Family Meeting offers chance for networking

A meeting for those with neutropenia and their families is coming in August 2005.

For five years now, patients and their families have gathered for medical updates on their rare blood disorder and to share their stories at this very special conference. Please consider joining us for this year’s meeting on Saturday, August 13 at the University of Washington in Seattle.

Dr. David Dale will discuss the latest medical news regarding neutropenia and research periodontist Dr. Frank Roberts will talk about gum disease as it affects those with neutropenia. The information is important, but organizer Anna Bolyard, RN said there is a deeper meaning to the meeting.

“There is a lot of value to the information, but I don’t think that is the sole value to the meeting,” she said. “I think the value to the conference is meeting other people that have this unique and very rare condition and having a chance to talk to them. That sharing of stories at lunch time and afterward is, I think, the value in the meeting.”

Dr. Dale sees the meeting as an op-

Continued on Page 3

Remembering Leta

This newsletter is dedicated to the memory of our daughter, Leta, who died at the age of twenty of a failed bone marrow transplant. Leta once said, "Mom I’m not really afraid of dying. I’m just afraid of being forgotten." Not only is she remembered with great love, her memory remains a vivid and powerful force in our lives and her vibrant spirit continues to inspire our days.

Leta spent the first twelve years of her life in and out of hospitals with infections resulting from Severe Congenital Neutropenia. Her early battles with illness and mortality gave her a unique view of life. Leta showed us how to see the world anew each day, how to embrace and celebrate the small things in life that many of us take for granted.

Leta Reeves was diagnosed in 1978 at the age of two. Her early years were harrowing with endless journeys to emergency rooms, surgery for a liver abscess that refused to heal, and months of hospitalizations for a myriad of infections. One of our greatest challenges in parenting Leta was the sense of isolation that comes with not knowing a single person with the same disease. We longed to compare notes with other parents who were facing the same challenges.

Continued on Page 2

In this issue

Diagnosis is a surprise 5
Family copes with CN 6
Registry information 7
Continued from Page 1

After Leta experienced the miracle of Neupogen® and her counts recovered, we all wanted to forget her disease, to put it on the back shelf. This made sense for a time, but concerns came up about the injections and she went through some emotional difficulties in her teen years struggling to come to terms with what normal was for her.

This newsletter is an attempt to provide information and support to neutropenic individuals and their families living in the United States. We want to revive a non-profit initiative started in the early nineties “to promote awareness, education and research and provide a support system for patients with neutropenia and their families through a national resource network.” The organization was active for several years but due to life changes among the members, it has lost steam. Fortunately the nonprofit legal framework is still in place.

Currently there is a wonderful neutropenia support group in Canada headed by Lorna Stevens. We see our effort as a complement to the Canadian organization. Our key distinction is our focus on the U.S. institutions that impact neutropenic patients and their families such as health care, education and research.

The key to our success will be member involvement. I’m sure many of our readers have helpful tips and stories to share, suggestions to make life easier for others facing the challenge of life with neutropenia. It may be a tip on oral hygiene, or an effective way to explain the disease to school officials, a technique to make injections easier, or advice on preparing for vacations. The idea is to communicate about the best practices for managing the disease of neutropenia, to inform about the latest research and ultimately to help each other through the hard times.

We believe there is much that we can do to improve the lives of those who live with neutropenia. We hope this newsletter is a step in that direction.

Sincerely,
Lee & Louis Reeves

The National Neutropenia Network
Newsletter is published twice yearly.
Editor/Publisher: Lee Reeves
Writer: Cyndi Lieske

Comments and contributions are always welcome. Contact Lee Reeves at (810) 229-5797 or e-mail at leereeves99@comcast.net, or mail at 4648 Pine Eagles Drive, Brighton, MI USA 48116 with articles, photos and letters.

Board of Directors

The following individuals have agreed to serve as board members to help invigorate the National Neutropenia Network. If we are to succeed we will need more dedicated individuals to join this leadership core, individuals willing to contribute time or resources in the area of communications, public relations and fundraising.

Kent Beall is the father of Grant, a young man with Cyclic Neutropenia and a powerful story that conveys the need for a more enlightened medical community on the disease of neutropenia. We plan to feature Grant in the next newsletter. Kent lives in Fremont California and can be contacted sbeall6@comcast.net.

Silke Deeley is the mother of Alyssa who has Idiopathic Neutropenia. Silke has held together the National Neutropenia Network in recent years. She has been involved since its inception over a decade ago. For many years she hosted an 800 number hotline in her home. Silke lives in Leesburg, Georgia. Contact her at sedjd3@msn.com.

Victor Lopez is a personal friend and accountant who has volunteered to help oversee the finances of the organization.

Lucy Lyman, a mother of two with Cyclic Neutropenia is featured in this newsletter. Lucy has wanted to see a strong support group for people with neutropenia for many years. She attended last year’s family meeting and followed up by creating an information data-base on the participants. She lives in Las Vegas Nevada. Contact Lucy at Thawke1@aol.com or (702) 914-0156.

Lee Reeves welcomes your calls or emails requesting help or volunteering to support the effort to revitalize the National Neutropenia Network. Email at leereeves99@comcast.net or call at (810) 229-5797.

Dennis Shoher is the father of Joli who is featured in this publication. Joli struggles with a particularly difficult and enigmatic form of the disease. The battle with Neutropenia remains a difficult complication in their daily lives.
Family Meeting Continued

Portunity for physicians to hear patients concerns and at the same time provide the most current information on neutropenia “I think we benefit from what people tell us in terms of learning what is important to them,” he said. “The closeness helps us to do better in our jobs.”

For many people, the conference offers a first-time chance for people to meet someone else who also has neutropenia. “There is such isolation with a rare condition or disease—imcredible isolation” Boylard said. When you have a chance to meet someone that is working through it, it lets you know that you can work through it too. It gives you hope that you can work through it.”

Each year people leave the family meeting with names and e-mail addresses of others they can reach out to for support and information. Connections are made that can help sustain families.

“I think that is where people become e-mail friends and become their own little support group,” she said. “They have a chance to share the difficulties they have had and how they have managed to overcome those difficulties.”

Bolyard believes that many of the adults attending the meeting will be interested in learning more about obtaining social security benefits.

“I think that is where the adults help each other,” she said. “They can ask each other, ‘What did you present to social security?’ and ‘What did you do to make that work?’ she said.

The parents of children with neutropenia will likely be interested in learning ways that other parents balance their child’s school life and extracurricular activities while keeping the child healthy. There are also issues of dealing with school administrators and making sure that accommodations are made for students with neutropenia. They can share what battles they have had to fight, especially in schools when their children do not feel well,” she said. “So they share ideas of helping each other become the child’s best advocate. It is unique and different for them to sit down together and say, ‘this is what I did.’ They can supplement their own work with what other people have done.”

For the children who attend, they have a chance to meet other children with neutropenia, Bolyard said.

“Children may feel that they look different from non-neutropenic children. At the meeting they see other children like themselves and see that those children look just fine. They start to realize they look just fine, too… it is of great value to children to realize they are not alone.”

The session includes a question and answer period with Bolyard.

“There is usually a kind of a free-for-all discussion time where participants get to ask questions,” she said.

Last year, more than 60 people attended the event. Participants come from throughout the United States to attend the meeting.

“Tennessee, Florida, California, Alaska, from just from all over the place,” she said.

This coming meeting should be one of the best ever with a special session devoted to managing the periodontal problems that come with neutropenia and time devoted to discussing the support needs of families and patients. ★

---

SCNIR Patients by Age, Gender and Diagnosis

December 2004

![Graph showing the number of patients by age, gender, and diagnosis.](image-url)

- **Number of Patients**
- **Gender**: Females, Males
- **Diagnosis**
  - Congenital
  - Cyclic
  - Idiopathic
  - Other

---

Pediatric

- Congenital
- Cyclic
- Idiopathic
- Other

Adult

- Congenital
- Cyclic
- Idiopathic
- Other
Bolyard works to teach others about SCN

In 1994, Audrey Anna Bolyard, RN had a major struggle with a search engine to have neutropenia recognized as a key search word.

“When we started in 1994 you searched under key words like ‘heart,’” she recalled. “I wanted the major search engine to add ‘Neutropenia.’ They refused.”

Bolyard said they were suspicious because the Registry only had a contact page at that time. There was not enough information contained on the page to warrant a key word she was told. She did not relent. She continued to request the key word.

After a few months she was successful.

“Through communications between myself and the search engine representatives I was able to convince them add a key word ‘Neutropenia,’” she said.

Now, there are plenty of resources on the Internet for learning about neutropenia, she said. One of them is a handbook that Bolyard helped to write.

“From the 1994 banner to the current web page, which is extensive,” she said. “We have come a long way.”

The site http://depts.washington.edu/registry/ has extensive information on neutropenia.

“I am extremely proud of the handbook,” she said. “It has a tremendous amount of information. The handbook will help patients, families, and health care practitioners learn about severe chronic neutropenia.

Over the years, Bolyard has become an activist for people with neutropenia.

“It has been interesting struggle,” she said. “I found that there was a real need for advocates for this patient population. Currently one of our goals is to supply information that will help patients working with the social security system. We are hopeful our efforts will help individuals with neutropenia (that need social security benefits) to be recognized as disabled.”

“When something doesn’t exist, how do we work through it enough until it does exist?” she said. “In 1994 it was key words. I think the same thing is happening with the social security system. I think the more we work to get people recognized as disabled, the easier it will for the next person and the next person to work with the social security system.”

### Neutropenia Patients By Country

<table>
<thead>
<tr>
<th>Country</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>47</td>
</tr>
<tr>
<td>Austria</td>
<td>12</td>
</tr>
<tr>
<td>Belgium</td>
<td>23</td>
</tr>
<tr>
<td>Brazil</td>
<td>1</td>
</tr>
<tr>
<td>Canada</td>
<td>35</td>
</tr>
<tr>
<td>Chile</td>
<td>12</td>
</tr>
<tr>
<td>Costa Rica</td>
<td>1</td>
</tr>
<tr>
<td>Cuba</td>
<td>1</td>
</tr>
<tr>
<td>Czech Rep</td>
<td>3</td>
</tr>
<tr>
<td>Denmark</td>
<td>1</td>
</tr>
<tr>
<td>France</td>
<td>6</td>
</tr>
<tr>
<td>Germany</td>
<td>111</td>
</tr>
<tr>
<td>Greece</td>
<td></td>
</tr>
<tr>
<td>Honduras</td>
<td></td>
</tr>
<tr>
<td>Hungary</td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
</tr>
<tr>
<td>Japan</td>
<td></td>
</tr>
<tr>
<td>Luxembourg</td>
<td></td>
</tr>
<tr>
<td>Morocco</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Norway</td>
<td></td>
</tr>
<tr>
<td>Poland</td>
<td>10</td>
</tr>
<tr>
<td>Portugal</td>
<td>1</td>
</tr>
<tr>
<td>Puerto Rico</td>
<td>4</td>
</tr>
<tr>
<td>Russia</td>
<td>10</td>
</tr>
<tr>
<td>Serbia</td>
<td>11</td>
</tr>
<tr>
<td>Spain</td>
<td>33</td>
</tr>
<tr>
<td>Sweden</td>
<td>1</td>
</tr>
<tr>
<td>Switzerland</td>
<td>2</td>
</tr>
<tr>
<td>Turkey</td>
<td>1</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>11</td>
</tr>
<tr>
<td>United States</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>1163</td>
</tr>
</tbody>
</table>
Seattle meeting solves mystery for mother of two

Attending the Family Meeting in Seattle in 2004 was a bright spot in a tumultuous year for 30-year-old Joli Shober of Helena, Montana.

In August, Shober traveled to Seattle for a consultation with Dr. David Dale where she was diagnosed with Severe Chronic Neutropenia.

Just one day later, Joli and her father, Dennis Shober, visited the conference where she met several others who have the disorder. She heard their stories and shared her experiences.

"That was perfect timing," Joli said. "That was a great experience we learned a lot. We were pretty lost before we went there. We didn’t know what to do or where to turn. There were not any people around here that had any knowledge of it. With the misdiagnosis we were not heading down the right path."

In the several months before her diagnosis Shober, a single mother with two young children, was in and out of the hospital with several infections and other illnesses. In December 2003, she was diagnosed with an atypical form of rheumatoid arthritis, Felty’s Syndrome and her enlarged spleen was removed.

"She was really having a tough time," Dennis Shober said. "By that time we were starting to get suspicious. We were at our wits’ end. She was really going downhill fast."

When her parents were not satisfied with the diagnosis of Felty’s Syndrome, they sought the opinion of the rheumatologist Shober had seen when she had juvenile arthritis.

The doctor told them she suspected SCN and referred Joli to Dr. Dale.

For Dennis Shober meeting Dr. Dale was the first step in making sense of his daughter’s illness.

“It was quite an extraordinary experience,” Dennis Shober said of the consultation with Dale. “It was very fulfilling and very rewarding. We finally found someone could tell us something. Nobody around here knows anything about neutropenia. They say you could practice medicine for a lifetime and never see a case.”

Before attending the conference the Shobers did not know what having neutropenia would mean for Joli.

“It was an amazing learning tool for us and I believe for everybody that was there,” Joli said. “Most of the people that were there were in the same boat as me. There were misdiagnoses and nobody knowing how to treat it.”

Currently, Shober is still trying to find the correct dosage of Neupogen® to help her body fight the neutropenia. “She has taken daily shots now and they just had to increase her doses because her neutrophils were just not coming around,” Dennis said.

As a child, Shober endured many infections and unusual illnesses. She was diagnosed with juvenile arthritis at age seven. Her parents suspect she may have had neutropenia for years before her diagnosis.

"Looking back at her childhood, we are wondering if she didn’t have this some time ago and if nobody knew what the problem was," Shober said. “That is our personal opinion, but I don’t know if that can be medically proven or not.”

Her parents remember last Christmas when Joli should have been hospitalized with a fever of 104 degrees, but she resisted because she did not know if it would be her last Christmas with her children, a daughter who is six and a son who is three.

Shober estimates she has been hospitalized “nine or ten times” in the past 18 months.

“I get a lot of toxic kidney infections,” she said. “I had my spleen removed and that has made me more susceptible to infection. I get bone infections in my jaw. I have a lot of mouth ulcers.”

Last year Shober had all of her teeth removed and she frequently has to live with the side effects of taking so many antibiotics.

“I have consequences from all around” she said. “One thing leads to another.”

Joli’s frequent illnesses in the past year meant a move for her and her children from Miles City, Montana to Helena, Montana so she could be closer to her parents. Shober’s parents care for her children when she is hospitalized.

“This thing is really debilitating,” Dennis Shober said. “I feel so sorry for her because we see what it does to her on a daily basis. With no white blood cell count you always experience extreme exhaustion. We really do admire what she is doing. She is a great mother and she is doing a great job.”

Earlier this year, Dennis Shober spent a lot of time trying to make sure that his daughter would get the Social Security Administration benefits she was due. When they first applied for benefits, Joli’s request was denied.

Continued on Page 8
Two in family learn to live with CN

Lucy Lyman has lived with Cyclic Neutropenia all of her 26 years, but it was only two years ago that she was able to meet another person with the blood disorder.

“It can hardly be put into words,” Lyman said. “It was just amazing to have someone to talk to that knows what you’ve been through.”

Lyman was first hospitalized at three months old and then frequently hospitalized after that with pneumonia and other illnesses that doctors could not determine a cause for. It wasn’t until she was nine, that she was diagnosed with Cyclic Neutropenia.

“I’ve been hospitalized too many times to count, I have had everything in the book you can possibly get,” she said. “That was before the medicine.”

When Lyman was 11 she was able to start with the second group of patients who received Neupogen®. Taking the medicine has changed her life and her daughter’s life. Lyman’s oldest daughter, Jessie, who is four, was diagnosed with Cyclic Neutropenia at six months old.

“For her first two weeks we did a blood test every other day,” she said. “From that we knew her counts were a little low. At her lowest point they did a bone marrow biopsy and they determined that her counts were too low and she started on the medicine at six months old. We were very lucky to know.”

Knowing means Lyman’s daughter has had a very different experience, than the one her mother had growing up with Cyclic Neutropenia. She has been hospitalized only once and she has been in good health much of her life.

“She has a hard time sometimes, just like you would expect,” she said. “She knows that she has a special body and she has to be especially careful and wash her hands. When she gets a cut we have to clean it out really well. She knows that. Other than that, she is a vibrant, energetic four-year-old.”

Lyman believes promoting awareness of Cyclic Neutropenia and all the support available to individuals with neutropenia and their families is very important. She has tried to contact other patients who see the same hematologist she does in Las Vegas, Nevada. She’s made up flyers and given out her phone number. So far, no one has contacted her.

“I have tried to start a support group through the hematology department,” she said. “I had the doctor hand flyyrs out to all of his hematology patients. I have no way to get a hold of them. It is just one of those mysteries. I think people are just hoping it will go away. This newsletter is the best first step that we could have taken.”

After living so many years without knowing others with the disorder, Lyman just wants to make sure others do not have to think they are alone.

“I think the hardest thing for me was that there was no one else,” she said. “The isolation and the lack of support were the major problems for me. I don’t want my daughter to have to go through that.”

There are still times that Lyman has to explain the disorder to doctors that can be frustrating. She would like to see more efforts toward educating the public about neutropenia. Lyman knows that the Cyclic Neutropenia was passed to her through her father.

“The thing with cyclic is it can be very mild or very severe,” she said. He had problems with his teeth, but nothing that would have ever have made him think he was sick. He has the gene mutation. We just got the results back last year.”

The blood test for her father took about three years to process. His blood was drawn in 2001 and the results came back last year. Lyman said. She knows her second daughter, who is two, does not have Cyclic Neutropenia.

She continued taking Neupogen® throughout both of her pregnancies. She was aware of the chance for a slightly higher risk for kidney or heart abnormalities, but she did not experience any problems.

Prior to her pregnancy, Lyman and her husband spoke with doctors about their concerns.

“That’s another good thing to get out there,” Lyman said. “People are scared to get pregnant they are either afraid to pass the disease on or they are worried about staying healthy. If you have the right doctors everything will go all right. I would like to have known that.”

Because there are so few people who have Cyclic Neutropenia, Lyman did not have a lot of information about what might happen during her pregnancy. She now knows the Neupogen® allowed her to experience a pregnancy with no complications.

“It has been great it was a lifesaver literally for me and for my daughter,” she said.
Getting Connected

Websites

The SCN registry currently has a website at United States the website is located at: http://weber.u.washington.edu/~registry

Delphiforum has a neutropenia site at http://forums.delphiforum.com/Neutropenia/

Neutropenia Support Assoc. Inc.
contact Lorna Stevens
President and Co-Founder NSAI
http://www.neutropenia.ca

We WANT TO HEAR FROM YOU!

* Do you wish to receive future copies of this newsletter?

* Do you have suggestions for stories that would be most helpful for you?

* Do you have a story to tell?

* Would you consider supporting the National Neutropenia Network with your time or resources?

If so, please contact Lee Reeves at (810) 229-5797 or by e-mail at leereeves99@comcast.net

Severe Chronic Neutropenia Advisory Board Members
revised April 19, 2005

David C. Dale, MD, Co-Director
University of Washington
Seattle, WA, USA
Phone 206-543-7215

Professor Karl Welte, Co-Director
Kinderklinik, Medizinische Hochschule
Hannover, Germany
Phone 49-511-532-6710

Blanche Alter, MD, MPH
NIH, National Cancer Institute
Rockville, MD, USA
Phone 301-402-9731

Mary Ann Bonilla, MD
St. Joseph's Children's Hospital
Paterson, NJ, USA
Phone 973-754-3230

Laurence A. Boxer, MD
University of Michigan
Ann Arbor, MI, USA
Phone 734-764-7127

Bonne Chamberlain, MD
CancerCare Manitoba
Winnipeg, Canada
Phone 204-787-2188

Jean Donadieu, MD
Service d'Hematologie et Oncologie Pediatricque
Hopital Trousseau
Paris, France
Phone 33-1-44-73-60-62

George Kannourakis, MD
Ballarat Oncology& Haematology
Wendouree, Australia
Phone (61) 3 5339 8000

Sally Kinsey, MD
St. James's University Hospital
Leeds, UK
Phone 44-113-206-4985

SCNIR Board member, Patient Advocate
Lee Reeves
Brighton, MI, USA
810-229-5795

SCNIR Offices

USA
Audrey Anna Bolyard, RN, BS
Seattle, WA
Phone 206-543-9749
800-726-4463

Germany
Beate Schwinzer, PhD
Phone 49-511-557105

Conrad Zeidler, MD
Phone 49-511-546-0918

A special thank you to SCNIR staff for assisting with the mailing of this newsletter.
continued from page 5

"I never heard anything for a couple of months," Dennis said. "I am kind of like a pit bull on a pant leg when I get my mind made up. I went down to the Social Security office and said 'What's going on here? We have a serious illness here and we need some answers.'"

After filing two appeals and making it through an extra review that took an additional week, Joli has now been approved to receive benefits.

Joli is among an unfortunate small minority of patients who have had a poor response to Neupogen®. She is hoping that she will respond well to a newly prescribed dosage and that she will soon experience an extended period of health.

"We just try to take one day at a time and be thankful for each one," Joli said. "This has been a tough year, emotionally and physically - the whole works."

She said she is grateful for the help from her parents, sister, cousins and many extended family members.

"Without them I would be lost," she said. "I have such a great support with my family I am not sure where I would be now if I didn't have them."  

---

**SCNIR Patients By Diagnosis**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital</td>
<td>422</td>
</tr>
<tr>
<td>Idiopathic</td>
<td>349</td>
</tr>
<tr>
<td>Cyclic</td>
<td>205</td>
</tr>
<tr>
<td>Autoimmune</td>
<td>68</td>
</tr>
<tr>
<td>Glycogen Storage Disease</td>
<td>42</td>
</tr>
<tr>
<td>Shwachman-Diamond</td>
<td>37</td>
</tr>
<tr>
<td>Barth</td>
<td>10</td>
</tr>
<tr>
<td>Myelokathexis</td>
<td>8</td>
</tr>
<tr>
<td>Immunodeficiency</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
</tr>
<tr>
<td>Total Patients</td>
<td>1163</td>
</tr>
</tbody>
</table>