

# Quarterly Advocate

Fall 2001

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## **Update From Gorlin Group UK Conference**

On October 12<sup>th</sup>, 2001 Kristi Schmitt Burr & Bud Caruso were fortunate enough to travel as delegates to Chorley, Lancashire, England to attend the Gorlin Group UK Conference hosted by Jim & Margaret Costello who head the organization.

Burr & Caruso were invited to open the meeting and took the opportunity to present the Gorlin Group UK and American Flag along with supportive & inspirational readings by Burr, including the Saint Francis of Assisi prayer & Saint Crispian Day.

The keynote speakers included Professor Peter Farndon a World famous genetic researcher from Birmingham Women's Hospital in Birmingham, England. Farndon provided an understandable & thorough explanation of the development and treatment of Oral Cysts, Basal Cell Carcinomas and the genetic defect responsible for the disorder. Farndon also described how the Costello family assisted in finding the defective gene responsible for the syndrome.

Also presenting were Dr. Allen M.D. and Dr. Moore M.D. of Christie Hospital in Manchester, England. They have been pioneers in the field of Photodynamic Therapy (PDT) and were responsible for the development of a highly specialized light source used to activate the drug used to destroy the tumors. The attendees viewed many slides revealing the tremendous results that have been achieved using PDT.

Mr. Graham M. C. Black M. D. Honorary Consultant in Genetic Ophthalmology at Manchester Royal Eye Hospital, Department of Clinical Genetics described in great detail the findings from a survey of Gorlin Syndrome Patients in the UK. Here are some of the results of his study.

- BCCs on Eyelids 29/29
- Meibomian Gland Disease 17/29
- Frequent cause of ocular discomfort
- Meibomian Cysts 9/29
- Posterior Blepharitis were common
- Unilateral Ptosis 1/29
- Cataract(s) 7/29
- Unilateral Vision Loss 10/29
- Squint 10/29
- Retinal Defects 10/29

Wrinkling of Epi Retinal Membrane were common

Black assured Burr and Caruso that he will publish the findings of his survey in the medical journals and provide the BCCNS Life Support Network with a copy. Of course, we will make it available to our members when we receive the material.

Genetic Associate Carol Giblin of the Clinical Genetics Department at Saint Mary's Hospital, Manchester, England described the role of the Genetic Associate. A home visit is made prior to

coming in for a genetic appointment in an effort to collect pedigree information and pertinent data in advance so the visit time isn't consumed by this process, allowing for a higher quality appointment. They are also collecting a closed database of patients with genetic disorders that can be contacted for surveys and trials.

The BBC (British Broadcasting Corporation) was represented by Julia Foot and Fran (what a hostess) Landsman. Julia and Fran are the producers of a four part series on genetic disorders and their effect on families. With over 1000 genetic disorders the BBC selected Gorlin Syndrome as one of four to be covered. After a caring and emotional introduction by Julia the group was treated to a sneak preview of the program, which is scheduled to be broadcast in January 2002. The group was deeply touched and many attendees were moved to tears. Many of the members of our group who attended the member retreat in Cleveland last April were seen in the documentary. The children played a big role in humanizing the disorder. We believe the broadcast by the BBC could be the biggest event ever toward creating awareness for Gorlin Syndrome. We are all indebted to the Costello family for allowing this intrusion of their lives. Especially Jane, Helen and Richard the children of Jim & Margaret who also presented their Mother with a very moving thank you for all of her sacrifices throughout their lives. Jane Helen and Richard also prepared gifts for Margaret. The group obviously echoing the feelings of the children gave Margaret a deserved standing ovation.

The meeting concluded with Gorlin Group UK describing their evolution into charitable status. This requires formalizing the group and necessitated appointing Officers, Trustees and committees. These positions were filled democratically.

The following morning Burr and Caruso were given a tour of Preston, England and parts of Lancashire. The Costello family was kind enough to provide this tour after a stop at a local Pub, Margaret invited us back to their home for tea. While we were there I took advantage of being able to access the internet in order to post a brief message on our patient forum.

As I sat down to login and access our website ([www.bccns.org](http://www.bccns.org)) it occurred to me that I may well be sitting at the Mecca of Patient Advocacy for Gorlin Syndrome and International support. I was actually sitting in the world famous "Office Under the Stairs" that has been the place where much healing, sharing and educating has occurred. I felt as a young guitar player picking up B. B. King's guitar to play. I later suggested to Jim that he should name his keyboard "Lucille" as it has provided much of the range of emotion that King has with his instrument. Somehow I managed to contain my excitement long enough to post a brief message to our members.

Next we were off to see "the man himself" Jim Costello. We drove into a stately manor, which is Saint Catherine's Hospice where Jim is recovering from an extensive surgery. The volunteers are more like employees of a bed and breakfast treating Jim like family. The facility was like a luxury hotel. Jim was in great spirits and expressed very little discomfort. We passed along dozens of hugs from all of you as requested.

The following morning we boarded a train bound for Bristol. To see the BBC facility where the documentaries were produced. Much to our surprise producer Fran Landsman was waiting for us

on the platform! Fran drove us to her office where we were able to see the production process for ourselves. It is incredible how much effort goes in to producing a 40-minute documentary.

On Fran's invitation we visited the adjacent town Bath, England where we toured a Roman Spa dating back to 200AD the lifestyle and engineering ability of the Romans was incredible. The town of Bath typified our Image of a European community. Stone buildings hundreds of years old housed volumes and volumes of history. Crescent shaped buildings and roads winding through the hillsides. Antique shops, galleries and pubs were endless. Kristie and I agreed we would love to retire there. After dinner Fran Graciously opened her home to us. We enjoyed a relaxing evening sipping tea and café au lait from her kitchen overlooking the lights of the city with famed Salisbury Hill in the distance. Thank you Fran for your efforts in producing the documentary and your generous hospitality, it enabled us to recuperate and reflect our mission for quality of life for our members and ourselves. It was the perfect finale for our marvelous trip.

Bud & Kristie worked on goal setting while on their trip to England. Immediate goals include enhancing the website to include additional medical information, additional links and encouragement for those undergoing procedures.

Our sincere thanks & appreciation to Bill Ginn and Wilbur & Eleanor Schmitt for their generous contributions to underwrite the expense of attending the conference.

### **Stem Cell Research**

Excerpts from Readers Digest Article October 2001 entitled "Hair We Grow"

From Modex Therapeutics, Switzerland

A new technique called "Epidex" is raising eyebrows, plugging holes and plugging skin.

By taking stem cells from hair follicles, the procedure cultivates them into skin cells. The company grows the patient new skin after harvesting 20 – 100 individual cells from any part of the body. (chiefly the scalp, sending the fresh follicles to Modex)

The stem cells are laid out with other skin cells that help create Keratinocytes, epidermal cells. The promising process allows the new skin to be frozen as skin discs and sent back to the patient's doctors to be applied to the damaged areas. Concerns from our director are that perhaps the cells could be utilized from a non effected parent or sibling and transplanted to a clean margin site. The process is currently being tested on small ulcers, but may revolutionize treatments for burn patients & perhaps give promise to fewer skin grafts, saving harvest sites and sparing the patient the painful process of harvesting grafts.

### **BCCNS Life Support Network Brochure**

Faces of Nevroid Basal Cell Carcinoma Syndrome

Informational brochure from the BCCNS Life Support Network is being developed and will be sent out to Oral and Maxillofacial Surgeons, Dentists, Dermatologist etc. at about 1000 per month for the next five months creating awareness for the existence of our organization and our upcoming conference in June.

### **BCCNS Life Support Regional Meetings**

Regional support meetings are being planned for various parts of the country to assist those who are not able to attend our annual national conferences. Here is the tentative schedule:

- Chicagoland first week in December 2001
- New York March 2002
- New Orleans October 2002 in conjunction with a national Oral Surgeon's convention.
- San Francisco, California 2002 date to be announced.

Regional meetings will be informational and social so that none of our members will miss out on presentations and the opportunity to become informed and meet with other members. Of course we encourage all of our members to attend the national meetings. We will be setting a date in June when children will be out of school and pools and theme parks will be open making it a more enjoyable trip for the whole family.

### **News from Norway**

Inger Tysland head of the Norwegian Gorlin Syndrome Support Group is to be commended for her efforts and accomplishments. Inger and her sister Rose, who also attended the Gorlin Group UK meeting have been responsible for several pieces of legislation which were passed in Norway due to their efforts. The Norwegian Government provides Gorlin Syndrome patients with Housekeeping assistance; assistance in covering travel cost for conferences and treatments not available in Norway and have begun the process of developing a medical clinic dedicated to Gorlin Syndrome Patients located in Oslo, Norway. If you read Norwegian I will be glad to forward you a copy of their first newsletter. GREAT JOB INGER, ROSE & FAMILY!!!!!!!!!!!!

### **Fund Raising**

That dynamic Jennifer Werkmeister is at it again! Jenni is coordinating a Pampered Chef fundraiser. Proceeds from the sale of Pampered Chef Products will be donated to the BCCNS Life Support Network. For more information on how you can purchase the products contact:

Jennifer Werkmeister

P.O. Box 123

Fifield, Wisconsin 54524

715-762-8210

The BCCNS Bears are in! They are adorable and sport a shirt that says "I AM NOT ALONE BCCNS Life Support Network" They are products of the Build-A-Bear corporation and come with a birth certificate and their very own house that each child can decorate as they please. Build-A-Bear has many location across the country and a website where children can purchase accessories. We hope to get one to each of our young members soon. They are also available for purchase at \$35.00 large bear or smaller bear at \$25.00 per BCCNS Bear including shipping USA & Canada.

Not interested in getting your own bear but would like to sponsor a child receiving one just send a check in the amount of \$35.00 made payable to the BCCNS Life Support Network and write BCCNS Bear on the memo.

### **Children's Contest**

BCCNS Life Support network is proud to announce our first annual Holiday Greeting Card Contest open to our artistic and talented younger members and their siblings.

Please submit your hard copy entry on a 8 1/5" by 11" paper to the BCCNS Life Support Office by November 9<sup>th</sup> 2001 to be among the first ever to have your artwork on our Holiday cards.

Please mail to:

BCCNS Life Support Network

P.O. Box 321

Burton, Ohio 44021

Be sure to include your name, address and phone number and relationship to the group or member.

The cards will be used for a fundraiser for the organization. Appropriate themes may be:

- World Peace
- Woodland or Animal Themes
- Winterscapes
- Universal Love
- Global Oneness

In effort to be politically correct please avoid using denominational themes.

Please help us by encourage your friends, family members, church members etc. to consider buying the cards using the form included in this newsletter. A local printer has generously donated their time to print the cards. Order by November 12<sup>th</sup> 2001 to insure delivery in time to mail them out. Sets of 12 cards featuring, 3 cards each of four different designs. Cost is \$10.00 per set.

BCCNS Life Support Network

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