

BCCNS Life Support Network

Quarterly Advocate

Winter 2003

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BCCNS Life Support Network Western Regional Conference San Francisco

On October 26th, 2002 the BCCNS Life Support Network hosted our first Northwestern USA Regional Conference at the University of California San Francisco. We were very fortunate to be the guests of Dr. Ervin Epstein Jr. and his staff.

Over 40 attendees were treated to a full day of learning, sharing & caring. The sessions started off with introductions and expectations of the day stimulated by Kristi Schmitt Burr. An explanation of our organization and our mission was presented by Bud Caruso.

Attendees enjoyed a very thorough explanation of Basal Cells and prevention by Dr. Ervin Epstein Jr. Dr. Epstein also explained their current study using Celecoxib (Celebrex) a Cox II inhibitor to prevent the growth of BCCs. The Celecoxib study is in the Clinical Trial stage and the results are very promising. Dr. Epstein also invited his staff to attend the meeting. As a result his team members left with a greater sense of purpose for their work and higher level of compassion and understanding for those affected by BCCNS. We all owe huge thanks Dr. Epstein. <http://bccns.org/celebrexupdate.htm>

Mohs Surgeon, Dr. Christopher Zachary (<http://www.ucsfhealth.org/adult/cgi-bin/prd.cgi?action=DISPLAYDOCTOR&doctorid=1389>) provided a very detailed presentation on how Mohs surgeons deal with BCCs that have developed aggressively and reconstruction of wounds created by their removal. Many important points were brought forward by Dr. Zachary's presentation including:

Electro-desiccation & curettage (ED&C), Mohs or laser as treatment options for surgical removal of BCCs
Recurrent BCC vs. new BCC in the same location
Healing by secondary intention vs. closing the wound
Harvest sites, "spare parts" and when to use them
Use of hydrogen peroxide & antibiotics after surgery (or not)

After Dr. Zachary's presentation our members agreed that prevention and diligent maintenance are paramount in dealing with BCCs. Thank you, Dr. Zachary!

Oral & Maxillofacial Surgeon Dr. Brian L. Schmitt also of UCSF Medical Center (www.ucsf.edu/omfs) enlightened us as to the various methods of removing BCCs. Dr. Schmitt was extremely informative and helpful

to our members. Some of the topics covered were:

Marsupialization (Draining the cysts over a period of time to promote bone growth)
Carnoy's Solution (An acid based solution used to kill off residual OKC cells and bacteria)
Chryotherapy (Use of liquid nitrogen to destroy residual cells and sister cysts)
Origin of Odontogenic Keratocysts (OKCs) (From bacteria)
Digital Imagery (3D images of the cysts are now available to the surgeon)
OKCs as neoplasms
Biopsy of cysts

Dr. Schmitt was an absolutely wonderful presenter who expressed genuine caring for his patients and a passion for his work & research. We are very thankful to announce that Dr. Schmitt has agreed to be an active member of our Medical Advisory Board. Thank you Dr. Schmitt.

Some of our members and new found friends gathered for an evening of fine dining at Yabbie's, one of San Francisco's many wonderful restaurants. If you are fortunate enough to have the BCCNS Life Support Network host a regional conference in your region you'll want to make every effort to attend.

AAOMS Convention Chicago

On October 2nd – 5th 2002 Jennifer Werkmeister, Kristi Schmitt Burr and Bud Caruso represented the BCCNS Life Support Network with an exhibition booth for the American Association of Oral & Maxillofacial Surgeons 84th annual meeting, scientific sessions and exhibition, at the beautiful Lakeside Convention Center in McCormick Place, Chicago.

The trio were exhausted after days of setting up displays and distributing information creating awareness of BCCNS and our organization. The organization and information were very well received. Many surgeons sought out our booth to obtain information for their patients. We were informed of many families in need of our services. We look forward to assisting them.

Dr. James Hanna was instrumental in obtaining the booth space and encouraging our attendance. We also had the opportunity to sit in on some of the scientific sessions where various methods of removing Odontogenic Keratocysts (OKCs) were presented debated. The sessions helped us in better understanding conservative methods of removal and continuing our mission of keeping up with the latest available information to our members.

On Saturday evening we joined with some of our members in Chicagoland for a social event held at Ed Debevic's restaurant. A good time was had by all.

BCCNS Life Support Network International Conference / Orlando Florida April 27th – 29th, 2003

We are excited to announce that our 3rd annual meeting will be held in Orlando, Florida April 26th, 27th, 28th & 29th, 2003! The location is the Coronado Springs Resort at Walt Disney World. Here is our agenda to date:

Friday April 25

6:00 PM Early bird Registration and Reception at the Coronado, poolside icebreaker session.

Saturday April 26th

8:00 a.m. Breakfast & Registration

9:00 Bill Ginn – Welcome

9:15 Bud Caruso General Overview BCCNS & Retreat

9:45 Kristi Schmitt Burr, Exec. Director "Dancing with BCCNS"

- 10:15 Break
- 10:30 Dr. Ervin Epstein Jr. University of California San Francisco “Of Mice, Men, Managed Care”
- 11:30 Lunch (included with the retreat registration) First Person Story
- 1:00 Group mtgs. 1) Support Persons; 2) Patients; 3) Gorlin Kids & Bear Club
- 2:30 p.m. to 8:00 p.m. An afternoon with our Kids –
Group Trip to Animals, Sightseeing; Picnic at the Park.

Sunday April 27th

- 8:00 am. Breakfast with Disney Characters & Bud
- 9:00 Photodynamic Therapy – QLT, Herma Neyndorff, QLT, Inc., Canada
- 10:00 Working with the Bills- managing your financial obligations
- 10:30 B.R.A.I.N. Child – Pat Pearsall, Canada: Diagnosis, Treatment, Care
- 11:30 Lunch --- First Person Story
- 1:00 Group Mtgs: 1) Men Issues; 2) Women Issues; 3) Support Persons;
4) Young Adults; 5) Gorlin Kids
- 2:00 Physicians Advisory Board
- 3:00 Attendees -- Activities on Your Own

Monday April 28th

- 7:30 Breakfast: Margaret and Sally from Gorlin Support Group, England
- 8:30 Oral Maxillofacial Considerations: TMJ; Displaced Mandible; Grafts
- 10:00 Break
- 10:15 Dr. Bickers & Friends: “What promise, Research?”
- 11:00 Reconstruction Following Surgery: “Save the Nose, Save the Ear”.
- 11:45 Lunch: First Person Story with Oliver and Sonya Dean
- 12:30 Sunscreens; Protective Clothing: Eye Protection
- 1:15 Organizing your Medical Records: Personal Management
- 2:00 Socialization on Your Own

Tuesday April 29

- A Day of Coping and Healing
- 7:30 Breakfast with Jennifer Werkmeister, Pres. Bear Club
- 8:00 Beyond the Meds, How to Manage Pain – A Seven Step Approach
- 9:00 Building a Medical Team; What tests, Which physicians; the GP
- 10:00 Break
- 10:15 Legal & Insurance: How to write a Letter of Appeal; Maintain Your Sanity
- 10:30 Group Meetings, 1) Parenting, 2) Support Persons
- 11:30 Lunch with Barry: X-Rays; Radiation and Comprehension
- 1:00 Round Topic and Wrap-Up Discussion with Bud & Kristi
- 2:00 Socialization on Your Own

Be sure not to miss this awesome opportunity to meet & bond with your fellow BCCNS patients and the ability to become informed on the syndrome by some of the world’s foremost authorities on the subject. We look forward to seeing all of you there.

We have attached a registration form in MS Word Format. Please complete the form and mail it to our office as soon as possible. If you have any questions or trouble downloading / printing the form please call us at 866-834-1895.

Gorlin Group UK Meeting

On November 9th, 2002 the Gorlin Group UK hosted its 10th annual meeting. Over 70 of their members were in attendance. The group was treated to a full day of information sessions. <http://www.gorlin-group.pwp.blueyonder.co.uk>

Professor Peter Farndon being the keynote speaker described in great detail the genetics responsible for the syndrome. Professor Farndon also described the crucial role of the Costello family whose DNA was used in discovering the defective gene responsible for the disorder. <http://www.bham.ac.uk/ICH/staff.htm#farndon>

Dr. Ernest Allan & Dr. James V. Moore addressed the group on the advancements in Photodynamic Therapy (PDT) in the UK. The team announced that trials with Photofrin II have started. Dr's Allan & Moore were kind enough to bring the actual devices used in the procedure. The Paterson Lamp used in PDT was developed at the Paterson Institute for Cancer Research. Attendees had the opportunity to see first hand the potential benefits of PDT and to ask questions regarding the therapy from two of the pioneers in the field of PDT. The group expressed a tremendous interest in the treatment. <http://www.christie.nhs.uk/default.htm> - <http://www.paterson.man.ac.uk>

Margaret Costello and Sally Webster provided the group with an update on the organization. A move toward charitable status is being pursued.

The BCCNS Life Support Network was represented by Bud Caruso who addressed the group on the progress of our organization and the importance of participating in clinical trials and various studies. We also took the opportunity to promote our conference in April. We are happy to report that, to date, three families will be attending our meeting as a result.

Our good friend and valued member Bill Costa also attended the meeting. I know all of the children now hold a warm place in their hearts for him. Having the opportunity to witness the interaction with Bill and the UK group members, I am certain many new friendships were also solidified. Atta Boy Bill!

While in the UK we had the opportunity to socialize with our good friend Jim Costello the founding member and driving force behind the Gorlin Group UK. Jim was instrumental in helping us form the BCCNS Life Support Network. With time we all became very close to Jim and the Costello Family. We feel Jim is a Brother to us all. As many of you know by now, Jim passed on just a short time after our visit. We are all devastated by his passing. Our deepest condolences go out to his many friends and his family.

The BCCNS Life Support Network was represented at his funeral by Kristi Schmitt Burr who expressed all of our sympathy. To our Brother Jim we say "*Au Revoir*", for we will meet again.

Here is a note from Margaret Costello Jim's wonderful wife and soul mate:

Dear Friends,

It is with regret and a deep sadness that I write to inform you of the death of Jim Costello. Jim passed away peacefully, surrounded by his family at St Catherine's Hospice, Lostock Hall, Preston on Monday, 9th December 2002.

Jim was a loving, caring husband and a devoted Dad to Jane, Helen, Anna (deceased) and Richard. Since his retirement in 1989 Jim dedicated much of his life to raising awareness of Gorlin Syndrome and supporting many fellow sufferers. I know Jim valued the friendship and support of you all. On behalf of Jim I offer my sincere thanks.

Despite personal difficulties Jim retained his dignity and never lost his sense of humor. I am sure you will agree, he was an inspiration to all. Jim will be sadly missed but remembered with affection.

Yours sincerely,

Margaret Costello

It was Jim's wish that donations in his memory be divided equally to benefit St Catherine's Hospice and the Genetic Research Trust Fund F06062 to aid research into Gorlin Syndrome. Cheques made payable to preferred charity can be forwarded to Mrs. M Costello, 11 Blackberry Way, Penwortham, Preston, PR1 9LQ.

First Meeting of Netherlands Group

While en route to the Gorlin Group UK meeting, Bud Caruso was fortunate enough to attend the first meeting ever of a support group being formalized in the Netherlands. Willem Breurken who has been providing services to people in Holland, Belgium and Germany for almost three years now, hosted the first meeting of people he has been helping and communicating with. <http://members1.chello.nl/~wf.breurken/Persoonlijke%20webpagina.htm>

Willem was kind enough to organize a meeting hosted in his home in Almere, Holland. Together with his wife Betty and their entire family, Willem provided the experience of a lifetime for his group. Those of us who have met in person, others with the syndrome are aware just how emotionally overwhelming the experience can be. After a lifetime of suffering from the disorder to have the ability to share with others who have walked in your shoes is a wonderful experience. Willem & Betty made everybody feel welcome. Willem distributed information on the disorder and played the BBC programme on Gorlin Syndrome for those who had not previously viewed it.

The group is off to a great start and I am certain the right man is at the helm. Willem recruited several members to assist in formalizing the group and their future activities.

In the days that followed Willem was an awesome ambassador for his country. He showed my Mother (Jean Thompson) and I a wonderful time with sightseeing and a private tour of the countryside. Willem was also keen enough to arrange a visit for us to the University of Amsterdam's Medical Museum. This was an event I will remember for life. Here medicine has been studied since the early 1300s. Their collection goes back just as far. Actual examples of bifid ribs and skeletal remains of persons with enlarged cranium, bifid ribs and scoliosis were observed. The tour was given to us by the Museum's director who is studying the origins of medicine. He was even kind enough to take us in the basement storage area to show us even more examples that were not currently being displayed. A wonderful experience! Many thanks to the Breurken family.

Band Aid Bear Recall

I am very sorry to say that I have some hard news to tell you. The Big Bear that has been sent out from the BCCNS Life Support Network has been recalled by the Build A Bear Company. They are no longer making it and it has been/will be taken off the shelves. I received a call today from the Build-a-Bear company informing me of the recall. You can read about the recall here at this link: <http://www.buildabear.com/GuestServices/SafetyMessage/>

I am going to be sending you a letter from the company instructing you what to do with the bear. The company asks that I send these to you. If you have a store near you, you will be able to go to the store and exchange or you will need to follow the instructions that I will send to you. You can see if there is a build-a-bear store near you by going to: <http://www.buildabear.com/>

I am sorry for any problems that this may cause. If you have any questions please feel free to contact me.

Sincerely,

Jenni Werkmeister
werky@CenturyTel.net

AAD Convention San Francisco

The BCCNS Life Support Network will be attending the American Academy of Dermatology 61st Annual Meeting March 21-26th, 2003 in San Francisco. The BCCNS Life Support Network will have its brochures and reprints available to attending physicians in the Coalition of Patient Advocates for Skin Disease Research (CPASDR) booth. This was a very beneficial event for our organization last year. We anticipate each year will provide new contacts and opportunities. We are thankful to be participating at this convention.

Clinical Trials Update

QLT Industries (formerly Quadra Logic Technologies) the company that originally developed Photofrin, one of the drugs used for PDT has moved into the clinical trials stage for their study of a new sensitizing drug Verteporfrin. The drug promises to be as effective at removing BCCs while the residual photosensitivity is dramatically reduced. For more information please visit <http://www.mbcstudy.com>

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If you wish to be removed from our mailing list, simply reply to this message with the words "remove from list" in the subject line.

For information purposes only. Always follow the advice of your Health Care Professionals.

BCCNS Life Support Network is a 501 (c)(3) non-profit corporation. Your generous donations are greatly appreciated and may be tax deductible.