Laughter, Lightness, Linking and Learning are found at 2011 Family Conference

Laughter, Lightness, Linking and Learning were the underlying themes of the 2011 Family Conference at the Marriott Eagle Crest Conference and Resort Center in Ypsilanti July 15-17 and most participants would agree there was plenty of all four during the weekend.

Children in the Kids Camp made sure there was plenty of laughter during a laughter yoga session for all following lunch on Saturday; there were many opportunities to “link up” with others to share stories and resources; lightness came in the form of being able to share the struggles with one another; and the days were filled with non-stop learning thanks to presentations from the many physicians who were on hand to provide the latest information regarding neutropenia and its treatment.

“I was really pleased,” said Shay Jones who was attending the conference and acting as a moderator for two group discussions. “No matter where I was standing I could hear people talking about blood counts, or taking Neupogen or having neutropenia. It was very cool for me to be in an environment where it was the norm. That never happens, you never get that. To have those conversations openly and freely—it was really cool. Having those conversations spontaneously was priceless, really.”

Physicians who presented included hematologists: Mary Ann Bonilla MD, Laurence Boxer MD, David Dale MD and Peter Newburger MD; Pediatric Endocrinologist Linda Dimeglia MD, MPH; Sam Zwetchkenbaum DDS, MPH; and bone marrow transplant specialist John Levine MD. Patients were able to have valuable one-on-one sessions with doctors on Friday afternoon. Following the sessions Dr. Peter Newburger told about Neutrophils, his favorite cells.

After a casual meal of hot appetizers Jones led a session designed to allow people to get to know one another while discussing coping skills for challenging times. After a time, representatives of each group gave a summarized report allowing for more exchanges of ideas and information.

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Mark Your Calendar for the 2012 Family Conference July 13-15.

Watch our website neutropenianet.org for details on the location and venue.

Next NNN newsletter:
~ Bone Health
~ Shot Talk: Tips
~ SCN Kids Camp

We are looking for tips to make injections easier for a feature in our next issue. If you have one– email leereees99@gmail.com
Because I believe the Neutropenia Family Conference changes lives and gives hope, I have always thought it was important to find a way to help those attend who simply cannot afford the cost of travel and lodging. This year I put out a call to everyone on my email list for donations to help those individuals and families who want and need to attend but are prohibited financially. The response was heartening. Many came forward with donations between $50 and $500 allowing us to help numerous families attend.

The first response came from Steve, the father of Mitch, a healthy young man in his second year of law school. In reminiscing about a conference he attended with his son several years ago he said, I’ll NEVER forget how touching and rewarding it was to watch young parents, scared to death about the "future" of their child, have their little one walk up to Mitch and shake his hand. Those parents could then see that there is a future, seeing a young man living a good and "normal" life, standing right before them, offering proof that there is hope for their child. I’m losing it now as I type this just recalling the looks on their faces of happiness…I hope that those who attend the conference can come away with even a fraction of the joy and hope it always brought to me.

This year we were able to help a variety of individuals and families with different but in many cases dire circumstances: a mother who has spent the past year in chemotherapy attended with her child who has neutropenia; a woman who experienced recurrent mysterious illnesses throughout childhood and wasn’t diagnosed until she was adult attended along with her child who also has neutropenia; a family with two young children struggling to understand why one has to take shots; the wife of a man who has fought neutropenia for many decades and has not been able to work for several years due to complications; the mother of two children with undiagnosed white count deficiencies, a patient contemplating a bone marrow transplant; a parent with a child whose medical care has not been optimal.

We are most grateful to the generous donors listed on page three—they gave these families hope through access to some of the world’s top experts on neutropenia and caring peers.

Generosity Gives Hope

Dr. Newburger pays Tribute to Early Researcher

With a light-hearted approach, Peter Newburger, MD, opened the 2011 Family Conference telling the story of “how he came to know and love the neutrophil.” He started off sharing the ornate and colorful prose of Ilya Illyich Mechnikov, a Russian scientist studying starfish larva in 1884 who devised the theory that the mobile cells of the larva might serve in the defense of the organism against intruders. He tested his idea by introducing a rose thorn into the body of a starfish and proved his hunch correct. The experiment formed the basis of phagocyte theory to which he devoted the next twenty five years of his life. Dr. Newburger paid tribute to the Russian biologist who was awarded the Nobel Prize in 1908 for discovering how immunity fights disease. “The field has been vibrant since the 1880s,” he said. “It was unknown before that. Scientists continue to build on the discoveries Mechnikov made,” he said.

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When Sam Zwetchkenbaum was in dental school his instructor gave him an unusual assignment. No teeth brushing for two weeks. He and his fellow students learned how quickly the bacteria in their mouths turned from benign to virulent. Zwetchkenbaum, DDS, MPH, told the story of his dental school experiment to illustrate how important good dental health is when living with neutropenia. “Removing plaque even just once a day is beneficial,” he said, adding that proper brushing and flossing is important.

Dr. Zwetchkenbaum, a specialist in maxillofacial prosthodontics, is the program director for the General Practice Residency in Hospital Dentistry at the University of Michigan School of Dentistry and U of M Health System in Ann Arbor, Michigan. He had many recommendations regarding dental health:

- If possible work with a dentist who has completed a general practice residency after dental school. These dentists are more likely to have encountered a wider variety of issues and illnesses than those who have not completed a general practice residency. “Those dentists are more fearless,” he said. “People who have done general practice residencies have a lot of experience working with patients with underlying medical conditions.”
- “Ask physicians you work with. Once you find a dentist you like educate him or her. Put your dentist and physician together whether it is e-mail, phone call, lunch, etc. We’d like every patient to have something called a dental home,” he said. “Our hospital is not able to be the dental home for everybody who is medically complex but we would be happy to educate an eager dentist on how to be an effective dental home,” Dr. Zwetchkenbaum said. “A place that is close to somebody, that they are comfortable going to where the dentist is fully comfortable managing their condition.”
- The prescription oral rinse Chlorhexadine (Peridex) is helpful and offers support to the gums. While it is not a substitute for brushing and flossing it has been found to be more effective than fluoride alone. Peridex is available in a non-alcohol version and most pharmacies can order it from Butler-Gum.
- Dry mouth, or Zerostomia is caused by radiation therapy, medications and autoimmune disorders. “Saliva is nature’s magic potion to keep our mouths healthy,” he said. “Without good saliva you are at significant risk for increased tooth decay.”
- Salagen and Evoxac are two drugs that can help stimulate the flow of saliva. Sugarless hard candy and sugarfree gum such as Laclede, Trident for kids with Recaldent, Orbit sugarfree gum, xylifresh gum and Koolerz sugarless candies are also helpful. ☩

Thank you to these Donors; they made it possible for many families to attend the Family Conference.

Mary & Mark Glazer
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Steve Ryan in honor of his son Mitch Ryan
Mary & Carl Schroeder in memory of their sons Louis and Matthew
Brittany and Chad Mothershead in memory of their daughter Joeli

The Neutropenia Family Conference is supported by an educational donation provided by Amgen.
Shay Jones Discovers New Role in Network

In 2007 Shay Jones attended his first Neutropenia Family Conference; at 2011’s conference he realized the greater role he’d like to play in helping others with neutropenia.

“I had a humbling moment where I realized,‘Wow, I’m part of this now. People are looking to me for some things. I’m not just watching from the sidelines. I’m a part of this now,’” Jones said. “That kind of evolved. I felt a real responsibility by Sunday to continue this. I don’t need to participate one weekend a year; I need to participate whenever I can.”

Jones, who was diagnosed with severe congenital neutropenia as a baby, has a Master of Arts in Counseling from St. Edward’s University in Austin, Texas and will become a Licensed Professional Counselor in October 2011. He acted as group facilitator for two sessions during the 2011 Family Conference and also met with individuals for counseling sessions on Friday.

About 15 people attended his Saturday afternoon session focused on coping with neutropenia. As a result of the session those attending decided to set up an online support group either through an e-mail exchange or perhaps a private Facebook group. Jones said he’d like to moderate the group, at least in the beginning.

It would be open to neutropenia patients only.

“That’s the hard part for me, only allowing those with neutropenia to attend, and turning others away. I hope those who don’t have neutropenia respect the notion that people dealing with it may sometimes need to have their own kind of proprietary conversations. I hope they can appreciate how helpful that can be”

He’d also like to offer his services as a counselor to talk or correspond by e-mail with anyone whose life includes someone with neutropenia.

“Talking to anyone affected by neutropenia is certainly welcome.” Jones said. It’s something he never had a chance to do as he was growing up. In 2005 he received his first Network Newsletter with a story about Leta Reeves who died of a failed bone marrow transplant after twenty years facing the same kinds of challenges he had experienced with neutropenia.

“It was a very profound moment for me,” he said.

Attending recent conferences heightened his awareness of the shared challenges people with neutropenia face.

He’s looking forward to offering assistance and sharing the coping skills he’s learned to help manage his own neutropenia.

“There’s a maturity for me,” he said. “I’m a participant in this and I’m involved in the infrastructure of this.”
Dr. Dale Offers SCNIR Highlights

This year the Severe Chronic Neutropenia International Registry is in its 17th year and as it has grown the number of patients and ages of patients have increased. “We started in 1994,” said Dr. David Dale. “Many patients, some in this room, have known of us and the researchers interested in neutropenia, much longer than that.”

His research has been ongoing for more than 40 years. “I was surprised to see a letter I wrote in the 1960s about the diagnosis and treatment of neutropenia,” he said referring to a private consultation with a patient earlier in the day.

The registry operates a European office and an office based in Seattle that deals with patients based in North and South America and Australia. There are more than 1,200 patients enrolled in the Seattle agency, he said.

The largest numbers are patients with congenital and idiopathic neutropenia. Both men and woman are enrolled in about equal numbers, although there are a few more women with idiopathic neutropenia than men.

“Over time, the average age of the registry has increased,” he said. “That’s good. That means people are living and getting older.”

However, that points to a growing problem. There are relatively few physicians in the U.S. who are expert in this area of adults with neutropenia, Dr. Dale explained.

“Maybe you can share with us in the education of adult doctors about how to manage neutropenia,” he said. “It’s an important problem.”

In terms of enrollment, the registry over time has grown and grown steadily. There are 50 to 100 new patients enrolled in the registry on an annual basis, he said. It is active throughout the world. Recently the registry worked to obtain blood samples for testing from a patient in Sri Lanka.

“We were very helpful to a family, but you can imagine how the distance and language and all the other barriers helped that become a very big project,” he said. The registry is very active in research.

“We just sent a report to the National Institutes of Health listing 41 research papers, reviews chapters and abstracts for the last year,” he said. “That’s important for a lot of reasons, but that’s where generally the work has been critically reviewed and reflects a lot of work to gather the information, organize it, analyze it and present it so that it is useful to doctors and nurses and, of course, to you.”

Conference Fosters Friendships between Moores, Jacobson Families

When Mary Moores and Nancy Jacobson met during the 2009 Family Conference they discussed how wonderful it would be if their daughters Ella and Katie could get to know each other.

A few months later Nancy’s daughter, Katie, who had been looking for a pen pal initiated a correspondence with Ella, and the two girls hit it off forming a friendship via the written word. Both girls are the oldest in their families and have a younger sibling with severe congenital neutropenia.

“That’s part of the connection, they’re the oldest sibling and as the oldest child they kind of take on some of the responsibility in the family,” said Mary Moores, Ella’s mother. “They take it more seriously. They can identify with each other.”

In the spring of 2010 Nancy and Eric Jacobson surprised their children Katie 11, Mary 9, and Anna 6, with a vacation that included a visit to the home of Mary and Jonathan Moores and their four children Ella, 11, Stephen 9, Elizabeth, 5, and Sophia, 3. It turned out to be such a great time for both families that the Moores followed with a visit to the Jacobsons home in Indianapolis last summer.

“There’s an instant rapport when you have gone through worry over your child,” Moores said. “We’re all worried about what kind of future these children are going to have.”

Mary Moores looks to Nancy Jacobson for advice and support.

“They’ve been through a lot,” Moores said of the Jacobsons. “They’re veterans. I can call Nancy and she can clarify whatever the issue is as a result of having to two daughters with neutropenia. We just click. It’s a big help.” All of the family members interact well together and they look forward to their time together at the Family Conference.

“It makes it more like a family reunion than going to a conference where you are going to learn about your child’s disease,” said Moores.
Transplant Means a New Life for Henry Moore

Receiving a bone marrow transplant at the age of seven has meant a life of new possibilities for Henry Moore. Now 11, he plays full contact football, is a basketball star and swims in the ocean. He enjoys a lifestyle he wouldn’t have dreamed before his transplant.

But his parents said getting to this point wasn’t easy. “The decision to transplant is so personal and no one can make it for you and that’s the hard part,” Patrick Moore said. “I begged someone to tell us what we had to do. It’s hard.”

In March 2007, Henry arrived in Ann Arbor at the CS Mott Children’s Hospital at the University of Michigan for his bone marrow transplant. After the first transplant failed, there was a second transplant in May 2007. He and his mother stayed in Ann Arbor until September 2007 when he was well enough to return home.

“It’s been four years, I can honestly say that probably not before this time would I ever be able to stand up and talk to you about it,” Angela Moore said during her presentation during the 2011 Family Conference. “It’s going to be very difficult today. I hope that we can give you some hope and maybe some insight into our whole process.”

When an e coli infection left him “hours away from death” at 9 weeks old, the Moores learned Henry had severe congenital neutropenia.

“We were told he had something called Kostmann’s Syndrome,” Patrick recalled. “At that time we had just gotten our computer at our home and I don’t even know if it was Google, but somehow we searched and it said ‘100 percent fatal by 12 months of age.’ ”

The doctor they saw at Duke University was encouraging and told them to just hold on.

“He told us for every six months we could keep him alive there was going to be some new treatment, some new medication, some new therapy that might make a difference in his life,” he said. “And, sure enough, four or five years before Henry was born I don’t think they even used neupogen for this disease. You can see now he’s living proof that miracles do happen.”

The Moores decided upon a transplant after meeting with Dr. Laurence Boxer and Dr. John Levine. “We really wanted to be told ‘just stay the course, he looks great, he’s doing great, just keep doing what you’re doing,’” he said. “Instead, I think we walked away with a different perception - that some of this healthy looking kid was smoke and mirrors. Superficially, he had been doing well.”

But they realized he might not be doing well indefinitely. There would come a time when his health would deteriorate.

“We knew the data suggested we didn’t have an infinite amount of time,” he said. “Sooner or later we were going to run out of time. We chose to do it while he was healthy. It appears that if you’re healthy you have a lot better chance of making it through the transplant as opposed to going in when you’re having organ failure and other things. It was a tough decision. It’s a lot of risk.”

After meeting with Dr. Levine and Dr. Boxer, the Moores knew they had found the right place for the transplant, and then they waited seven years to find a donor. Their two younger sons were not matches.

“We got a call that we had a really good match,” he said. “The first transplant was rejected. These guys took another swing at it, and they got him and us through it.”

“We love Dr. Levine with all our heart and we’ll never ever believe that he didn’t save our kid,” he said. “There was some divine intervention that brought us to him.”

Patrick came to Ann Arbor for visits, but Angela was with Henry for the duration of the transplant and recovery time. Her husband stayed in Virginia with their two younger sons. When they finally arrived home there were new challenges to face.

“I can honestly say the time after we went back home was harder for us as a family than being in Michigan itself,” Angela said. Her husband agreed. “It’s tough on your family,” he said. “All the things in your marriage that you suppress because it’s not as important as your baby’s life – all those little things suddenly when your kid gets better come to the surface. And, you’ve got to just work yourself through it.”

While making the decision is one of the most difficult the Moores believe they’ll ever make, they felt peace once they decided to try for a transplant.

“You guys may be going through the same thing,” he said. “You want someone to tell you, ‘this is your only option. Do it now’ and we can’t tell you that. I don’t think there’s any doctor here that can tell you that, but we did have to make that decision. I will tell you whether you decide to do it or not there’s a tremendous load off your back when you decide.”

Henry shared that while he doesn’t remember much of his time in Ann Arbor he does have a few memories of playing pranks on nurses and others at the hospital. He told stories of shooting water guns and hiding under his bed so he could startle the nurses.

The Moores consider the man who donated his marrow to Henry a part of the family now. “That family is now our family,” he said. “We spend every Thanksgiving with them.”
Diagnosis Treatment and a Life Style Change

Greg was a healthy 42-year-old plumber who’d worked at his job for 23 years, but had noted that his sometimes-abnormal white blood cell counts were a concern.

Dr. Dale and Dr. Laurence Boxer encouraged patients to use a “pain ladder” of measurement to express the severity of bone pain they experience. Dr. Dale said it is possible there will be studies conducted to determine the best ways to deal with pain. NSAIDs, antihistamines, antidepressants, gabapentin and narcotic analgesics all have been shown to help with controlling pain as a result of mouth ulcers, gingivitis, abscesses and cellulitis and abdominal infections.

In addition, aromatherapy, acupuncture and massage are part of integrative therapies used as a helpful approach to pain caused by neutropenia and bone pain from taking G-CSF.

Dr. Mary Ann Bonilla reported that several of her patients have found relief using integrative therapies such as therapeutic grade oils. She outlined several oils that have been used including: camphor, wintergreen and eucalyptus for pain; lavender and lemon for insomnia/nausea; ylang ylang, rose and lavender for anxiety and depression and clove, lemon, cinnamon, eucalyptus and rosemary for their anti-Septic, anti-bacterial properties.

“These can be very helpful,” Bonilla said.

She told of a patient who found that using the therapeutic oils provided the only relief he could find from chronic pain from chemotherapy.

Dr. Bonilla said she frequently sees young patients nonchalantly waiting for their treatment with acupuncture needles poking from their ears. The sterile, fine needles stimulate trigger points and can be used to treat nausea and pain from chemotherapy. Massage therapy can relax patients and increase delivery of blood and oxygen to massaged areas. It has been used effectively to increase warmth and decrease pain, she said.

Giggles and guffaws ring out during “laughter yoga” session

The children attending the 2011 Family Conference had a chance to share something they’d learned during the family conference — the importance of laughter. Child Life and Recreational Specialist Jessica Doletzky, BS, CTRS, led the children in a mini laughter yoga session that sparked a room full of laughter with people big and small giggling together.

Doletzky explained that the body does not differentiate between real and fake laughter, so the same physiological and psychological benefits can be found by doing either one. Often, by faking laughter a person can find themselves laughing naturally at the silliness of the activity, she explained.

The children prompted the adults out of their seriousness with exercises such as: acting out a funny telephone conversation, concocting a laughter drink and saying funny phrases guaranteed to bring out smiles and laughs.

Dr. Newburger pays Tribute to Early Researcher

Dr. Newburger went on to show short video clips of phagocytes surrounding and then absorbing a germ, “This You Tube video is very popular among my set,” he quipped. For readers who would like to see this video of the neutrophil in action, visit neutropenianet.org and click on the tab neutropenia what is it, then click on video explanation.

Newburger outlined the ways neutrophils are studied, how they are formed and how they function. Emphasizing their unique and wonderful characteristics in protecting us from harmful bacteria—the neutrophil first engulfs and devours bacteria, and then it releases a toxin to complete the job of destroying the invading microbes—these toxins are made of the same chemicals found in the household cleaning product, Clorox.

Newburger also talked about the possibility of too many neutrophils in the wrong places causing inflammation and tissue damage, such as is found in arthritis.

Dr. Newburger’s entertaining and informative talk was a great way to start off the weekend. He geared it to adults but made it entertaining enough that many of the children in attendance followed along and enjoyed learning about a topic so important to their lives.
Greg was a healthy 42-year-old plumber who'd worked at his job for 23 years, never calling in sick for more than a few days each year. Then in November 2008, he suddenly started having pain in his lower back and pelvis and sores in his mouth and on his feet. In May 2009, a superficial cut on his hand became infected and led to a hospitalization that resulted in the diagnosis of idiopathic neutropenia.

“My fingers swelled up like sausages,” Greg said. “They hooked me up to every antibiotic they had.”

With a neutrophil count at 0, Greg was treated with Neupogen, and in four days his blood count had risen to acceptable levels. He now injects himself with 25 micrograms of Neupogen every other day.

The disease has had a profound effect on Greg’s life. His doctors have told him he should no longer work as a plumber because of the risk of infection from the bacteria he dealt with on the job. He’s now collecting disability payments from Social Security and his union pension while he looks for another career, possibly in real estate.

Greg, who lives in Folsom, N.J., attended the NNN conference in Rancho Bernardo with his wife, Georgeann, and their children, 16-year-old Daniel and 13-year-old Julia. It was their first visit to the West Coast.

“Hopefully, we’ll learn a lot,” he said as the conference began.

Greg, now 44, is still learning to deal with the pain associated with neutropenia, and he suffers from headaches with sensitivity to light and sound. He’s been told not to take Tylenol, so he’s searching for other pain relievers.

Georgeann said she’s also learned a lot about Greg’s condition.

“I think I qualify for a nursing degree now,” she said.

Greg said the conference helped him connect with other people who have neutropenia.

“I’m not alone,” he said. “It got me out of that mode of feeling alone and sorry for myself.”

Greg said he is now confident that he can manage his disease.

“It’s not a death sentence,” he said. “If you do the right things and take the medication, you can live a normal life.”

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“I was totally charmed by the children. . .
I’d volunteer again tomorrow.”

Dagmar Moore / Kids Camp Helper