A Letter from Lee

The 2014 Family Conference was a weekend to remember for the families and patients who gathered at the Marriott Eagle Crest in Ann Arbor. For some it was a first time event, for others a reunion. This newsletter is full of stories and images that reflect the high energy, enthusiasm and concern palpable throughout the weekend.

I am pleased to announce that we will be hosting the Neutropenia Family Conference again in 2015 from July 17–19 in Seattle. With the Severe Chronic Neutropenia International Registry entering its third decade of research and patient advocacy, and with the Registry’s clinical manager, Audrey Anna Bolyard, a confirmed Conference participant, Seattle holds a special place for neutropenic patients. The NNN board agreed we should not miss the chance to meet in this epicenter of neutropenia research.

Knowing that Seattle can be an expensive place to visit, we have negotiated the best price possible for guest rooms at the beautiful Seattle Airport Marriott with plenty of meeting rooms to accommodate our program. The Conference fee covers the cost of all meals, handouts and sessions. (See details below) We will have a children’s program but it will not be as extensive as the one we have in Ann Arbor. We expect fewer children in 2015, but we will create a fun and meaningful program for those who do attend. I hope this early announcement allows interested individuals an opportunity to plan and save for a very special weekend.

Audrey Anna and her assistant Lan are excited about the chance to meet some of the people they have grown to know through their phone and email communications over the years. We have commitments from physicians on the Severe Chronic Neutropenia Advisory Board who will contribute their extraordinary knowledge and expertise as they present the latest information on managing neutropenia. Mara Lim, conference coordinator, is native to Seattle. For those who wish to explore the city after the Conference, she will share her extensive knowledge of the area with suggestions for interesting places to visit. Dr. Dale is also pleased for the opportunity to welcome patients and families to his hometown.

2015 Neutropenia Family Conference

Dates: Friday July 17 from 4:00 PM through Sunday July 19, 11:00 AM
Location: Seattle Airport Marriott
Room Cost: $145 plus tax (these rates are available on Friday and Saturday night. The going rate at this popular time of year is over $250 per night)
Registration Fee: Early Bird from Jan 1, through April 1 $190 adults (twelve years and up) and $90 for children (4 to 11 years.) After April 1, Adults are $210 and children are $100.

Cutoff date for our room rate is June 15.
Check neutropenianet.org after Jan 1 for more details.
Registration begins Jan. 10
Serious Fun kicks off NNN Family Conference

Folks who turned out for the National Neutropenia Network’s 2014 Family Conference, July 11-13 in Ypsilanti, Mich., may have expected to clock some serious time learning about this rare condition caused by failure of the body’s bone marrow to manufacture enough white cells … and they did.

But Serious Fun was on the agenda when the conference kicked off Friday afternoon in the big white tent, dubbed the Garden Marquee, that served as combination dining hall/gathering spot for the group. The session was designed to bring people who are affected by neutropenia together and launch the weekend in a fun but meaningful way, said the Network’s director and co-founder Lee Reeves.

Participants, sitting at tables in family groups, were charged with filling a poster-sized sheet of paper with drawings that “defined” their families. Facilitated by staff members of North Star Reach Camp, a special place in nearby Pinckney, Mich., for children with life-threatening illness, the opening session was designed to help families get acquainted, to appreciate their individuality, and to realize that they have one big thing in common: neutropenia.

“It was a great way to get to know other NNN families,” said Mary Moores, of Abbottstown, Penna., there with her husband, Jon, and their four children. The couple began bringing their family to the annual NNN Family Conference five years ago, soon after their youngest child, Sophia, 6, was diagnosed with neutropenia, she said. The “mural” that the Moores created to define their family included depictions of a campfire to indicate the family’s love of camping,” said Ella Moores, 14. It also included a heart, to signify the family members’ love for each other, stick drawings of each family member, and a large rendering of Mt. Katahdin, the highest mountain in Maine, where the family has camped and hiked on numerous occasions. Several Moores family members have hiked to the top of this 5,300-foot mountain, the northern terminus of the Appalachian Trail.

Once all the families had finished their murals, participants stepped up one family at a time to a microphone and explained their drawings to the rest of the group, thereby giving everyone in attendance a glimpse of everyone else, and reassuring all that they aren’t alone in dealing with neutropenia.

“We had one of those ‘Aha!’ moments when we met the Jacobson family here two years ago,” Mary Moore said. “They have two children with neutropenia. It was an eye-opener for my daughter. She had never met anyone else who had neutropenia.”

It was a theme that was repeated dozens of times throughout the conference: “I finally met someone else who has neutropenia!” said Liam Lahkia, age 8. He and his brother Evan, age 11, gave a presentation on what it’s like to live with neutropenia. Liam added, “It was so good to meet others with neutropenia! I’ve met two others, besides myself, who have it.” Evan, who does not have neutropenia, said he appreciated learning more about the disease.

Lee Reeves agreed saying that the Conference helps combat the isolation that comes from having a disease like neutropenia. “With neutropenia being so rare, this weekend will be the first time most participants will meet another person with neutropenia. It is a very powerful experience.”

This year’s conference drew 175 people, including 60 under the age of 18, from states including Alabama, New York, Ohio, Pennsylvania, and Texas, as well as from Canada. “This was our top attendance ever, 50 percent higher than the record.” Reeves said. “For children, it was more than double the record.”
Two Brothers Talk about Neutropenia

Brothers Liam and Evan Lakhia, ages 8 and 11 respectively, look and act like any other kids their ages. But there is a significant difference; Liam has Severe Congenital Neutropenia. The diagnosis, when Liam was just 1 month old, has affected both boys’ lives, and they brought the story of their experience with the condition to the 2014 NNN Family Conference.

Their presentation, on July 12, to adults attending the conference, was so successful that the boys were asked to present a second time later that day to the children attending the Kids Kamp.

Liam spoke first, telling his audience how having neutropenia has affected him. “I have to get a shot (of Neupogen in his arms or legs) every day,” Liam said. “The shots tell my body to make more white blood cells. They help me to not get really sick. They don’t hurt too much.”

He can tell that his shots are working, Liam said, because his labs every 4 months if he is healthy reflect greater production of white blood cells. Also, his bone marrow biopsies, done every 2 years, show that the bone marrow is working properly.

“Some things that I do to keep germs from making me sick, almost everyone else does too,” he said. “I wash my hands a lot. I try not to eat too many foods that are bad for me. I wash my scrapes and cuts really good. I don’t drink out of the same bottle as someone else.”

Still, he said, he is able to do most of what “normal kids” do: Go to the beach, overnight camp, school; play sports.

Liam gives his neutropenia presentation yearly for his class. “They think it is really cool,” he said. He also holds fundraisers to support neutropenia research and raise awareness about it.

“Even though I have neutropenia, I really am just a normal kid,” he said.

Evan then took the microphone to talk about his experience having a brother with neutropenia. He said he began to have some understanding of what neutropenia is when he was about 3 years old. “I thought ‘Well, it can’t be that bad, right?’” Over the years I have learned the exact opposite,” Evan said.

“Having a brother with neutropenia is tough. I have to help out all the time when he is sick and help keep our younger brother brave when Liam is in the hospital, so he doesn’t get scared,” he continued.

“Neutropenia can be hard for kids, but if they know what it is and stay brave, they might find that it doesn’t have to affect what they can do.”

He said he thinks Liam is not greatly affected by neutropenia because “I play with him like he is a totally normal kid, Liam is just as goofy and funny as everybody else in the world!”

Having said that, Evan said, he knows that the condition has at least some effect on this brother because of the frequent labs he must do, hospital visits at least once or twice a year, daily shots, the bone marrow biopsies, and more. “But he is always brave!” Evan said. “Liam’s attitude about his neutropenia helps to keep things in perspective.”

An observation that Liam made to their mom recently sums it up, Evan said: “If I didn’t know what neutropenia was, I wouldn’t like it. But since I know what it is, I actually kind of like it. I don’t like what it does to my body, but it is who I am. It is what makes me, me.”

And probably also part of what makes Evan, Evan.
NeutroNews from the Experts

A series of updates Saturday morning by medical experts intimately involved with neutropenia research and treatment provided conference attendees with up-to-the-minute information on the disease that affects them and their families.

First to speak was David C. Dale, MD, professor of medicine at the University of Washington and co-director of the Severe Chronic Neutropenia International Registry (SCNIR). His overview of the current state of the 20-year-old registry and of research into neutropenia noted the increasing diversity that has been a feature of the registry. There are still a relatively small number of African Americans and Native Americans enrolled, Dr. Dale said. Also, enrollment by state is uneven, with a relatively high enrollment in Michigan and fewer in some other states.

Among the current and historic trends noted by Dr. Dale: If you take too much G-CSF (Neupogen) or take it infrequently, you will get symptoms. “Dose and schedule are terribly important,” Dr. Dale said. Bone pain, a side effect experienced by some G-CSF users, tends to diminish over time, with treatment. Also, G-CSF does not lose effectiveness over time. The increased risk of progressing to AML (acute myeloid leukemia) is only a concern for those patients with severe congenital neutropenia. This is true with or without G-CSF.

The SCNIR has allowed researchers in a systematic way to study the disease and the effects of G-CSF therapy, Dr. Dale said. In 1987, before Neupogen was approved by the FDA, the only effective therapy was antibiotics. In that same year, doctors found that G-CSF could be given subcutaneously, rather than via IV, rendering treatment something a layman could do.

G-CSF stimulates the relatively quick production of more neutrophils, and causes these cells to be released into the blood. Studies of a prototype group of 6 patients led to the founding in 1989, of the Severe Chronic Neutropenia Trial, which studied the new drug’s effect on various forms of neutropenia. All responded well to treatment with G-CSF.

Government approval of Neupogen came in 1993. “The government wanted monitoring, and that was the origin of the registry,” Dr. Dale told the audience.

Ongoing research includes work on understanding the process of evolution to leukemia and the discovery of a mutation that tells doctors that leukemia is about to occur. A paper on pregnancy and neutropenia will soon be published, he said. Researchers, including Dr. Dale, will begin a trial in September to work on home monitoring of blood counts. An oral therapy is under investigation, and researchers are working on continued NIH funding.

Prevention of Infection, presented by Peter Newburger, MD, vice chair of Pediatrics and Hematology/Oncology at the University of Massachusetts Medical School and SCNIR board member, looked at precautions and mechanisms of transmission. Reasonable precautions should be followed if you are neutropenic, “but don’t let prevention control your life or your child’s,” Dr. Newburger said. “If you are taking Neupogen and are no longer (clinically) neutropenic, then no prevention is necessary. Having an adequate number is adequate protection, so live a normal life.” If your ANC is 500 to 1000 or more, you have no increased risk of infection. Below 200 put you at very high risk. Between 200 and 500 carries a significant risk, Dr. Newburger said.

Human immunity depends upon the health of your surface barriers, including the skin, mucous membranes, lungs and GI tract; upon your reticuloendothelial system (liver and spleen), hormonal immunity and cellular immunity (neutrophils).

“To some degree, we are under constant attack from microbes,” Dr. Newburger said. “Most of
those are inside us.” Some 100 trillion microscopic bodies reside in our bodies, most of them friendly. “Every body has its own flora.” To some extent, then, “Dirt is good,” he said. “Having a normal set of organisms in your body and on your skin is important to good health.”

To get rid of the bad bugs, Dr. Newburger advises “Handwashing, handwashing, handwashing.” The only way to remove all bugs from your vicinity is through laminar airflow rooms (such as the one the Bubble Boy lived in) and HEPA filtration. “Everything else is not effective,” he said.

Since most infections in neutropenia patients come from their own bacteria, it does little or no good to go on a “neutropenic diet,” wear gowns and gloves, take “prophylactic” antibiotics, or disinfect the home or playground. Children should definitely go to school, he said.

In fact, frequent use of antibiotics can play a role in good bugs going bad, as can the hospital environment, good bugs in bad places (like the bloodstream) and breakdown of other defenses, such as skin, gums, intestinal wall and immune system.

Reasonable precautions, Dr. Newburger said, would include mouth care (such as regular dental checkups, good oral hygiene, antibacterial mouthwash (only for poor oral hygiene or periodontal disease), avoiding sweets and using a fluoride toothpaste); getting all routine immunizations, including yearly influenza shot; good general hygiene (thorough handwashing, good nail care, no rectal thermometer or suppositories, and cleaning scrapes and cuts).

For foreign travel, consult your physician and the CDC website. Neutropenia is not a factor in social interactions.

“The bottom line,” Dr. Newburger said, “is to balance the small risk of getting a virus against the psychosocial and emotional benefits of school attendance, family gatherings, play with peers, ball games, etc.”

Rounding out the morning’s updates was Dr. Mary Ann Bonilla, assistant Professor of Pediatrics, Hematology/Oncology Specialist, St. Joseph’s Children’s Hospital. Dr. Bonilla discussed Bone Health and Neutropenia. She started with an overview of bone growth and remodeling which she explained as a lifelong balance of bone resorption (removal) and bone formation (deposit) that replaces bone following injuries such as fractures and responds to the demands of the body. Bone size increases during growth, she said, and so does bone mass or density. Peak bone mass is reached during the years between 20 and 30, then declines more or less rapidly throughout the rest of life.

Osteoporosis, a condition characterized by low bone mass and deterioration of bone tissue, leads to increased risk of fractures of hip, spine and wrist. It is a “silent disease,” Dr. Bonilla said, with no symptoms until a fracture occurs.

A special radiation scan called a “DEXA” scan (for dual energy x-ray absorptiometry) can detect osteoporosis before a fracture occurs, Dr. Bonilla said. For SCN patients, the scan should be repeated every 2 to 3 years of ANC is normal, every year if abnormal.

Some risk factors for osteoporosis can’t be changed, such as gender, race, genetics, stature and age. Factors that can be changed are eating a diet including adequate calcium, phosphate and vitamin D, getting plenty of exercise (particularly weight-bearing exercise, such as walking, hiking,
dancing and climbing, where your feet and legs support your body), altering lifestyle if necessary (not smoking and moderating intake of caffeine and alcohol, for instance), maintaining adequate estrogen levels and avoiding drugs that may contribute to bone deterioration. An incomplete list of such drugs includes aluminum-containing antacids, proton pump inhibitors, steroids, and certain birth control pills (Depo-Provera).

The jury is not in on whether G-CSF (Neupogen) contributes to the development of osteoporosis. Some animal studies have shown a connection between G-CSF and bone loss, and the drug causes production of a chemical associated with osteoporosis, Dr. Bonilla said. But other studies indicate that low bone mass and vertebral fractures existed before beginning G-CSF. In addition, there is no relationship between total G-CSF intake and development of osteoporosis.

Diet plays a lifelong role in the preservation of healthy bones, Dr. Bonilla said. Good sources of calcium, in addition to dairy, are fish (especially canned sardines and salmon, with bones) and fruits and vegetables (the dark green varieties, such as collard and turnip greens, kale and broccoli, score high here). Fatty varieties of fish such as salmon, tuna, mackerel and sardines provide vitamin D, while tomato products, spinach, okra, sweet potatoes and potatoes contain magnesium. Get phosphate from foods such as: dairy, meats, nuts, tofu, and beans.

Adequate calcium intake ranges from a low of 210 mg/day at birth to a high of 1300 mg/day during the growth spurt years from ages 9 to 19. Thereafter, the need drops to 1000 mg/day from ages 19 to 50 and rises to 1200 mg/day for adults ages 51 and older.

Screening that should be done, in addition to DEXA scans, includes blood tests for calcium, phosphorous, 25-vitamin D (the stored form of vitamin D), and parathyroid hormone. Urine calcium test can determine if enough calcium is being absorbed.

Medications available for the prevention and treatment of osteoporosis include bisphosphonates, calcitonin, estrogen and estrogen agonists and denosumab. An anabolic drug, teriparatide, increases the rate of bone formation and is approved only for adults. A decision to take such medication should be reached jointly following careful evaluation between the family and their doctor. It is crucial to find a doctor experienced in treating osteoporosis in children, Dr. Bonilla said. Frequently, an endocrinologist is your only available option.

Parenting When a Child Has Neutropenia

Parenting a child with neutropenia and other chronic illnesses is fraught with challenges: There will be effects on behavior, health, nutrition, education, socialization, siblings and more, said Jennifer Butcher, PhD, Clinical Assistant Professor at the University of Michigan Medical School. Dr. Butcher, a pediatric psychologist whose focus is children with chronic health conditions and their families, spoke to parents of children with neutropenia during the 2014 Neutropenia Family Conference, July 11-13 in the Ann Arbor area. She offered information and strategies designed to help them deal with their
children’s chronic illness and have a positive impact on their health outcomes.

In her presentation, Dr. Butcher summarized the great wealth of literature on parenting, some of it useful and some of it not, reviewing what is currently known about parenting in chronic illness (much less), and how to apply this knowledge to real life.

Her overview of the impact of four main parenting styles (Uninvolved, Permissive, Authoritarian and Authoritative) revealed that children whose parents are authoritative tend to be generally more competent, with greater self-control, upbeat mood, and better ability to handle stress and challenges than children whose parents fall into any of the other parenting style classifications. By authoritative, she said, she meant parents who are assertive and supportive, as opposed to those who are dictatorial, or uninterested, or those who set no guidelines.

“Overall, authoritative parenting has the strongest relationship to improved child outcomes,” Butcher told her audience.

And, although day-to-day life can be pretty much the same for children with or without chronic illness, parents of the chronically ill (including those whose children have neutropenia) may find themselves under more stress. They have more daily responsibilities that carry large consequences if they are not completed. Additionally, chronically ill children are ill more often, requiring more parent time and attention. They also display more behavioral and emotional challenges when they feel ill.

Still, she said, all children have the same need for love and attention and go through the same developmental stages.

Strategies that parents can employ to make life with their chronically ill children easier include establishing family routines and consistency. “For example, pizza night on Friday, taking meals at the same time each day.” Other helpful strategies include parental monitoring, contingency management (If you clean your room, you get X dollars.), positive communication (Thanks for doing the dishes, or Great job at the doctor’s today.), problem-solving, presenting the child with appropriate choices (Do you want your injection in your right or left leg?) and using rewards and consequences.

She suggested that parents should seek help when they see changes in their child’s behavior – excessive sleepiness; changes in eating, diminished interest in activities, or time spent with friends; school problems; moodiness, fearfulness or anxiety; problems completing their medical regimen. Also, it may be necessary to seek help during periods of increased illness and family stress.

“If possible, when seeking help, find a pediatric psychologist, who has special training to work with chronic illness,” Butcher said. Alternatively, find someone who only sees children and uses cognitive behavioral therapy approaches. That might be a psychologist, psychiatrist, adolescent medical specialist or social worker or counselor, she said.

Finally, Butcher advocated getting siblings involved, especially those who fear what their neutropenic sister or brother must do to stay healthy. “Have them sanitize the spot where the shot will be given. Or push the plunger on the syringe,” she said.
Special Friendship Made at Neutropenia Kids Kamp

One might say the friendship between Dagmar Moore and Clint Strawser had a “rocky” start.

Dagmar was working at the Kids Kamp during the 2011 Neutropenia Network Family Conference when Clint Strawser began telling her about his lucky rock.

As it turned out, Moore was also a rock collector and the two had a long conversation. They also discovered they both loved reading.

“He struck me as particularly sweet and smart,” Moore recalled. “We just clicked. I had a son who had cancer as a young child. After the meeting was over, I thought, “My God that was nice little kid.’ I contacted Lee (Reeves) and asked if it would be okay to keep in touch and she facilitated it.”

They’ve exchanged e-mails and a few phone calls. The friendship between the two families has grown.

“She’s kind of like my third grandma,” Clint said. “She’s always really nice to me. It is really incredible how much we have in common. We love cats and dogs. We like the same type of food.”

“I can talk with her about anything my illness, anything I want, she just listens and understands.”

Michelle Strawser, said Clint had been diagnosed with cyclic neutropenia only a few weeks before the conference in 2011.

“It’s meant a lot having the grandma aspect and having someone that he can talk to besides just doctors,” Michelle said. “She’s another adult that he can go to and complain. She just listens and sends emails back to him. It gives him something to look forward to.”

Two years ago, Clint and his sister, Natalie, traveled from their home near Columbus, Ohio, to stay with Moore and her husband Robert Kyes for a long weekend at their home in Ann Arbor, Mich. Dagmar e-mails Clint each week and frequently sends him care packages of books and a “a little candy.” When she travels, she collects unusual rocks for her pen pal.

After this year’s Family Conference Dagmar and her husband took Clint and Michelle out for dinner to Real Seafood Company in Ann Arbor, where Clint feasted on king crab legs and filet mignon. Later, they stopped at Moore’s favorite book store Nicola’s Books where she treated Clint to a book-lover’s shopping spree.

She wanted to help him stock up on plenty of reading material knowing that he is scheduled for a tonsillectomy in August.

“He is a voracious reader and he likes these Lord of the Ring type fantasies,” Dagmar said. “I like to send him books a few times a month or once a week or so. It depends. When he is sick I send more. It depends on if he is need of more reading. I took him to the bookstore and told him the sky’s the limit.”

Moore said she knows that Clint faces many health challenges and she feels happy to provide encouragement to him through her care packages.

“It always amazes me how positive he is,” she said. “I have never heard him offer any kind of self-pity. My husband is 81. I am 71. We were talking about how pitiful we old geezers can be about our ailments and we realize there are children who are dealing with life threatening illness that controls their lives at such a young age. We have learned an awful lot form these children about how to be positive. We are pretty committed to this organization now.”

One Family’s Journey with Neutropenia

Kathy and Kurt Carlson and their children came from Jamestown, NY, to attend this summer’s NNN Family Conference. “We came so that we could learn as much as we can (about neutropenia) and to network with other people who are dealing with the disease,” said Kathy Carlson, whose husband and 3 children all have cyclic neutropenia.
Kurt Carlson was very sick as a child, his wife said. “The doctors then chalked it all up to 'he's just a sickly child, who's still building his immune system,’” she said.

A family trip to Florida for Spring Break, when Kurt was 14 years old, was very nearly the end for him, Kathy related. “He had a high fever that wouldn't come down with Tylenol, and he looked gray and was listless, so his mom took him to the emergency room,” she said. There, the doctors were concerned that he might have HIV, but failed to give him any antibiotics, and he became septic. ER personnel took a rectal temperature on him, which resulted in an ulcer that ruptured and caused peritonitis and quickly became a form of gangrene that causes toxic gas in the bloodstream, Kathy said.

“He’s lucky to have survived that incident,” she said. During treatment for the gangrene, he received a large amount of blood, and he had to have porcine skin grafts. He “coded” twice before he was stabilized. He was in the hospital for 3 months. “He should have been given antibiotics off the bat,” said his wife.

When this occurred, Neupogen had not yet been developed, and Kurt went home from the hospital on no medication, left to pretty much fend for himself, at least until Neupogen was developed and approved to treat neutropenia.

Flash forward: Kurt is now married to Kathy and their baby, Maggie, gets infections … on an observable cycle, just like her daddy. At about 8 months, the state of her health was bad enough that they took her to see the doctor, who reassured them that “it would be very rare for her to have what her father has.” But he also said, “To be honest, I know nothing about this,” a phrase that many other individuals who live with neutropenia, have heard too often from their own doctors. The exceedingly rare condition is frequently misdiagnosed by doctors who simply are not aware of it.

Eventually, the Carlsons’ research on neutropenia brought them to Ann Arbor, Michigan and Dr. Lawrence Boxer at the University of Michigan. There they learned about the Registry and access to Neupogen. “We were worried about having any more children, but Dr. Boxer said, ‘We now have this miracle drug,’ and he said, ‘Go for it!’” Neutropenia was no longer a death sentence.

Still, they knew that there was a 50/50 chance that their children would have neutropenia. As it happens, daughter Maggie, now 5, and twins William and Vivian, 19 months, all have cyclical neutropenia, and all take Neupogen, along with their dad.

“Looking at Maggie, you’d never know there is anything wrong with her,” said Kathy. Unfortunately, the shift from healthy to sick can happen very quickly. “It’s so frustrating. If they get a fever, you never know if will turn into something more.” Equally frustrating, she said, is how little most doctors know about neutropenia. “Most times, I know more than they do,” said Kathy, who is a nurse. “Because of my medical background, I can make judgments about the doctors’ opinions.”

“We’ve accepted that this is our life,” Kathy added. “Shots every day, worrying. But we now have a doctor at Pittsburgh Children’s Hospital, 2 hours away, who worked with Dr. Boxer and who we can reach very easily by phone. It’s very comforting.”

For Kurt, his wife said, one of the biggest takeaways from the conference was meeting others who have the same condition that he and his children have. Neutropenia, as anyone who lives with the condition can tell you, can be very isolating because it’s so rare. “This is the first time that Kurt has met anyone else with cyclic neutropenia.”
Amgen Representatives Inspired by Family Conference

Amgen representative Alex Chapman noted the “tremendous amount of passion” he saw on the part of organizers and families attending this year’s family conference.

Chapman, Amgen senior manager of corporate affairs, and P.K. Morrow, Medical Director of Global Development, at Amgen, attended the conference for the first time this year and left with many good memories of the people they met and spoke with.

“Between the doctors, organizers, and patients, it’s like a big family, really,” Chapman said. “It was a really nice thing to be a part of.”

Chapman praised the work of the NNN with the wealth of information provided to families through the conference, from the one-on-one sessions, to the breakout sessions, to the Kids Kamp.

“It’s such an important cause,” Chapman said. “It was amazing to see the impact the National Neutropenia Network is having on patients and families.”

This year is the 20th anniversary of Amgen and Dr. David Dale creating the National Neutropenia Registry.

“It was incredible to see the amount of data generated by the registry,” “The 500 plus published papers, 50 plus reviews in book chapters, 300 plus abstracts. This is a whole wealth of information that has helped shape the understanding of the disease. Dr. Dale has brought together a global network of doctors.”

It was touching for both he and Morrow to talk with those whose lives have been positively affected by Amgen, Chapman said.

“Our attendance was an opportunity for Amgen to learn from those affected by neutropenia,” he said. “People were thankful to Amgen. It was overwhelming and so reinvigorating to spend time with the families and patients and see the impact of that.”

A Lectureship in Honor of Dr. Boxer

A lectureship to educate and familiarize faculty, residents and medical students into recognizing disorders of the blood is being established at the University of Michigan in honor of Dr. Laurence Boxer. The vision is that esteemed experts, educators and scientists will visit the University to share their knowledge and expertise in the area of childhood blood disorders. One of the diseases that will be covered is severe chronic neutropenia, a centerpiece of Dr. Boxer’s research and work as a physician. “We are pleased to know that this wonderful lectureship will result in more physicians who understand how to treat and manage neutropenia,” said Lee Reeves, Director of the National Neutropenia Network. “This is important to our patients and families who often struggle to find knowledgeable physicians. We hope to hear the good news that Dr. Boxer’s lectureship is soon funded.”
A Fun Event for Our Cause

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

In 2013 sixteen teams across the country bowled for neutrophils raising thousands of dollars to help assure that neutropenia research continues and that patients and families are supported through educational programs and patient outreach.

Ella Jewell Foundation founder and president, Kristin McGuinness, spearheaded the effort as a way to reach out to patients and families throughout the United States. “We were thrilled by the response. Not only did we raise funds for a cause that means the world to us but we had so much fun doing it.” McGuinness says they hope to double team members for the second year. “We are passionate about our cause.”

Lee Reeves is optimistic about the growth of Bowling for Neutrophils. The NNN gets regular requests from people who want to do something for neutropenia but don’t know what. “I will suggest they start a team. Ella Jewell Foundation has made it easy.”

All that is needed to set up a team is: four to six players, access to a bowling alley, a date between November 1st and March 15, some friends and family willing to support the effort and the desire to make a difference for those who live with severe chronic neutropenia.

For more information and step by step details on how to start your own team visit neutropenianet.org and click on the Bowling for Neutrophils logo.

Special Thanks

Many thanks to the family of Mary Ford for directing memorial gifts in her honor to the National Neutropenia Network.

We are grateful to our sponsors for their generous support of the 2014 Family Conference.

Taylor Carlton: Friday Night Reception
The Ruge Family: Saturday Dinner
The Ella Jewell Foundation: Kids Kamp
Ron and Vicki Bloxham: Kids Kamp T-shirts

Many people who attended the 2014 Family Conference counted on the generosity of friends of the NNN who understand the challenges of living with neutropenia. We thank them for giving so that others could attend.

Kate Bottiger	Taylor Carlton
Leslie Chapman	Gwen Field
Paul Harrington	Eric & Nancy Jacobson
Gretchen Long	Kristin & Robert McGuinness
Dagmar K Moore	Louis Reeves
Mary & Karl Schroeder	Sharon White

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

The National Neutropenia Network congratulates the Severe Chronic Neutropenia International Registry for twenty stellar years of research and patient care.

On behalf of Patients and Families throughout the world we are deeply grateful for two decades of research, and extraordinary attention to patient well-being.

1994 – 2014 PUBLICATIONS SUMMARY
Papers – More than 900
Reviews and Chapters – More than 50
Abstracts – More than 600
Editorials – More than 100