The Quarterly Advocate
BCCNS Life Support Network
Summer
2013

Always Look for the Bright Side (in the Shade)

By Annewil Stelloo, The Netherlands

My name is Annewil. I am 30 years old and live in The Netherlands. In 2010, at age 27, I learned that I had Basal Cell Carcinomas (BCCs). Two 'normal' moles were removed for 'cosmetic' reasons according to my doc and turned out to be BCCs. My gut feeling told me, all along, that there was something wrong. As long as I can remember, I have had these pits on my hands, which turned out to be the 'famous' palmar pits.

Because of the multiple BCCs and palmar pits, I was referred to University Hospital of Rotterdam. One of the first things they told me was that I was too old to be diagnosed with BCCNS. During this process, a lot of doctors and trainees were surrounding me. I was feeling like a fairground attraction. They found a few spots which could be BCCs and made a plan for the removal of those spots. Also, genetic testing was done. But no mutation was identified.

Being told to avoid UV-light and (radioactive) radiation, I had difficulty performing my job as a laboratory technician in a hospital where radioactive assays were done. So, I had to tell my team-leader about my condition and a couple of weeks later (August) we had a meeting with the staff advisor. They told me that my contract would be terminated by the end of the year. This was a big shocker, because I was in permanent employment!

The next months were very difficult for me. Losing my job and hearing about the genetic disorder were life-changing, along with the treatments that were planned for the next couple of months. My world existed of applying for a new job, being referred to an oral surgeon, surgical treatments, and dealing with the possibility that our one year old (at the time) daughter could also have BCCNS.

Annewil, Noa and Edwin Stelloo from The Netherlands

In March 2011, I applied for a job as a lab technician for a company which specializes in floriculture. Within two weeks, I got hired and started to work there. It is one of the best things that happened. The job is great. I have incredible colleagues. It is a lot of fun. I even developed a new hobby: photography. With the help of two colleagues, I got inspired to create nice images! On a good day, with inspiration, the camera is glued to my hands (despite my daughter's wishes).

Surgery for five dental implants was planned and new BCCs were appearing. Our Continue Page 14

You are Special, Unique and Soulfully Made

by Kristi Schmitt Burr, Executive Director

You are not a mistake . . .
We are part of nature; the inherent path of creation. Blips, skips, deletions, and omissions are all part of the plan. Observing birds at the feeder, calves, lambs and turkey chicks at the farm reveals that some arrive with extra digits, or sporadic coloring in their wool or mane, others need extra TLC to survive the birth. But they are all a part of this amazing world.

Celebrate who, where, and what you are . . .
Be happy you know what the condition is called, what the manifestations are and that you can manage this condition with a network of information, families, friends and caregivers. There are thousands of people with unrecognized and unmanageable conditions. You have scores of options available to you.

Continued Page 14

Contents...

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Birthdays

July

Jonathan Andrade
Alexa Breurken
Michiel Breurken
Margaret Costello
Daniel Cox
Rachel Cox
Nathaniel Ibuaka
Sue Koenig
Tommy Massimino
Toby Mattingly
Paul McGoldrick
Stephen Michalowski
Cherie Pelman
Cindy Shelley
Morgan Stickley
Joseph Swierupski
Lisa Tack

August

Savannah Douglas
Danny Dower
Chris Dower
Richard Fest
Jessica Fest
Adam Haugh
Holly Hunt
Marshall Ibuaka
Kaitlyn Langemeier
Rachel Marshall
Molly Marshall
Linda Morrison
Harlan Neal
Loretta Owens
Judd Penske
Melissa Phillips
Audrey Rancourt
Teresa Roe
Kristie Roller
Stephen Stroud
Shandra Tuck
Michael Vaccaro
Cathy Wells
Jack Wood

September

Allicyn Allen
Gustavo Andrade
Bryant Bradley
Helen Costello
Danielle Fest
Pat Ford
Bridget Koenig
Luke Lamm
Melody Stroud
Chirsty Sweet

Support

Rachel Andrade
Matt Barrett
Ethan Birch
Bryant Bradley
Durst Breneiser
Vincent Chupka
Brycen Davis
Nichole Fest
Mary Kathryn Harrison
Carol Johnson
Steve Johnson
Caleb Keim
Journey Krahn
Lords Family
Nick Mercer
Sarah Mouhtarim
Andrew Murley
Marlee Nichols
Brandon Pearsell
John Petkewicz
Hartley Plyler
Cindy Rosenthal
Morgan Stickley
Polly Temple

New Families

Belin (SC)
Costa (FL)
Cushta (PA)
Holewinski (WI)
Kiernan (NJ)
LaRowe (NY)
Nichols (DE)
Tuil (The Netherlands)

News from Around the Globe

Alexis Griggs was selected to be a member of the William J. Brennan High School Chapter of the National Honor Society.

Jane Gastelum is expecting a grandchild.

Gary & Debbie Lombardo are expecting a grandchild.

Stephen Douglas earned his high school diploma this spring in West Virginia.

Cara & Jason Truitt are expecting a baby.

Nick Mercer graduated from Mansfield Legacy High School in Texas this spring. He plans to study special education at Tarrant County College in the fall.

Congrats to Miranda Uren and her fiancée, Adam, on their engagement.

jingle bells for cancer cells

There is no question that Jade Bailey, Kristi Easterly, and BCCNS Life Support Network member Christen Gullatt were destined to be friends. These ladies started to hang out after they met in 2011, while their sons were in the same preschool class. Their husbands soon met one another and family friendships were established.

They did not know it at first, but God had great plans in introducing them to one another. Two of their families were connected through a church, two through the experience of raising brothers, and two of the mothers were tied by the realization that they were raising children with diseases beyond their control. Their strongest bond is their mutual desire to prioritize God, family and friends.

Being like-minded and working together, they felt compelled to found the 501(c)(3) non-profit organization **Hearts and Minds that Care Presents** (HMC Presents). The goal for HMC Presents is to introduce and produce fund raising events for three specific organizations. Each lady chose an organization that touches her heart personally:

Methodist Justice Ministry protects women and children from abuse and violence.

Children's Tumor Foundation raises funds for researching a neurological disease called Neurofibromatosis.

Basal Cell Carcinoma Nevus Syndrome (BCCNS) Life Support Network develops programs and activities for awareness, research and advocacy for people with BCCNS, also known as Gorlin Syndrome.

HMC Presents is organizing the merry event **Jingle Bells for Cancer Cells**. Their mission through Jingle Bells for Cancer Cells is to raise awareness and funds that will aid all three non-profit agencies. The celebration will be held 4-8:00 p.m. on December 7, 2013 at the festive Sundance Square Plaza (www.sundancesquare.com) in downtown Fort Worth, Texas. Jingle Bells for Cancer Cells will be held outdoors with live concerts by stellar performers (including Nashville recording artists Robert Sebastian, Bryan Simpson and gospel singer Rick Bernard James), holiday sing-along, silent auction and delicious food vendors for families to enjoy.

Hearts and Minds that Care Presents is asking for your support, participation and generosity by attending and donating to the joyful Jingle Bells for Cancer Cells. Your contribution will help make this inaugural event a jubilant success. If you feel inclined to contribute to Jingle Bells for Cancer Cells through sponsorship or by serving on a committee, please E-mail hmcpresentsfw@gmail.com. It is requested that donations be received by July 1, 2013, in order for proper recognition to be given for event materials. For more information visit www.hmcpresents.org and register there.

In conjunction with Jingle Bells for Cancer Cells, BCCNS Life Support Network is hosting its regional member meeting, **Deep in the Heart of Basal Cells**. The conference will be held December 6-7, 2013 in Fort Worth, TX. Members will be attending interactive classes on current care and treatment options and case management all day Friday, December 6. Presentations will be delivered by knowledgeable health care providers and researchers. Friday evening's bountiful western buffet is sure to kick-off the weekend's festivities. Watch www.BCCNS.org and our newsletter as details develop. For more information you can contact our office by calling (440) 834-0011 or E-mailing info@bccns.org.

Kristi Easterly, Christen Gullatt and Jade Bailey.

In Times of Trial, You are Not Alone

by Jenny Hershberger

Sometimes circumstances are completely out of our control. We have done everything that we are able in attempt to bring remedy to a situation, but evidence of improvement eludes us. As we yearn to have things go our way, our humanity becomes discouraged for lack of fulfilled expectations.

It is not good that any of us should be alone, especially in times like this. God is gracious to provide fellowship through others. There is strength in numbers. Ecclesiastes chapter four says "Two are better than one because they have a good return for their labor. For if either of them falls, the one will lift up his companion." Companionship is helpful when we are overwhelmed by a heavy load. It is important to seek friendship when we need it and it is equally essential to lend our steel for others who bear a burden.

BCCNS Life Support Network was recently contacted by member Patricia Pearsell. She informed us that her 19 year old son Brandon has been diagnosed with inoperable osteosarcoma in his right pelvic and hip bone. The tumor is about 17cm long and is increasing pressure on his nerves. This young man has already mustered through other tribulations and is now in the midst of yet another hard battle.

Good cheer from friends, family and even strangers can hold a great deal of weight in a person's life. BCCNS Life Support Network is asking that you take a few minutes to send a card or write a note of encouragement to Brandon Pearsell. We want to let him know that he is not alone by picking him up with our edifying words. Please send a note directly to:

Thank You **Christa & Shelby Newhouse of Bois Blanc Island, Michigan**

Christa Newhouse and her husband Shelby are the innkeepers of Insel Haus Bed and Breakfast (www.inselhausbandb.com) where BCCNS Life Support Network has hosted numerous regional meetings. Christa knit this pillow and sent it to our office as a gift. It is beautiful and we are enjoying her skillfully crafted present. Thank you Christa!

Hedgehog Inhibitor Support

Find out what helpful hints fellow Network members have to offer regarding living life while taking hedgehog inhibitors . . .

"When you are broke, do something charitable. When you are exhausted, do a lil more. Diving for lobster and outta breath, hold it a lil longer. Feeling hateful, love a lil harder. Truly, our minds are the weakest muscle we have. It will fool you into believing you are at the end when you reallllllly aren't even close. For me, I find peace in that. I trust that when I feel I have reached the end, I just catch another gear. Bring it on life, I will kick your rump!! Is that all you got?" —Robert J. Tuck

"I volunteer for our local cancer support, driving patients to their appointments . There is always someone with a lot more trials than you have. Just be thankful that what we are doing will help our future generations."
-Linda Cox

"What helps me a lot when I'm 'down and out' is just being able to laugh (at myself, my friends, at movies) and thinking 'it could be better, but it could be worse'." -Jenn Finkbiner

"Find those little things that help, a certain food, exercise, music whatever it is that puts a smile on your face. I could eat cookies and still lose weight." -Paul McGoldrick

"Sometimes you have to take it one day at a time." -Rocki Finkbiner

FDA Launches New Online Resource

In April, the FDA Patient Network commenced operation. Its target audience consists of patients, caregivers and advocates. www.PatientNetwork.fda.gov is an interactive website intended to help educate people on how medications (prescription, non-prescription or over-the-counter) and medical devices go from concept to market.

A primary purpose of www.PatientNetwork.fda.gov is to utilize patients and consumers as partners by encouraging them to share their ideas and concerns regarding the medical product development process. Individuals will be able to comment on a regulation, making it possible to voice their opinions. If you have questions, join a scheduled live chat with FDA experts and get some answers.

Additionally, people can learn how decisions are made about the approval of drugs, devices, and other medical products by perusing www.PatientNetwork.fda.gov. Also, timely information will be available about product safety and new product approvals. Finally, interactive tools are available to find approved drugs and to search for a clinical trial.

Creating an ER Protocol for Your Child

By Complex Child E-Magazine / www.ComplexChild.com

As we all know, going to the Emergency Room involves a lot of sitting around and waiting, even if your child is very ill. Children with serious medical conditions may have their health and safety negatively impacted by waiting periods, and may become very sick if the appropriate interventions are not provided quickly. In order to streamline the process and get your child the care he needs quickly, it is best to have an official ER protocol for your child.

Why Your Child Needs an ER Protocol

Let's take a look at a little girl with mitochondrial disease who is brought into the emergency room (ER) with dehydration from a virus. Mom reports to the triage nurse that her daughter has had a runny nose, fever, and cough for three days, and has been vomiting occasionally. She cannot keep her hydrated even using a feeding tube, her heartrate is elevated, she is sleeping a lot, and she is beginning to look worse. In most cases, the triage nurse--who probably has never heard of mitochondrial disease--will perceive this child as not that acutely ill, and will not place her in a room or have her seen by a doctor immediately.

What the triage nurse does not know is how quickly children with mitochondrial disease can decompensate, and how immediate rapid intervention can prevent a major decline in the child's health, if implemented appropriately. Despite the mother trying to explain multiple times that her child needs to be seen urgently, the triage nurse dismisses her as a nervous mom. As a result, the child sits in the waiting room for three hours. Her blood sugar begins to drop and her vital signs become progressively more unstable. By the time she is seen by a physician, she is in a crisis. She ends up being admitted and is inpatient for five days.

Had this child had a letter from her physician explaining her condition and clearly outlining a protocol for testing and treatment, her crisis likely would have been avoided. She may have been able to receive the appropriate treatment in the ER without needing to be admitted, or she may have only needed one night in the hospital.

Any child whose condition requires special precautions, who is complex, who can decline rapidly, or whose presentation may be atypical should have an ER protocol letter. Not only will it get your child in to see the doctor faster, but it will also ensure that the appropriate treatment and tests are performed.

What Should Be in an ER Protocol Letter?

The content of the protocol letter will vary depending on the child, her condition, and past illnesses or experiences. Many disease organizations have templates for ER protocol letters. (See, for example, the following: MCAD Deficiency, Mastocytosis, Mitochondrial Disease.)

Your child's protocol will be highly individualized, but should contain all of the following general information: child's name, birthdate, primary or coordinating physician's name and contact information, specialist physician's name and contact information (if appropriate),primary or most critical diagnoses, any allergies, general medical considerations, and physician's signature.

The remainder of the ER protocol should contain very specific instructions for care and testing of your child, delineated by presenting symptoms. Any commonly presenting set of symptoms or conditions should receive a separate protocol. If, for example, a child often presents with respiratory distress, a specific protocol should be developed for respiratory distress. Common conditions that are included in letters are respiratory infection, gastrointestinal distress, suspected systemic infection, hypoglycemia or hyperglycemia, autonomic crisis, pain crisis, and so forth.

Instructions should contain the following elements, as applicable: presenting symptoms, vital signs to expect and that need to be monitored, testing to be initiated, treatment to be initiated, medications that should or should not be administered, things that should be avoided (such as fasting), when to contact the specialist if greater assistance is needed, and anything else of urgent importance.

Here is an example of instructions for a child with a central line who has a fever, who we will call Child A. Child A has a central line for IV nutrition due to chronic feeding intolerance. With a central line, she is susceptible to serious bacterial infections in the blood stream. Our general rule with children with these lines who have fevers is as follows: blood culture from the line daily until negative cultures x48 hours, empiric

Creating an ER Protocol for Your Child

Continued from Page 8

antibiotic coverage with Vancomycin and Ceftazadime, and admission until we prove there is no bacteremia.

Here is another example for a teen with mitochondrial disease presenting with a new acute illness. Treatment goals during a crisis period center on stabilization and treatment of whatever process precipitated the crisis (i.e. infection, dehydration, etc.). However, basic care parameters aimed at some of the specific problems associated with mitochondrial disease are indicated and implemented as needed.

If acidotic, IV sodium bicarbonate as necessary. IV access for intravenous fluids and monitoring. Rehydrate as necessary. Maintain hydration using D5 1/2 normal saline solution along with KCl if urine output is normal administered at a maintenance rate up to 1 1/2 maintenance. Modifications in solutions as indicated by age or circumstance. Monitoring of following blood tests aimed at detecting abnormalities seen in mitochondrial disease including complete metabolic panel, lactate, CPK, and blood gas.

Your child's plans may look entirely different, but should present a clear plan of action as illustrated by the two examples above.

Other Helpful Information

It is also very helpful to have a document available with a brief medical summary or history for your child. This can be a helpful reference for you and for the physicians treating your child.

It is best to have a very concise emergency form, such as the AAP/ACEP Emergency Information Form, that can be read quickly in an emergency. This form only includes vital information, such as diagnoses, normal vital signs, and medications in a universally accepted and simple format.

A more complete medical history, by organ system if possible, can also be extremely helpful, especially for a child who is very complex.

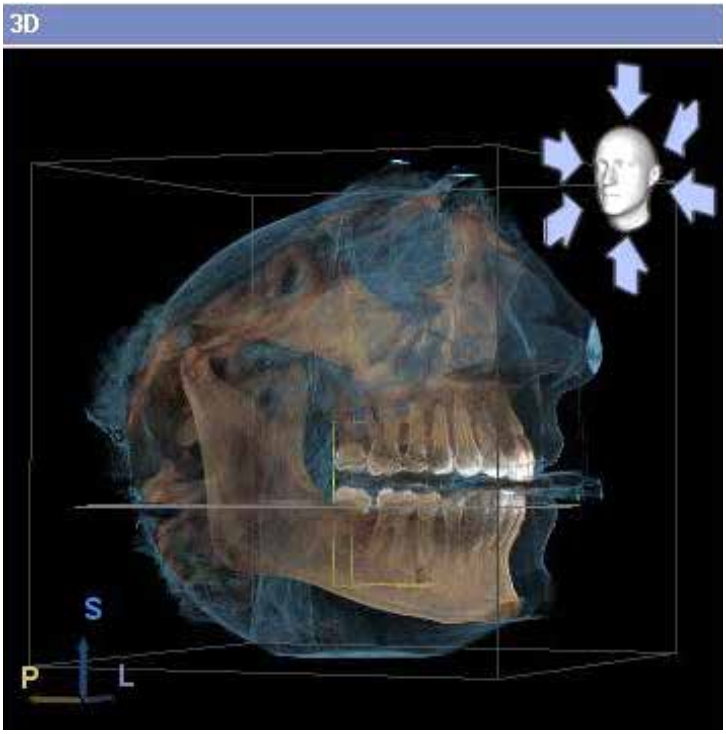
With an appropriate ER protocol and additional emergency information, your child should be treated appropriately at the emergency room. Many children's lives have been saved by protocol letters, so make sure to have one for your child with complex medical issues.

http://articles.complexchild.com/feb2012/00364.html

Ask the Doctor

Question: What is Cone Beam Computed Tomography (CBCT)?

Answer (by The Alliance for Radiation Safety in Pediatric Imaging, www.pedrad.org):



Over the past ten years, cone beam computed tomography (CBCT) has become increasingly available for use in dental offices. CBCT produces images similar to computed tomography (CT) used in medicine except that CBCT may expose a child to less radiation dose.

In CBCT an x-ray device rotates around the head to create many individual pictures of the child's jaw and teeth, and these individual images are used to build a virtual three-dimensional (3D) representation (main advantage of CBCT vs. other dental radiographs).

This virtual image may contain diagnostically important information that is not present in other dental images such as bitewing or panoramic image. However, taking a CBCT image results in more radiation dose to the child than other commonly used dental images.

Sherry Chupka is from Butler, PA.

Sherry and Brian's youngest son Vincent.

Everything Will Work Out for the Best

by Sherry Chupka

My journey with Basal Cell Carcinoma Nevus Syndrome (BCCNS) began when I was six years old. During a regularly scheduled dental appointment, the staff saw something on the x-ray and sent me to an oral surgeon. An extra permanent tooth was discovered in the roof of my mouth. The oral surgeon removed three jaw cysts and the extra tooth. This required a lonesome overnight stay at the hospital. I was scared and not sure what was wrong. At the time, I did not know why I had jaw cysts.

This happened in the first grade and I did not enjoy missing a week of school. Upon returning to school, the teacher dropped all the assignments on my desk, including a test that did not count toward my grade. After flying through the test, since it did not count toward my grade, I learned that the test was to measure my eligibility for participating in the gifted program. I was one point away from becoming accepted, as was another girl in the class. Her parents requested that she be allowed to retake the test. I was not allowed to retake the test. (It was probably because I cried in school every day, up until sixth grade, for being called ugly.) I liked school, but did not get along well with others. I still do not have many friends.

Two more jaw cysts were removed at age 18. The cysts formed in the mandible where wisdom teeth would normally be. That surgery was in the doctor's office over Christmas vacation during 12th grade. The whole way home my mouth was filling up with blood and my mother did not believe me. She finally believed me after we got home and I spit it out in the kitchen sink. It was disgusting. Then we went back to the doctor and he fixed the missing stitches. I still did not know I had a genetic disorder.

At age 25, I returned to community college to study computer science. My aforementioned classmate's father was one of my professors. He helped me find my first job in software testing. I have been a quality assurance

Sherry with two of her three sons.

test engineer for 15 years. Things would be different if I had been accepted in the gifted program, but it all worked out in the end.

My husband Brian and I met when I was 16, he was 19. We married in 1993, almost two months after our oldest son was born. I was 21 and he was 25. We have three sons. Andrew (20) is in his second year of college, Trevor (19) will be starting his second year of college and Vincent (16) is in high school.

People ask why I had children with a genetic disorder. I did not know I had BCCNS at the time. Even if I had known, it would not have stopped me because I do not have very many problems.

In 1994, I had a huge jaw cyst removed from my lower jaw. There was not much left of my lower jaw bone. They took a bone graft from my knee and removed the lower teeth. I remember hearing the saw and music playing during surgery, but could not feel anything or move. The cyst came back in 1995 and I went to a different doctor who let my jaw bone heal on its own after surgery. It got infected afterward and they had to drain it. That was the last time a jaw cyst appeared, so I have been pretty lucky.

After that, I started to worry more. How were we going to pay for a family and all these medical bills? That is when I decided to return to school. Shortly after enrolling, I became pregnant with our third son. A final was scheduled on his due date. He was born one day early. Luckily, the professor canceled the final at the last minute. Somehow, my husband and I made it through school while both of us were working, taking care of two young children and sharing only one car. I still do not know how we managed to do all that.

In 2000, at about 30 years of age, my first skin cancer was removed and I was diagnosed with BCCNS by a knowledgeable MOHS surgeon. The doctor looked at the pits in my hands and knew right away. Thankfully, I was a somewhat aware of BCCNS from reading about it online. Otherwise, I would have probably fallen out of my chair in shock. So far I have been lucky; having fewer than ten basal cell carcinomas removed and being able to use acne medicine for cystic acne and skin cysts. I still worry about what could happen to everyone if I got sick and could not work. But things have a tendency to work out.

Only one of our three sons has shown signs of BCCNS. Our youngest son Vincent has had two surgeries to remove five jaw cysts. He had two removed from the roof of his mouth in 2010. Then he had three removed from his lower jaw in 2011. His primary care doctor sent us to for genetic tests in 2012 and found a mutation of unknown significance on the PTCH1 gene. So we have an unidentified variant of BCCNS. The endocrinologist ran a bone scan which revealed that his bones are three years behind schedule. He was screened by a dermatologist and his skin looks good. He is lucky since he knows to wear sunscreen and stay out of the sun.

I am very grateful to have found BCCNS Life Support Network and have met lots of nice people. I had no idea what to expect from MOHS surgery and everyone was very helpful in answering my questions. Things are working out for the best.

Sherry, middle son Trevor, Sherry's husband Brian, and their eldest son Andrew.

What Siblings Would Like Parents and Service Providers to Know (Part III)

Sibs' Concerns about the Future. Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitude toward the extent of their involvement as adults may change over time. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

Including Both Sons and Daughters. Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings — including brothers — should be considered.

Communication. While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as How to Talk So Kids Will Listen and Listen So Kids Will Talk and Siblings Without Rivalry (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

One-on-One time with Parents. Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.

Celebrate Every Child's Achievements and Milestones. Over the years, we've met siblings whose parents did not attend their high school graduation — even when their children were valedictorians — because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

Parents' Perspective is More Important than the Actual Disability. Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

Include Siblings in the Definition of "Family." Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs — the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered"— instead of "parent-centered"— services.

Actively Reach Out to Brothers and Sisters. Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

Learn More About Life as a Sibling. Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

Create Local Programs Specifically for Brothers and Sisters. If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families. Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

Fund Services for Brothers and Sisters. No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone — longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

About the Sibling Support Project
The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs — and to increase parents' and providers' understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is a national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact:

Don Meyer
Sibling Support Project
A Kindering Center program
6512 23rd Ave NW #322
Seattle, WA 98117
206-297-6368

Always Look for the Bright Side (in the Shade)

Continued from Page 1

daughter would begin her annual check-ups (brain-MRI, dermatology, pediatrician). I told the staff advisor of this company about my condition. They accepted me for the things I CAN do, instead of the things I CAN'T do like my former employer did!! That was such a relief!!!

The real downside of BCCNS is that the doctors advised us to stop our family planning. We were very lucky to have our little girl, for now she looks happy and healthy. People around us were asking when she would be getting a little brother or a sister, which was and still is very painful at times. It is not that we do not want to have another child. It is because of the 50% chance of transferring BCCNS that we decided to stop our family planning. Maybe in the future foster care, or something like that, can make it a bit easier for us . . . But still, it's tough when people can't accept/don't understand our decisions . . .

I have quarterly dermatology visits and the annual dental implants check. The last derm appointment was April 22nd and the doc now trusts my gut feeling (because I have never been wrong before, concerning the BCCs). Four biopsies were taken. The only thing I want to know is which treatment they will plan for me and when.

I am grateful for the things Basal Cell Carcinoma Nevus Syndrome (BCCNS) has brought me: a job which I love, a new hobby and an opportunity for self-development. Beside that, a large family on Facebook. The sentence: "Consider yourself hugged!' means the world to me. Thank you all!!

You are Special, Unique and Soulfully Made

Continued from Page 2

Intervention and prevention are preferable to treatment. Incorporating sun protective clothing including hats that cover the ears and back of the neck are vital instruments in your arsenal. The products & articles from Coolibar Clothing; Sun Precautions: Tilley Hats & more, are worth the investment. Swimming, gardening, outdoor sport activities need to be participated in late afternoon or evening, not in the "sun of the day".

We belong to a virtual platoon of people seeking kinder, gentler treatments, but at least we have treatments for what ails us. Yes, having BCCNS does require rigorous scrutiny, adherence to treatment protocols including screenings, excisions, and systemic treatment. We are fortunate to have the choice. Take hold of that, grasp it not just in your routine, but in your mind. Researchers are willing to study this condition more, but it takes coordination, funding and concerted effort.

To the children of our Network, in answer to a little girl's question posed to me, as I attended her oral cyst surgery, "Am I a freak of Nature?" "No darling, you are a blessing and beautifully made. God has great plans for you. Your parents and I are here to help you and the doctor make the repairs. But then, you can get on with your life . . . learning, playing and exploring, with purpose."

"Thank you" to all the people of this Network. You have taught me to be a more compassionate person and to grasp what is real in this world. I still have no tolerance for deliberate ignorance. Safety is no accident. We must carefully carve out, individually and collectively, our path, charting our course in this world. But we do belong, even with a relatively rare, very complex condition called Basal Cell Carcinoma Nevus Syndrome.

–Kristi

Faces of Skin Cancer: Strength, Courage and Support

BCCNS Life Support Network has partnered with other organizations, including Genentech, to sponsor Faces of Skin Cancer. www.FacesOfSkinCancer.org is an online forum that gives people affected by advanced skin cancer a place to share their stories and help others understand what it really means to live with this disease.

An online survey in early 2012 revealed that many individuals would like additional ways to support and connect with others affected with the disease. Based on those results, Genentech developed www.FacesOfSkinCancer.org featuring the narratives of men and women with advanced skin cancer and those who support and care for them.

Faces of Skin Cancer includes video, audio and written tales that highlight different emotional and physical aspects of advanced skin cancer. Visitors can show support by sharing with others and are also invited to submit their own advanced skin cancer chronicles.

Currently, two of our Network members are featured on the website. Kathlyn Roth and Sheila Lokant have already posted their experiences. Visit www.FacesOfSkinCancer.org to find out what they have to say. While you are there, we ask you to participate too.

Advocating for Our Children

Advocating for our children is critical when they are unable to speak for themselves. We often become defenders when we least expect it, but by doing your research, you can become an effective champion for your child. Here are some useful tips for advocating for your child's health rights and needs:

- Do your research and be prepared.
- Be fierce and assertive.
- Stay on top of your child's care at all times.
- Find medical providers who treat you as a partner in your child's care.
- Do not be afraid to ask for things that you or your child need.
- Find a support group (try looking on www.DiseaseInfoSearch.org)
- Educate others about your child's condition.

Save the Dates...

One Voice Against Cancer
July 8-9, 2013 Washington D.C.

Commission on Dental Accreditation
July 12, 2013 Chicago, IL

"Deep in the Heart of Basal Cells" Regional Member Meeting December 6-7, 2013 Fort Worth, TX

Jingle Bells for Cancer Cells
A Christmas Concert, Sing-a-Long and Silent Auction
December 7, 2013 Fort Worth, TX

jingle bells for cancer cells

B.C.C. Nevus Syndrome
Life Support Network
P.O. Box 321 • Burton, OH 44021
Return Service Requested

Share Our Information

Is there someone you know that would benefit from receiving an educational packet about BCCNS and the services our organization provides?

Would you be willing to put them in contact with us? (440) 834-0011 / info@BCCNS.org.