



national neutropenia network

awareness, education, research and support

A Letter from Lee

The 2015 Family Conference was a weekend of firsts. It was the first time Audrey Anna Bolyard, clinical manager of the SCNIR, was able to join us for the entire weekend. It was the first time we videoed the educational sessions to make them available to all patients via the internet. It was the first time we had our own official t-shirts for sale. It was the first time we hosted a session on transitioning from pediatric to adult hematology, and for many it was their first Family Conference.

The new features and first-time attendees are an important aspect of the Conference, but something else caught my attention this year, there was a core of visitors who have returned repeatedly over the years. For them the Conference has become a warm hearth, a place where they can be themselves, where they can talk about their struggles with neutropenia without fear of judgement, without having to explain to puzzled faces how their bone marrow doesn't work.

When we started hosting the Conference over a decade ago, I wanted to create the kind of experience I could only dream of as the mother of a child with severe congenital neutropenia in the 1980s. I wanted to give patients and families a chance to meet and get to know each other, a chance to ease the pain and stigma that comes from having a disease virtually unknown to the rest of the world. We have done that but I never could have imagined the ties that would form among patients and families, the deep camaraderie that would grow and strengthen over the years—a second family bonded together by a rare disease. It's a welcoming family, an open hearted one where new visitors can feel immediate trust and comfort.

One family that has been integral in fostering a hospitable atmosphere is the extended family of Conference coordinator, Mara Lim who has spent countless hours working to assure the event runs smoothly and meets visitors' expectations. Her mother Charlene Teel has volunteered for several years. We are especially grateful that Charlene agreed to spearhead the successful new ConnectCare clubhouse on Saturday afternoon. Mara's brother, Mat Solomon, volunteered this year, and found himself inspired by the chance to share time with others who have neutropenia. In past years Mat has not seen much benefit of discussing his neutropenia, but this year he found his voice, talking about his struggles and sharing coping mechanisms he has developed over the four decades he has lived with neutopenia. Mat hopes to come back in the future and to continue to make a difference by sharing his own story and listening to others. Mat started a Facebook page called, Neutropenia for Dudes and Everyone Else.

In addition to families returning year after year, we are fortunate to have a core of physicians who join us regularly: Laurence Boxer MD, Maryann Bonilla MD, David Dale MD, Peter Newburger MD, Akiko Shimimura MD. They share their expertise in formal presentations and private consultations, they join participants during meals and informal times. We are so fortunate to



WHAT'S INSIDE

- 2016 Conference Basics.....2**
- Practical Wisdom from Audrey Anna 4-5**
- Olivia's Story6**
- Ron's Story.....7**
- Vanessa's Story..... 8-9**
- Australian Family Conference..... 10-11**
- A Fun Event for Our Cause 11**

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Cont. on page 2

A Letter from Lee Cont.

have such a dedicated knowledgeable group of physicians willing to freely share their expertise and time, a rarity in today's world.

Another facet of the Conference that gives it a family feeling is the presentations from individuals with neutropenia. For many years Shay Jones MA LPC who has congenital neutropenia has headed up popular sessions that address the psychological and emotional challenges of living with neutropenia. This year we added a talk on Integrative Medicine Therapies for Better Living with Neutropenia, presented by Galie Jean-Louis who began her presentation by sharing the challenges she has faced living with idiopathic neutropenia. We heard from Kristin McGuinness, founder of Ella Jewell Foundation who talked of her journey as the mother of a child with congenital neutropenia, and Olivia Schroder who shared her experience growing up with neutropenia.

I cannot close an article about the family feeling at the Conference without noting the feature nearest and dearest to my heart, Neutropenia Kids Kamp. I know how much it would have meant to my daughter to go to a camp with children who lived under the constant threat of life-threatening infections as she did. Even in today's world where neutropenia is far better managed than it was thirty years ago, children still experience feelings of isolation, of not being normal, but at Neutropenia Kids Kamp for the first time in their lives, they are among peers. They spend happy active time with other children who also must take shots and get bone marrow aspirations. They learn about their disease in a safe open atmosphere where having fun is a priority. It is a joy to see their happy faces, and to watch their friendships form and grow. This I believe is the most life-changing aspects of the Neutropenia Family Conference. It is what inspires me.

On the weekend of July 8, 2016 we will once again welcome many returning friends to Ann Arbor and they will reach out to make the newcomers feel at ease and part of the family. I hope you can make it.

2016 Conference Basics

The 2016 Neutropenia Family Conference will be held July 8-10 at the beautiful Marriott Eagle Crest www.annarbormarriott.com. The National Neutropenia Network has reserved a block of rooms at a discounted price of \$114 plus tax, per room. We recommend reserving as early as possible.

Conference fees are inclusive. They include all presentations, handouts, children programs, and meals: Friday reception, breakfast, lunch and dinner on Saturday and Sunday breakfast.

Early Bird (Before April 1): \$175 each for 12 years and up; \$100 each 4 to 11 years

Regular Registration (April 1 and later): \$195 each for 12 years and up; \$120 each 4 years to 11 years

Visit neutropenianet.org, and click on the Conference tab to register. Registration and hotel booking will be available after December 14.

How about asking for help with Conference attendance as a Christmas gift!

Important: There will be NO Family Conference in 2017.

Patient Assistance Grants

As in past years we will award grants to patients and families who cannot attend the Neutropenia Family Conference without financial assistance. The grants generally only cover partial costs of attendance. Preference is given to those who have not attended a Conference. We do not yet know how much funding will be available. We depend entirely on donations from friends and family who understand what it means to live with neutropenia.

Donors may contribute to the NNN through neutropenianet.org or the National Neutropenia Network PO BOX 1693, Brighton, MI 48116. Donations are tax deductible. Check our website in early spring for more information on Patient Assistance Grants.



Kampers create their own planet



Dr. Dale talks about the SCNIR



Dr. Newburger talks about staying healthy



Kids Kampers 2015



Shay Jones facilitates group discussion



Taylor Carlton, Shay Jones, Mat Solomon

Practical Wisdom from Audrey Anna

Audrey Anna Bolyard, the Clinical Manager of the SCNIR (Severe Chronic Neutropenia International Registry), has witnessed a lot of “firsts” during her 37-year association with neutropenia.

In 1988 she joined the clinical trial team at the University of Washington, headed by Dr. David Dale that first tested neutropenic patients' response to Neupogen given daily to manage severe chronic neutropenia.

In 1994, she was involved with the creation of the Registry for severe chronic neutropenia patients, establishing a global database of treatment and disease-related outcomes for persons diagnosed with SCN. The Registry tracks members' medical data for use in research related to the causes and treatment of the blood disorder.

“I started working at the University in 1978, in those early years working as a research nurse on the wards I met the person who would become the first person to take long-term Neupogen therapy,” Bolyard said.

She became the Registry's clinical manager in 1994, a position she holds today.

It seems fitting, then, that she experienced another “first” this past summer at the 2015 NNN Family Conference in Seattle when she met, face-to-face, Registry patients whom she had known for years, but only by telephone or through the Internet. “It was great to meet people for the first time that I've known for years through the Registry,” Bolyard said. “We get to know each other over the phone, so it was like meeting an old friend. One woman said she remembers me when I had long red hair and was surprised to find that it is gray now! It was just lovely to meet people I've actually known for years.”

Her role as clinical manager has evolved since 1994, when the Registry was started, Bolyard said. “It was the first registry at the University, so we didn't have a model or know how to create a registry. We developed systems about how to collect data from people over years and years. It was much like a clinical trial in the beginning.”

Now, she said, the Registry also is heavily involved in outreach, providing expertise to help doctors, patients and their families to learn about neutropenia. “It's rare for most physicians to understand what it is,” she said. “When they find that a patient has a low blood count, the first thing they assume is leukemia. They are not even aware that there's another possible diagnosis.” A focus of the Registry is to increase awareness about and understanding of neutropenia, among both patients and the medical establishment.

“We also publish a great deal,” Bolyard said, adding that the SCNIR website at www.depts.washington.edu/registry includes a comprehensive bibliography of publications covering the period from 1993-2008. For more focused information on pertinent publications, interested patients and other individuals can contact Bolyard at bolyard@uw.edu.

Bolyard's job description expanded as the Registry grew, said Lee Reeves, director of the National Neutropenia Network (NNN). “If someone is having trouble with their dose, she talks to them. She has probably talked to more patients than anyone else over the years. Everybody loves her. She is an icon in this world.”

Although neutropenia is a relatively uncommon condition, more than 1400 patients are registered on the SCNIR, Bolyard said. That figure represents only a portion of the total population of those who have neutropenia because there are several forms of the blood disorder and many patients are undiagnosed at this point.

The most important thing that people who have or suspect they have neutropenia can do is to get educated, Bolyard said. “Find out everything you can. Do your homework. Get online. Find out what the current thought is about medication. You may have to educate your doctor about neutropenia.”

“We let people know that there are other pathways,” Bolyard said. “The most important part of this story is that there IS help with rare conditions, and the work is generally done by the family and the patients. The world is very small now, thanks to the Internet. You can find local, national and international experts. Once you locate the experts,” she said, “you CAN get help.”

But first and foremost, she said, get educated!

The “Spit Test” seeks clues

As part of ongoing research into the causes of neutropenia, Audrey Anna Bolyard collected saliva from neutropenic participants who attended the 2015 Family Conference in Seattle. “We collected samples of DNA in the easiest way possible” (by having people spit into a test tube), Bolyard said. DNA also can be collected through samples of blood, bone marrow and skin.

This collection is a sub-study of the Repository Study, whose goal is determining causes of neutropenia specifically through DNA samples, Bolyard said. “We are looking at a large group of people who have long term neutropenia, focusing on neutropenic patients that do not have a known genetic mutation. Our goal is to discover if there are other genetic causes for neutropenia.”

The collection was so popular that Bolyard ran out of tubes to test everyone who wanted to donate their saliva, she said.

***“Audrey Anna has been instrumental to the Registry’s success. She has supported hundreds of patients with thoughtful guidance and compassion. Her value to the neutropenic patient community is beyond measure.”
–David C. Dale MD***

Applying for the Registry

Tips provided by Audrey Anna Bolyard, clinical manager of the Severe Chronic Neutropenia International Registry (SCNIR)

1. The process may be initiated by the patient or the doctor.
2. The patient’s registration form will include requests for the following:
3. 3 or more CBCs with ANC less than 0.5×10^9 within 3 months before the initial dose of G-CSF (Neupogen). If cyclic neutropenia, then provide 3x/week for 6 weeks.
4. Bone marrow and cytogenetic evaluations done prior to enrollment. This includes one stained and one unstained bone marrow slide if available.
5. Bone density evaluation if available.
6. Genetic testing if available: Common tests are ELANE, HAX1, GSD 1b, SBDS, and TAZ.
7. Autoimmune testing if available: common names for tests are Anti-Neutrophil Antibodies, Granulocyte Antibodies, and ANA.

Obtaining the medical records from the procedures and tests can be time consuming. Keeping copies of tests will help when you apply to enroll in the Registry.

Olivia's Story

Olivia Schroeder is lovely, vivacious, talented and, she likes to say, a normal 20-year-old who enjoys soaking up the sun in the still warm days of fall, writing poems, designing her own clothing and walking her puppy. She has attended the Art Institute of Chicago and is currently working on developing her art.

She has also lived with neutropenia for all of her life.

It can be difficult, Schroeder said, "but I'm still living a happy life."

Those words were the focus of her talk about living with neutropenia at this past summer's NNN Family Conference in Seattle, emphasizing the positive aspects of her struggle with the bone-marrow disorder. "It was an incredible experience to speak at the Conference," said Schroeder, who said she believes she was at the first NNN Family Conference ever held.

"I think I had something to say that needed to be addressed," she said. "I live a very normal life and had a very normal childhood. I think a lot of parents don't realize that their children can be normal, successful and happy." She advises parents not to be afraid of their children going to a playground, or to daycare or a public swimming pool. "I wanted them to know their kids can be happy."

Schroeder's father also has neutropenia, which she said has made it easier for her to deal with it. "I was lucky to grow up with another neutropenic person, my dad, so that helps me normalize," she said. "My parents have always been very supportive." Indeed, said Network founder Lee Reeves, her entire family has been supportive of Schroeder and of the Network, as well. "Three generations of her family were at the Conference this year," she said. "Olivia's grandmother was one of the first to donate to the Network."

"When I saw Olivia go up to the podium (at the Conference), I was proud and happy," said her

grandmother, Mary Schroeder. "There was my granddaughter, who I had seen grow up living with neutropenia, and she was about to share her experiences with people who she hardly knew. Many of them were just getting used to either their diagnosis of neutropenia or that of their children," she said.

"I felt sure that Olivia could give them a true message of how living with the ups and downs of the disease could still enable you to have a full, rich life. She could give them that hope. Yes, I was proud of Olivia!"

Attending the annual NNN Family Conferences nearly every year since she was 8 years old, Schroeder has had the opportunity to meet many others who have neutropenia. It helps to know you are not alone, she said, and that having neutropenia doesn't make you a freak.

Yes, she said, there are times when it gets her down, but since starting Neupogen in 1996, she has had fewer illnesses. "I have had bone pain, from the medication, but I can live with it," she said. "For a while, I didn't realize bone pain wasn't normal. I'm pretty darn functional and I rarely have to go to bed because of the pain."

So, sometimes, living with neutropenia can be a challenge, Schroeder said, adding, "My disease does not make me any less human, and it does not stop me from pursuing and achieving my goals. You've got to be tenacious. I had to separate the neutropenia from my self-worth. Once I did that, my future was limitless!"

Olivia's Conference presentation is available on the NNN website under Conference Highlights.

To follow Olivia Schroeder and her art, check out her new website at oschroederisthenucleus.tumblr.com

Ron's Story

"We are losing her!" said the doctor on a fateful summer evening nearly 30 years ago. His daughter's organs were shutting down, and Ron Bloxham stayed with Lucy as doctors rushed her by helicopter to Good Samaritan Hospital in Phoenix, Ariz.

After two weeks in hospitals and innumerable tests, 8-year-old Lucy inexplicably began to recover. Subsequent testing determined that she had had toxic shock. And so began a roller coaster of illness followed by complete recovery that put Bloxham and his wife on a quest to find the cause of their daughter's frequent illnesses and high fevers.

In 1989, a Las Vegas physician referred them to a new program at the University of Washington overseen by Dr. David C. Dale, Dr. William Hammond and Audrey Anna Bolyard. The whole family underwent tests, and it was determined that Lucy had cyclic neutropenia, and she began treatment with Neupogen immediately. Ron also was found to have neutropenia, but none of Lucy's siblings or her mother had the bone marrow disorder. Some 26 years later, two of Lucy's three children have neutropenia.

In 2012 Ron attended his first Family Conference in Phoenix. The experience brought home the profound impact neutropenia has had on his daughter's life. Meeting other families and hearing from the experts gave him a greater understanding of the disease and the struggles that come with it. After the Conference he accompanied Lucy as she revisited the hospital where she almost died twenty years earlier. It was an emotional experience for the whole family, and Ron resolved he wanted to do something to make a difference. Several weeks later he called Lee Reeves and offered to serve on the board of directors for the National Neutropenia Network.

Lee Reeves said she was very pleased when Ron called. Lucy's is serving her final term on the board. She had served as chairperson and was pivotal in revitalizing the flagging organization in 2005. "Lucy



was instrumental in helping to revive the Network over ten years ago. I don't know what I would have done without her help and encouragement. She was always available." Reeves said. "Now her Father has stepped in with dedication and support. This kind of family commitment is important for an organization like ours." After Phoenix, Ron attended two more Conferences with his wife, Vicki, who fully supports Ron's work with the NNN. They make a point of getting to know other families who attend the Conference and they make themselves available to volunteer as needed. This past year they committed funds to help underwrite the cost of videoing the educational sessions in Seattle.

Ron, who retired in 2011, was a prosecutor for the Clark County District Attorney's office in Las Vegas for 34 years. He worked his way through college by writing for a newspaper and put himself through law school by working as a welfare hearing referee, also working for his law school.

He currently engages in church service missions in the Family History Center of the Church of Jesus Christ of Latter Day Saints. He also works with Brigham Young University-Idaho. In addition, he sits on the Nevada State Bar disciplinary committee.

Having witnessed the difficulties Lucy experienced as a child with neutropenia in a world where there was no Network, no Family Conference, no Registry, Ron understands the value of these services. "I want to express my appreciation for all the great work that has been done on behalf of myself and my family," he said. "I also appreciate the wonderful work done by Dr. Dale and Audrey Anna and the help of Amgen in providing medicine that has saved lives and helped so many people."

Vanessa's Story

"It was 2008, I think. I was 31, married, and I went for a regular medical check-up that showed that my numbers were very off. Something was not right."

That was the beginning of a very long and difficult journey for Vanessa Enrizo, one which took her to doctor after doctor, through dozens of tests and bloodwork, and resulted in diagnoses ranging from infectious mononucleosis to anemia, from leukemia to lymphoma.

"It was all very scary," Enrizo said. "It was several years of craziness. But I felt like I needed to survive to be there for my son."

Eventually, a doctor sent the Miami resident, now 38, for a bone marrow biopsy. "But it took two hours," Enrizo said. "And they couldn't get in on the first try. I have an incredible threshold for pain, but it was really awful. What kept me going was thinking about little kids who have much worse things. If they can do it, how could I not?"

Another thing that helped her through the unpleasant process was repeating a prayer that her father prayed when he was in the military in Cuba. "I took it everywhere I went and would repeat it during that difficult time," she said. She promised that, if her illnesses were caused by something she could live with and be with her son, she would never complain. "I'm a very tough person, and it's difficult to explain that vulnerable moment, but I didn't feel alone."

After this long process of elimination, Enrizo finally found an interventional radiologist who was able to do a painless bone marrow biopsy and correctly diagnose her problem: chronic severe idiopathic neutropenia. "He said to me, 'I have good news and bad news. The good news is that you do not have lymphoma or leukemia. The bad news is that you have neutropenia, and we don't know very much about it.'"

She said to herself, "I'm not going to cry about this. I'm going to do whatever it takes to learn more about it and figure it out." And so began years of research and learning to live with neutropenia. Enrizo

spent a lot of time on the Internet, reading about the condition. "I didn't get sick often, but when I did, it was bad. I would be in the hospital for a week."

In all of this time, Enrizo rarely shared information about her medical situation with friends or work colleagues. "I didn't want my family to worry," she said, although they were very supportive. "I was afraid people would feel sorry for me. I look completely normal, but when anyone in the office had a cold, I'd spray Lysol all around. Only my boss knew." She was essentially living a double life, Enrizo said.

She took a year-long leave of absence from her job while she tried to find answers. Her job as a business manager at a large Florida university was stressful, with constant deadlines. "I felt I didn't have the patience to deal with work because I didn't know what was going on with my health," Enrizo said, adding that her boss has been very supportive. "She's been amazing."

In the course of her research, she came across the National Neutropenia Network and Lee Reeves, one of its founders. Lee encouraged her to attend a Family Conference, but Vanessa didn't feel she could afford it at the time. "I looked fine, despite getting sick once or twice a year," Enrizo said. "But I had to accept the fact that there was something going on." In May of this year (2015), she was hospitalized with a cold, so weak she couldn't get out of bed.

"Lee called me and urged me to attend the Conference, Enrizo said. "She said it could be life-changing for me. I decided it was time to give the Conference a shot."

So, she and her brother, Orlando Enrizo, an interventional radiologist, traveled to the NNN 2015 Family Conference in Seattle. "Lee was right; it changed my life," Vanessa Enrizo said. "For the first time, I was able to talk with people who have what I have. I couldn't stop crying, there were so

many emotions. It was such a relief. I learned so much and now, I can educate my doctors about neutropenia.” In addition, her brother is now able to share information about neutropenia with the medical community, which is largely unaware of this rare blood disorder.

“I’m proud of Vanessa for not just accepting [the incorrect diagnoses] that some of the physicians gave her,” said Dr. Enrizo, who first learned about neutropenia when his sister was correctly diagnosed with chronic severe idiopathic neutropenia. “It was Vanessa who discovered the National Neutropenic Network online.”

Her brother said he learned a great deal during the conference. “It opened my eyes,” Dr. Enrizo said. “I learned from these expert physicians how to treat it, and I saw some interesting trends. It’s the same disease process and the same treatment for all types of neutropenia.” Dr. Enrizo said a take-away for him is becoming an advocate to help educate other oncologists and physicians. “When I see an oncologist at my hospital, I say ‘Do you know about neutropenia? My sister has it.’”

That question can open the door to increased awareness of this rare disorder, something that the neutropenic community knows is necessary. “The first thing that most doctors will think of when they see these numbers is HIV, or leukemia or other bone marrow abnormality,” Dr. Enrizo said. He said he has sent articles about neutropenia to oncologists and other doctors at his hospital to help raise awareness.

He also noted that a preponderance of the patients he spoke informally with at the conference said that their bone marrow biopsies, like his sister’s, were very painful. But, as done by interventional radiologists and using CT scan imagery, bone marrow biopsies can be pain-free, so patients might want to discuss procedural options with their doctors before having their biopsies.

Since the conference, Vanessa Enrizo is in the process of getting on the Registry, she said. Once that is accomplished, she will qualify for daily Neupogen and will likely see fewer neutropenia-related illnesses in the future. That certainly is the hope, her brother said.

“One of the biggest lessons I learned at the Conference is that it’s okay to ask for help,” Vanessa Enrizo said. After years of carrying the burden of her neutropenia largely alone, she has found a new source of support in the NNN and the people she met at the Conference. “I learned that you don’t always have to be the strong one.”

Conference Videos Online

We know that many cannot take the time or spend the resources on Conference attendance. With that in mind this year we videotaped many of the presentations. Visit neutropenianet.org and click on Conference Highlights. You will find the following videos of:

- **The SCNIR—How it Works and How to Make it Work for You**, Audrey Anna Bolyard RN
- **Life Management for Those Who Live with Chronic Neutropenia**, Audrey Anna Bolyard RN
- **Kristin McGuinness Shares the Story of her Journey with Congenital Neutropenia**
- **Olivia Schroeder Shares the Story of her Journey with Cyclical Neutropenia**
- **My Beloved Neutrophil**, Laurence Boxer MD
- **The Registry—Past, Present and Future**, David Dale MD
- **Living with (and without) Neutropenia**, Peter Newburger, MD
- **Integrative Medicine Therapies for Better Living with Neutropenia**, Galie Jean-Louis LAC EAMP RYT

Australian Family Conference

The Henry family, of Sydney, Australia, has been dealing with neutropenia since their son, Sam, 21, was diagnosed at 8 months of age. This past summer, they flew 7,750 miles from Sydney to Seattle, Washington, to attend the 2015 NNN Family Conference, in part so they could learn how to structure a similar conference in Australia.

Kath Henry, Sam's mother, said she and her husband, Phil, decided to put together a Neutropenia Family Conference in Australia, modeled on the American conference. Their intent is to provide an accessible opportunity for Australians who are dealing with neutropenia to learn more about the rare blood disorder and latest treatment information from the experts. It will also afford an opportunity to get questions answered and to meet and network with other neutropenic individuals and their families.

Planning for the Australian Family Conference is well underway, with the dates set for Sept. 30 and Oct. 1, 2016, at the Quality Hotel in the Sydney suburb of Mascot, a shuttlebus ride from the airport.

- The keynote speaker will be David C. Dale, MD, professor of medicine at the University of Washington and co-director of the Severe Chronic Neutropenia International Registry (SCNIR). She is hoping to set up a session for Dr. Dale to speak to the medical community, as well.
- There will be presentations by Sam and a young woman in her 20s about what it's like growing up with neutropenia.
- A Q&A session will allow families to ask questions and get one-on-one information.
- Audrey Anna Bolyard, clinical manager of the SCNIR, may do a presentation via Skype.
- A children's program is also in the planning stages, Henry said. "I want the families to be able to come, which was one of the wonderful things about the American conference," she said. "You could just see it was so helpful for the young ones."

So far, she is aware of just 10 families in Australia who have a neutropenic member in their midst, but hopes that more might be found through the SCNIR. Professor Frank Firkin, an honorary professor at Melbourne University and Vincent's Hospital in Melbourne, is investigating the possibility of starting a registry in Australia to help locate more patients in that country and to provide education about the disease and allow researchers a vehicle for studying it in Australia. He will also participate in the Conference.

Kath Henry, with encouragement and support from her husband and son, is now working on the administrative details of the Australian conference. "The main thing I'm trying to figure out now is how to responsibly cover the costs," she said. "The management of the hotel has been very accommodating and cooperative and we are looking at other options to help offset the costs," she said. Henry hasn't decided yet what the cost to attend will be. That will depend on how much the other costs amount to, but right now, she is looking at \$300 per adult and \$50 per child, but she hopes to bring that down.

This will be a chance for Australians to hear from some of the top specialists in the field of neutropenia, Henry said. "Accessibility to specialists is greater in the States," she said. "It's not just that they have incredible knowledge, although the bulk of the research has been done in America, but they have a great compassion because of their personal interest." Henry hopes that holding a neutropenia conference in her country will provide the access to expertise that is not generally available there, and therefore, raise the level of understanding of the disorder.

The trip from Australia to Seattle is long—about 17 hours by air—and expensive, but one that the family undertook because they felt it would be worthwhile. "It was so important for Sam because, for the first time, he was able to talk to people who have the same thing he has. It was so encouraging for him."

"I met someone with neutropenia, and someone my age, as well! That was awesome," said Sam



Henry, who is in his last year of collegiate IT studies, currently spending 6 months at Loughborough University near London, England. "Also, it was great to be honest and open about dealing with the emotional side of it. It gives you perspective." His cyclic neutropenia was difficult to diagnose because it is usually inherited, but no hereditary link could be found.

"It's an expensive trip to the States," he continued. "My family was blessed to be able to go [to the American Conference]," Sam Henry said. "Having a conference in Australia will be great for families who don't have the money to travel to the States and for patients who are too sick to travel."

The template for an Australian Family Conference was, of course, provided by the American conference, Kath Henry said. "We are so grateful to Lee Reeves, the Director of the National Neutropenia Network, and to the team who put the conference together in the States. They were so welcoming to us coming from Australia. It's a gift we can never repay."

In summing up the experience and the planning for an Australian conference, Phil Henry expressed some of the excitement shared by his family: "Going to Seattle was fantastic," he said. "Kath is doing very well in planning the conference; I'm her enthusiastic supporter. The idea of Dr. Dale coming out to Australia is just spectacular." Kath added, "We just want to be a blessing to people."

For more details on the Australian Conference, contact Kath Henry at: kath@northridge.org.au

A Fun Event for Our Cause

Join friends and families across America for the third annual Bowling for Neutrophils fundraiser event sponsored by Ella Jewell Foundation. Proceeds benefit neutropenia research through EJJ and patient support through the NNN.

If you've always wanted to do something to support our cause but have been unsure of what to do, this may be the perfect opportunity for you. Kristin has made it a turnkey operation. All that is needed to set up a team is: four to six players, access to a bowling alley, a date between **January 15 and March 30**, some friends and family willing to support the effort and the desire to make a difference for those who live with severe chronic neutropenia.

Registration begins on December 1. For more information and step by step details on how to start your own team visit www.bowling4neutrophils.org



More Ways to Make a Difference

While shopping online this holiday season all Amazon purchases can benefit our cause. An **Amazon Smile** link is posted on every page of our website neutropenianet.org. When a shopper clicks that link and makes a purchase a percentage of the purchase will be donated to the National Neutropenia Network.

Here's an idea for a holiday gift. We have the official National Neutropenia Network t-shirt for sale on our website. It's an great way to tell our story and support the NNN.

Thank You to the Sponsors and Donors who helped make the 2015 Neutropenia Family Conference a success.

The Ella Jewell Foundation

Taylor Carlton

Mary and Karl Schoreder in memory of Thomas Docherty and Matt and Louie Schoreder

Ron and Vicki Bloxham

Gayle and Lorne Gold

Galie Jean-Louis & Dr. Vincent Matteucci

Paige Scyocurka

Derek Tate in honor of his niece Morgan Osborn

The Reeves Family, in memory of their daughter, Leta Reeves

The 2015 Neutropenia Family Conference was supported by an educational donation provided by Amgen.

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Mariel Lewis, Director

Krista Moroder, Director