to be chosen as president of the Royal College of Physicians and Surgeons of Canada.

"I keep hearing...how well she has done for us," said Joan Wheeler, executive director of the Children's Hospital Research Foundation. "She's been an outstanding advocate for child health care."

Jim Rodger, assistant to the president of the Health Sciences Centre said Bishop is "first class all the way."

Bishop was elected last September to a two-year term as president of the Royal college.

Bishop is also chairwoman of the department of pediatrics at the University of Manitoba and holds the position of physician-in-chief of the Children's Hospital.

Last year, she was appointed head of pediatrics at St. Boniface General Hospital.

Bishop's term as president will give her the chance to further develop her Canada-wide reputation.

"She is a very compassionate person, very warm," said Dr. Ken Brown, registrar of the College of Physicians and Surgeons of Manitoba.

Bishop said she's already thinking about her role as president of the Royal College.

"I want to make sure our programs are in line with the needs of patient care," she said.

("She gave us the best advice we've ever had," said Janis and Jim Benzelock. "Let Jamie live as normal a life as possible and we'll take care of any problems that arise." This advice from Dr. A. Bishop gave the Benzelocks "a sense of normality in their life".

"She was always approachable. *No matter what*, she was always there. Her sensitivity was part of her patient care and we love her!!)

Jamie Benzelock was first diagnosed with SCN BY Dr. Agnes Bishop in 1976.

Rare blood disease eludes detection

20 cases in Manitoba 'just the tip of the iceberg'

By Randy Turner, Wpg. Free Press Reporter

By the time Jamie Benzelock turned 14, he'd seen enough of the inside of a hospital room.

Born with a rare blood disorder, Benzelock never knew when he'd be fighting off fevers or infections which would keep him in a hospital bed 40 to 50 days a year.

A sniffle or a little over-exertion could lead to a week-long stay in an isolation ward.

"It got to be one of those things," he said, "where I would look at a calendar and said, "This week I'll be sick, that week I won't, this

week I'll be sick, that week I won't..."

Benzelock, a Grade 12 student at Miles Macdonell Collegiate, still suffers from congenital neutropenia, a little-known disease that robs the blood of white cells, which surround and destroy bacteria in the body.

Symptoms of the disorder range from ear infections to cold sores to pneumonia—and it can be fatal.

Still, so little is known about neutropenia that many doctors are unable to recognize the disease, which can also develop in cancer patients who receive chemotherapy.

In fact, most victims are only diagnosed properly after repeated check-ups.

Lorne and Lorna Stevens' son Lindsey, for example, was not diagnosed with neutropenia until he was 18 months old. Doctors kept treating his infections, while telling the parents: "Don't worry."

"It may take four or five months even to get a blood test," Dr. Bonnie Cham, a pediatric haematologist at the Manitoba Cancer Research Foundation, said. "With a rare disease, it takes longer to make the diagnosis."

Stevens said some people who suffer a mild form of the disease can live their entire life warding off infections with antibiotics and never even know they have the disorder.

In Manitoba, there have been 20 cases of neutropenia diagnosed. But, Stevens said, that's only the beginning.

"We know because of a lack of awareness that's just the tip of the

Woman searches for answers about rare disease

By Randy Turner, Wpg. Free Press Reporter

When Lorna Stevens discovered her son Lindsey was born with a rare blood disorder, she wanted to learn everything she could about the potentially deadly disease.

"I'm the kind of person who needs information," Stevens, 40, explained. "And there wasn't any information that we could put our hands on."

So, for the last number of years, Stevens has been tirelessly searching for, and collecting, every morsel of knowledge about a little-known disease called neutropenia.

Now she wants to tell the world.

From the family's River Heights home, people from around North America—including doctors—call Stevens with questions about the disorder caused by a low white-cell count in the blood.

Those who suffer from neutropenia have difficulty fighting off infections, everything from cold sores to pneumonia.

And, if not properly diagnosed and treated with antibiotics, the disease can be fatal.



The Stevens family—Lorna, Lorne, Lindsey (9) & Lee (4).*

That is why Stevens founded the Neutropenia Support Association Inc., a Winnipeg-based group which now is making inroads around the globe.

In recognition of her efforts Stevens will receive the prestigious 1993 Canada Volunteer Merit Award from the Federal Department of Health. Dr. Jon Gerrard, Secretary of State for Science, Research and Development, will make the presentation today at the Westworth United Church.

In an interview, Stevens said neutropenia is so rare that many doctors do not yet know how to diagnose the disease. And patients and parents of children born with the disorder lack both support and answers.

Not only does the support group distribute information about neutropenia in a newsletter, but the association allows people affected by the disorder something they lack—understanding. Stevens has logged upwards of 1,000 calls from across North America on the association's toll-free line—a phone in the family's basement—since it was set up last January.

The Stevens' son, now 9, is still being treated with antibiotics. ■



Janis, Jim, Jenna (14) & Jamie (18)*

iceberg," Stevens, founder of the Winnipeg-based Neutropenia Support Association, said.

Not too many years ago, children born with neutropenia often didn't live past the age of two. Then antibiotics were developed, allowing doctors to keep kids like Lindsey Stevens and Jamie Benzelock alive.

The biggest medical breakthrough, however, has been the development of a drug called granulocyte colony stimulating factor (G-CSF), a hormone the body produces naturally to make white blood cells. For many patients, it's a miracle cure. Their infections disappear.

However, due to its expense and infancy, only those with the most severe cases of neutropenia use G-CSF. ■

Thank you to:

- The Winnipeg Free Press
- CKND-TV
- The Winnipeg Sun
- CJOB/97.5
- Canadian Publishers
- MTN-TV

- for increasing awareness
- 5 "new" families responded to news
- Also, sincere appreciation extended to Rev. Eleanor Geib, Shirley Watts and others helping host the event at Westworth United Church.



Pictured are Bill Burns, "W.C. Fields" and Lorna Stevens

Congratulations!

The management and staff of DELBRO Real Estate recognized the outstanding volunteer work of Lorna Stevens at their recent awards presentation.

Concern for the needs of others has marked the career of Lorna and our community is the better for her work.

— Bill Burns

Reductions in Pharmacare Coverage

It is our view that the access to health care is fundamentally undercut when patients cannot afford the medications which are prescribed by their physicians. As more and more Manitobans lose their ability to purchase these necessary medications for themselves and their families, the incidence of more serious illness and hospitalization will undoubtedly increase.

We support the view that there are other ways to successfully combat the rising cost to government of pharmaceutical products without gutting this program. Specifically, a partnership between the Prairie Provinces in the purchase of pharmaceuticals and other medical supplies, similar to the recent arrangement entered into by the Maritime provinces. The establishment of a Drug Use Management Centre is currently being considered by the Manitoba Pharmaceutical Association and the College of Physicians and Surgeons. This Centre would evaluate the effectiveness of pharmaceuticals and act as a resource centre for physicians seeking to prescribe the least costly effective medication.

This is an important time to take a stand for the Pharmacare program. It is an essential component of our health care system. ■

Send your viewpoint to Premier Gary Filmon, Manitoba Legislative Assembly, Winnipeg, Manitoba, R3C 0V8

The N.S.A.I. has provided a Neutropenia and Chemotherapy article to the Candlelighters Childhood Cancer Foundation of Canada. Excerpts will be printed in Vol. 7.

"Making A Miracle Happen"

Available in May at Saan Stores, Winnipeg: Children's Hospital Research Foundation T-Shirts.

(In Canada) WOULD YOU LIKE TO BE A VOLUNTEER? INFORMATION ORDER FORM

AREA OF INTEREST AS VOLUNTEER: _____

_____ Would like a N.S.A.I. "buddy" or "penpal"

_____ Would like Canadian Neutropenia Registry information

NAME _____

ADDRESS _____ PHONE NUMBER _____

PROVINCE _____ POSTAL CODE _____

SEND TO: P.O. Box 243, 905 Corydon Avenue, Winnipeg, Manitoba, Canada R3M 3S7

OR CALL: In Winnipeg 489-8454 **TOLL FREE:** 1-800-6-NEUTRO

SCN DISEASE REGISTRY

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) 543-3947

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

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

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.

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