

# Quarterly Advocate

Fall 2003

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# Report on 3<sup>rd</sup> Annual International BCCNS LSN Retreat

Article by: Maria Michalowski & Kristi Schmitt Burr

## **BCCNS Life Support Network 3rd Annual Retreat**

April 26-29, 2003

Coronado Springs Resort

Walt Disney World

Orlando, Florida

The Annual Meeting of the BCCNS Life Support Network combined the best of the past, embraced the present and celebrated the future of the many members who enjoyed fun in the welcoming and beautiful state of Florida. The stay at the Coronado, a part of Walt Disney, was memorable for the wonderful childcare, flavorful food, and joy of togetherness in the shade. Presentations by Susan Charron, Dr. Sherri Bale, and Dr. Karen Mallin, offered both insightful hopes for the future, while reflecting on how to overcome some of the challenges of living with NBCCS.

Helen Buchser, Paul McGoldrick and Sonya Dean eloquently shared their journeys with BCCNS and the impact it has had on their families.

Dr. Bale's presentation includes brilliant slides with well-depicted photos of many of the so-called "minor manifestations" of these diverse conditions. She has donated her presentation to the organization, and will continue to help with physician referrals, advice and consultation.

Dr. Karen Mallin looked at the many psycho-social dimensions of people living with a chronic condition, and offered ideas on identifying the specific feeling and working through the actions and reactions we as patients have to those surrounding us, in the work place, at school, and in our social environment. Karen continues to keep us updated on happenings, and deserves hearty thanks for sending up samples of products that can help the office with understanding how to alleviate some of the gap in product versus use and side effects.

Stu Needel offered his great assistance to the audiovisual duties, staying up late at night to make sure the next day's presentations would run smoothly. He led an opening group

participation ~Drum Circle~ then continued the beat of enthusiastic mogul the entire conference. Through his network, Stu helped secure the piece de resistance, comedian, David Feldman, who had even the doctors rolling with laughter, with a comedy sketch of music, jokes, rhyme, and lively interplay surrounding the humorous side to visiting the doctors' offices, using preparations, the feelings before testing and surgery. What a hoot!

Applause did not nearly capture the sincere appreciation by all attendees. Special thanks to the volunteered performance of Comedian Extraordinaire David Feldman.

Dr. Bickers and Dr. Epstein continue to keep us informed, reporting on their continued efforts to find, test, and remedy the genetic complexities of NBCCS. They have generously donated their airfares, time and accommodations, so willingly and graciously. Both have been available for your doctor or intern to communicate with when a particular concern arises.

Herma Neyndorff introduced us to her company, QLT, Inc. of Canada. She explained the 'hows and whys' of clinical trials and introduced QLT's current clinical trial involving Photodynamic Therapy.

Patricia Pearsell introduced the group to B.R.A.I.N.child (Brain Tumor Research Assistance Information Network) from Toronto, Canada. Patricia's son has BCCNS and is a Medulloblastoma survivor. She shared her story, and also gave a thorough explanation of the organization of B.R.A.I.N.child, its mission, and the impact this group has made on her family.

Margaret Costello and Sally Webster introduced themselves and updated us on the Gorlin Support Group in the UK.

Dr. Allan Osseroff gave an informative presentation on the Photodynamic Therapy being done at Roswell Park Cancer Institute in Buffalo, New York. He also addressed the impact of several topical BCC treatments such as Aldara and Effudex.

Juntae Yu flew in from California, where he has been working closely with Dr. Epstein on the Celebex Study. Juntae presented a look at the progress as the study nears the halfway mark. Regrettably, Juntae has since returned to Medical School, where he will enter the world of Dentistry. His patients will be sure to know that he won't wait to remove a keratocyst. "The focus of our retreat was coupling wellness with patient medical management," noted Kristi. Many of the children were able to meet others with the same condition, and see each other for their joy, the spirit that outshines even the most difficult moment. Special thanks to Nita and Bob Tuck and family for helping donate gift bags for children, and for his family members helping to entertain even the babies. Well done!

The schedule allowed many, many opportunities for social interaction. Members enjoyed the Coronado's pool, shared meals, and enjoyed the various parks together. Friendships span miles, even oceans.

### ***We Are Not Alone.***

All of the doctors in attendance gave generously of their personal time, providing many personal consultations, and offering their contact information publicly. Their care and compassion raised many spirits and hopes. Thank you, Thank you and Thank You.

Beyond the presentations are the sharing moments, at breaks, between dips in the pool, and over a beer.

Our sincere thanks to Jennifer Werkmeister who helped with registration, Maria Michalowski for facilitating ahead of the retreat with organizational forms, letters, mailings; and Jeff Burr and Bill Ginn for all the support both mental and physical in tugging, mailing, folding, sorting, and coordination. HIGH FIVES TO YOU ALL!!!

If you would like to view some photos of the event you can see them online at:

<http://www.cornerdepot.com/orlando.htm>, a web page of pictures submitted by our members and compiled by Bill Costa. Thanks Bill!

## **Need to Update Contact List**

**Article by: Sheila LaRosa**

We are in dire need to update our contact information. Please take a few moments of your time to notify the BCCNS office of your information, including whether you have BCCNS and how many children you have with BCCNS. You can e-mail, call or write with the information. Thank you in advance for your help.

## **BCCNS Board of Trustees Adds New Members and Committees**

**Article by: Bud Caruso & Kristi Schmitt Burr**

With the past success and continued growth of the organization, it has become necessary to share the tasks at hand and daily duties of running the organization. It was also apparent that, in order to achieve the goals that we had set forth, we would need to recruit the assistance of our talented and willing members.

BCCNS Life Support Network Board of Trustees has added new members to the non-profit Board who will be inducted on November 22, 2003. They are entrusted with the mission and direction of the BCCNS Network; therefore are charged with the responsibility to serve you - the public, patients, families, caregivers, healthcare professionals, and teachers.

This dynamic and energetic group serves as a steering group, and is subdivided into committees with the general charge of providing educational materials and experiences for families and healthcare professionals, who all share in caring with and for people experiencing the many manifestations of BCCNS. Each member is responsible for fundraising, assisting in grant proposals, budgetary concerns, and furthering the information, activities and outreach of the organization with activities designed to be both holistic and medically based. Please feel free to contact them, and lend them your support.

"These newly elected Board Members have demonstrated a sincere interest in furthering the needs of a global effort for NBCCS patients, and meeting the objectives of a whole wellness approach to the many manifestations of Gorlin Syndrome. They have stepped up to the plate to accept the responsibility of keeping our organization whole, healthy and have shown a willingness to help others through the organization," offered Executive Director, Kristi Schmitt Burr. "I look forward to them taking on their individual committee responsibilities and teaming up for collective goal setting."

Please welcome:

Bryant Bradley-Savannah, GA  
Kristi Schmitt Burr-Claridon, OH  
Anthony Caruso-Steger, IL  
James Finkbiner-Lancaster, PA  
William Ginn-Chesterland, OH  
Paul McGoldrick-Macunigie, PA  
Tracy McVicker-Mountain View, MO  
Maria Michalowski-Valencia, PA  
Carl Hans Muller-Cleveland, OH  
Stuart Needel-Plantation, FL  
Patricia Pearsell-Ontario, Canada  
Cindy Shelley-Creston, IL  
Layna Taylor-Tempe, AZ  
Linda Teachout-Conover, NC  
Robert Tuck-Punta Gorda, FL  
Christopher Walton-Aurora, IL  
Jennifer Werkmeister-Fifield, WI

Newly formed committees consist of:

**Annual Retreat and Event Planning Chairpersons- Cindy Shelly/Sheila LaRosa**

Members- Stu Needel, Bob Tuck, Layna Taylor, Rocki Finkbiner, Cara Shelley, Maria Michalowski, Tracy McVicker

### Finance/Fundraising

Chairperson- Bryant Bradley

Members - Tracy McVicker, Jennifer Werkmeister

### Participant / Member Services

Chairperson- Maria Michalowski

Members - Bud Caruso, Linda Teachout, Chris Walton, Kyle Watkins, Jennifer Werkmeister

### Professional Outreach

Chairperson- Bud Caruso

Members - Kristi Schmitt Burr, TBA

### Technology

Chairperson- Annette Walton

Members - Stu Needel, Chris Walton

Congratulations to our new Chairpeople and Members. Thank you for your support and dedication.

We are charged with an enormous task. The mission at hand is overwhelming, but it must be conquered. As we go along in the process of undertaking our tasks, we realize that the more we accomplish, the more there is to be done. Let us not take our duties lightly, nor our commitment to the members that we serve. When planning for the future of the BCCNS LSN, keep in mind the words of famous Chicago architect Daniel Hudson Burnham who, when rebuilding the city after the great Chicago fire said ***"Make no small plans, they have no magic to stir men's blood"***

We must have the foresight to determine the needs of our members and the BCCNS LSN for many years to come. Now is the time to establish the foundations that will carry us for many years in the future. It is your commitment, dedication and effort that will determine our success. Best of luck to all involved and **THANK YOU!**

Welcome Sheila LaRosa BCCNS LSN Administrator

Hello, my name is Sheila LaRosa. As the new Administrator for BCCNS Life Support Network, I bring to this position an 18-year background in healthcare, most recently as The Admissions Director for UHHS/Heather Hill Hospital Health and Care Center where my primary responsibilities included database management, supervising the department, marketing and public relations. I am married and have two active children, I enjoy scrap booking, gardening and camping.

I am excited about my new position at BCCNS Life Support Network and look forward to working with all of you in the future. So far, the people I have met are an outstanding group of diverse people with an abundance of talent and enthusiasm. Together, the accomplishments we can achieve are endless.

My goals for BCCNS Life Support Network are: to improve communication within the network, with all of your cooperation; to create a comprehensive database of patients, families and health care professionals; and to expand our pool of volunteers. We have many new committees formed, including Technology, Finance/Fundraising, Event Planning, Participant Services, and Professional Outreach, as well as expanding the Board of Trustees. I believe this is a great start to a new and improved BCCNS Life Support Network.

If you would be interested in volunteering your talents for one of our committees, or could help the organization in another way, please contact me and I will help to get you started. Again, I look forward to working with each of you and if there is anything I can do to assist you, please do not hesitate to contact me. I welcome your input positive and negative (as long as it is constructive).

With your encouragement and assistance, the sky's the limit.

Sincerely,

Sheila LaRosa

Administrator

BCCNS Life Support Network

### **Gorlin Group UK Meeting**

Article by: Bud Caruso

On October 25<sup>th</sup> 2003 the Gorlin Group UK hosted its 11<sup>th</sup> annual meeting of its members in Charley, England. The group has experienced tremendous growth under the leadership of Margaret Costello and is looking forward to its biggest and best meeting ever this year. The event will be held at a "Camelot" themed hotel, conference center and amusement park. In the past we have had the opportunity to meet with NBCCS / Gorlin Syndrome patients from

England, Scotland, Ireland, Norway, Italy, Holland and yes, even those loveable folks from the USA.

This is the first meeting for the group since their beloved founder and friend to all has passed, Jim Costello. The group has a big push on to get as many people out as possible this year in Jim's honor.

For more information on the meeting or the Gorlin Group UK visit their website at: <http://www.gorlin-group.pwp.blueyonder.co.uk>

This year the BCCNS LSN will be represented by Kristi Schmitt Burr and Bud Caruso, who traveled at their own expense to bring back knowledge gained at the event to our members. While abroad, Burr, Costello and Caruso traveled to Berlin to meet with medical professionals who are researching the syndrome and a group of patients who have the disorder.

### **Band Aid Bear Update**

Article by: Jennifer Werkmeister

The BCCNS Life Support Network has sent out 37 bears since beginning the Band Aide-Buddy Club in 2001. When we began, you had a choice between a big bear and a little bear. Just recently we have changed a few things - now you can pick any stuffed animal from <http://buildabear.com/>. Once you decide on an animal you can e-mail me at [werky@centurytel.net](mailto:werky@centurytel.net) to tell me what animal you would like, what you would like the animal to be named, the name to go on the birth certificate, and do you have a special day that you want the animal to be born. We do send the bears out to our member children who have the syndrome for free. If you wish to donate to the Band Aide-Buddy Club you can send your donations to the BCCNS LSN office.

### **Green Tea Lotion for Skin Cancer**

Article by: Bud Caruso

For some years now the benefits of drinking Green Tea and even Black Tea relative to skin Cancer have been known. Recently researchers have discovered benefits of applying green tea topically for the prevention of skin cancer. If you would like to learn more about the subject you can read the full article online at:

<http://news.bbc.co.uk/1/hi/health/3090190.stm> Could this give new meaning to the expression "One lump or two?"

### **First Person Story**

Article by: Jayne Dower (writing about her experiences with her Son, Danny)

Danny had not lost any teeth until his 8<sup>th</sup> birthday when he lost his lower two. Then a month later when his teeth had grown in one was almost on its side and they were crooked. There was also a tooth that had grown in behind another. Previously I had taken him to the Doctor and Dentist with concern about not having lost any teeth, and had been told they will lose them when they're ready. And when I took him this time (a month after his 8<sup>th</sup> birthday) I was told that it's actually a good thing that he hasn't lost any teeth, because this will allow his jaw to grow and make room for the adult teeth (because his mouth/jaw was very small). I had inquired about seeing an Orthodontist and was told that there was not need to do that, and that they would just keep an eye on things.

Five months later I found out from another mom that you don't need a referral from your Dentist to see an Orthodontist. So I contacted her Orthodontist and took their next appointment, which was one month later. In addition to his teeth being crooked and just not looking right, his lower gum area seemed to be different from his twin brother. It protruded out from where his teeth were (like his teeth were the top of a mountain and it went down at an outward angle from there).

When we went to the Orthodontist he took a Panoramic X-ray, which unlike regular dental x-rays that only go to the root of the teeth, it films the entire jaw. The Orthodontist immediately saw the severe bone loss due to the cysts and arranged an immediate appointment for us to see an Oral Surgeon. He advised me that my son had a very severe medical condition that may be part of a syndrome. There were several cysts in his lower jaw, one that took up an area of about 2/3 of his jaw, and left him with only a hairline of a bone. There was also concern that there may be something on his top jaw, but the picture was unclear and I was told that they would probably be doing a CT-Scan later, which would provide better information.

The Oral Surgeon said that with his extremely advanced condition, that she is not the right Doctor. She indicated that we needed a team approach, and that the only place we would find that is at a Dental College such as Shands at USF in Gainesville, Florida, or The University of Miami, in Miami. She said that when people in the south have an unusual dental condition that they go to Shands, and that Miami has the same level of experience.

She said that this is a medical condition, and that she would write a report/letter to my son's Pediatrician. One of the syndromes that she thought it could be is Cherubism, as well as a couple others. Gorlin Syndrome was not mentioned or suggested initially.

## INSURANCE

The next step was involving the Pediatrician because we had an HMO for insurance.

## PEARLS OF WISDOM FOR DECOMPRESSION OF OKC'S

Initially I didn't know how I would ever do what we need to do. After the surgery they can barely open their mouth, and there is so much in the way of stitches, etc., that it's just heartbreaking. BUT unless you follow the steps of this process, then everything your child has gone through in the way of the surgery would have been for nothing. AND the risk of infection is so severe, that you just do it.

After trial and error, this is what seems to work:

1. Get a flashlight that straps to your head with elastic and has an adjustable light (mine clicks up and down and stays exactly where I put it). You need to see things at different angles, and this way you don't need someone to hold a flashlight OR risk poking their already sore mouth, because when you do it is very painful for them. My husband found it through a tool supply; it is made for a mechanic. The cost was about \$30; it uses 4 AA batteries (which last about a month), but the light is great.
2. Tongue depressors, you will need 3 per day of the STERILIZED/INDIVIDUALLY WRAPPED (you don't want to run the risk of infection, so it's worth it). I use the tongue depressors when I try to move the skin that is blocking the drain lines. Swelling occurs in the mouth, so this helps you to see what you're doing. ALSO it helps to have them keep their mouth open when you're working in there. Initially when I left the hospital an intern had suggested using the other end of a spoon - there was no way that that was going to work. Initially I called my Doctor's office (locally) and they had a few that they gave me to try before I bought a case.
3. Cheek retractors - I obtained a pair from our Orthodontist, however they indicated that a Dental Supply would be able to provide them (you could check with your Orthodontist too). USING THESE WAS THE ONLY WAY WE COULD INITIALLY SEE IN HIS MOUTH. Now I only use it for the lower front drain, but I would suggest having these before you have the surgery.
4. Syringes - I have one for each drain line. What I do is I premix and measure everything before I have him come in. THE TIP SIZE IS IMPORTANT AND SO IS THE CAPACITY. Mine are 12cc in capacity, and the tips are the "blue" plastic tips that the needles come in. There are green and blue, the green is thicker and gets stuck in the drains (at least in his). I fill it to 5 or 6 with the oral rinse, and the rest of the way to 12 with the saline. I do this for each drain line.
5. Curved tip syringe - BEFORE irrigating with the

## FILLING PRESCRIPTIONS

I recently discovered that with my HMO insurance company (Aetna) they have a mail order pharmacy for maintenance prescriptions (which the oral rinse and saline are). With their mail order the co-pay for a 3 month supply is identical to the co-pay for a 1 month supply locally. They give you 3 for the price of 1 when you go through them directly.

ALSO, you will want to measure what you use and calculate your monthly needs. What I found for Danny is that in order to irrigate with the oral rinse and saline mix 2 times per day and straight saline 1 time per day, I need 2 of the Pint Bottles of the oral rinse, and 4 bottles of the saline (1,000 ml). Originally the prescription written by the Doctor gave me half of that, and when I brought it to his attention and gave him my calculations, he re-wrote it (because otherwise you're paying your co-pay more often than necessary - and everything adds up so fast).

## BRUSHING TEETH AND RINSING:

For the first 4 months we were dipping his toothbrush in the oral rinse and cleaning the gum line (not using toothpaste). We have just started using toothpaste again over the last week. With the use of the oral rinse to brush his teeth, they have changed color, and they look bad also because of a lack of fluoride. The way that he is able to rinse is by shaking his head (because it's not working to try and swish it around with the drain lines and all the surgery).

FOUR MONTHS LATER he is still not healed; you can still see all of the stitching that is holding him together. I've been told it will probably take about a year for all of the stitches to fully heal. As far as the re-growth of the jawbone, that time is uncertain (could be a year or more, but as long as it happens that's all we're concerned with).

*Thanks to Jayne, Tom, Danny and Chris for sharing their story! Good luck to both of you and your entire family!*

## **Development of BCCNS "Patient/Family Handbook"**

Article by: Sheila LaRosa

Jayne's story has inspired me to think what a great idea it would be if we had some type of handbook with first person tips like those Jayne has given. She has graciously agreed to work on this along with Maria Michalowski, Kristie Roller and Tracy McVicker. If you would like to contribute, contact the BCCNS office and I will get you connected with the group.

## **Dr. Gorlin Receives Gold Medal Award**

Article by: Sheila LaRosa

On October 19, 2003, Dr. Robert Gorlin was presented with the Gold Medal Award for excellence in research by The American Dental Association and Unilever Home and Personal Care USA.

Those who are affected by NBCCS, Gorlins Syndrome together with those who are a part of our support team, know better than most how his intuitive, persistent research and prolific writings have shaped knowledge, diagnosis, treatment, understanding and progress in coping with oral cysts, basal cells and all other manifestations characteristic of this genetic disorder.

Dr. Gorlin quotes our friend, Confucius, when talking about his career, “Choose a field you really love, and you’ll never work another day in your life.”

Congratulations Dr. Gorlin!

### **19<sup>th</sup> Congress of the International Association of Pediatric Dentistry**

Article by: Bud Caruso

The BCCNS LSN was proud to host an exhibitor’s booth at the 19<sup>th</sup> Congress of the International Association of Pediatric Dentistry (<http://www.iapd.org.uk>) in New Orleans, Louisiana. The Congress was held October 16<sup>th</sup> - October 18<sup>th</sup> 2003 at the Hilton Riverside Convention Center. The BCCNS LSN was granted a dramatically reduced booth fee by the American Association of Pediatric Dentistry (<http://www.aapd.org>), making it possible to have a presence at the event.

The Congress is held every other year and alternates countries between its member organizations. The next conference will be in 2005 in Sydney Australia ([www.iapd2005.com](http://www.iapd2005.com)). There will not be another Congress in the USA for well over thirty years. For this reason the BCCNS LSN felt it was very important to have a presence at this Congress.

Delegates from around the world were in attendance for the sessions. Over 450 attendees from over 37 different countries converged on New Orleans to share their knowledge and gather information to bring back to their members. Many of the attendees took the time to visit the BCCNS booth. Our booth had excellent positioning being a corner booth located directly across from the American Academy of Pediatric Dentistry and right next to where the daily food and coffee breaks were served. We were one of only two support groups represented at the meeting.

The information distributed was well received and among the attendees there were several medical professionals who had actually been published on the subject of BCCNS and had collaborated with Professor Gorlin. Of course we will pass along their regards to him.

Several who came across the booth later brought their entire delegation back to have the syndrome described to them. This provided a wonderful opportunity to pitch our message of the Pediatric Dentist being in a position of making an early diagnosis on the children and the

importance of such a diagnosis saving multiple surgeries for the child and in severe cases possibly their life. If just a few children are helped by this event or eventually one child's life is saved certainly it is a worthwhile venture.

An audience of the Australian delegation was gained and taken advantage of to express the importance of having patient support groups at such meetings and how well received we were by the medical professionals. Of course there is the issue of the financial burden associated with hosting groups like ours at such events.

Board member Richard P Widmer, who is in charge of the 2005 Congress, has not only agreed to set aside exhibitor space for patient support groups but has seen the importance of having them at the meetings and will seek out their involvement at the same. We see this as a huge accomplishment for future meetings not only with the IAPD but a useful tool in the future when negotiating for booth space with other professional medical associations. Kudos to Richard and the IAPD! Oh, and of course the BCCNS LSN.

*Thank You Bud for going the distance and taking the message to this esteemed audience. Well done!*

## **2004 Annual Retreat**

Article by: Sheila LaRosa

After much research and discussion by the Annual Retreat/Event Planning Committee, the Annual Retreat for 2004 will be held at YMCA Camp Lakewood/Trout Lodge in Potosi, Missouri in May 21-23, 2004. You can access their website at <http://ymcaoftheozarks.org>. More details will follow as they become available. Thank you to everyone on the committee (Cindy, Cara, Layna, Tracy, Bob, Stu, Maria and Rocki) for all of your hard work!

## **Camp Wonder**

Article by: Sheila LaRosa

The children in our BCCNS family have a unique opportunity this summer. Camp Wonder, a summer camp for children with Skin Diseases, in Livermore California has offered to extend an invitation to the children with BCCNS and their siblings to attend their camp this summer free of charge. I do not have all of the details but you can look at their website at <http://www.csdf.org> or contact the BCCNS office if you would like more information on Camp Wonder. More details to follow as I have them.

## **You Meet the Nicest People**

Article by: Sheila LaRosa

At the AAOMS covention, a wonderful, creative, positive woman bubbling with enthusiasm, Susan Beaudette RN, had a booth a few aisles from ours. She and her supportive husband were

demonstrating her innovative product: “Zip-N-Squeeze” bags. This is the best product I have seen in decades which addresses the needs of patients having post-operative liquid diet needs. Simple, easy to use, I heartily encourage you, dear readers, to look up her website at <http://www.zipnsqueeze.com>, take it to your oral surgeon or dentist and get a dozen for you home.

In addition, she offers a recipe book entitled “The Healing Jaw and a Liquid Diet” which is a liquid resource and recipe guidebook for maxillary trauma and reconstructive jaw surgery. Chock full of *nutritious* recipes, it also has “Pearls of Wisdom” for coping with the challenges of a liquid and soft food diet. Her wisdom and wit are immediately helpful. She answers the most asked question of young mothers, “what and how do I feed my child after oral cyst surgery.” Get it for your family for a great addition to your cookbook library. A five star recommendation from the BCCNS office. \*\*\*\*\*

### **BCCNS LSN Patient Forum**

Recent Discussion Topics Include:

- As you get older will the BCCs get worse?
- Just a Kid!
- Update on surgery
- 20 tips to avoid leg pain
- BCCs on feet?
- Flying to treatments or studies.
- Hello I am new but, I feel old