

Quarterly Advocate

Winter 2000

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Manchester Feedback

All attendees had a great trip to Manchester. Upon arrival on Friday evening Jim Costello of the UK Gorlin Group hosted an icebreaker session where members had the opportunity to get to know a little about each other prior to the formal meeting on Saturday. This was a wonderful event. How interesting to sit with so many other syndrome patients and discover how differently we are all affected by this syndrome and at the same time how much we share in common. We had the opportunity to meet with fellow NBCCS patients from around the world. Many new relationships have developed that I feel will last a lifetime. We shared stories of miracles as well as horror stories we have faced in our common battle. The evening slipped away rapidly and although we all new we must get up in the morning for the meeting, nobody wanted to leave. I hope to obtain permission to publish some of the most remarkable stories with you in the near future.

On Saturday we were greeted by the group again and had a short time to mingle and grab a cup of coffee or tea to start the day. Our first presentation was on homeopathic therapy including massage and reflexology. Other methods were discussed and the members felt this was a great addition to their overall care as well as stress relief and for healing the soul. Barbara Watkinson did a wonderful job of delivering this information.

The next presentation was an update on the advancements in genetics with NBCCS / Gorlin Syndrome. This was a very thorough and understandable presentation on how the defective gene works along with cell development. We were also provided an update on the subject of Photodynamic Therapy. Their methods have come a long way since the early days when I first had the treatments. The study is showing great results. Slides of before and after photos were shown and the results are remarkable. The presentation by Professor Farndon and Dr Evans was fantastic. Both have been very helpful and dedicated to the UK Gorlin Group. We all owe them a big "Thank You" for their interest and work with NBCCS / Gorlin Syndrome.

The group broke for lunch and although the food was excellent and mostly consumed I am surprised anyone had a chance to eat. We were all eager to share in one another's company. After we were refreshed we all collected back in the facility and commenced with the remainder of the information. Speakers and vendors were represented from sunscreen, camouflage makeup techniques, custom hat manufacturers, sun protective clothing and an abundance of regional health care information. We were provided an opportunity to address the group and asked for their cooperation in registering with our organization as well in order to assist in numbers of people served when requesting grants. All members were also encouraged to participate in our patient forum and so far the response has been great. We thank the participants and look forward to future communication. Kristi Schmitt Burr presented the group a generous donation in honor and remembrance of Mr. Ren Bradley from the Basal Cell Carcinoma Nevus Syndrome Life Support Network.

I would like to thank Mr. Jim Costello, his family and the UK Gorlin Group for being such wonderful host. I would especially like to thank Mr. Wilbur & Mrs. Elanor Schmitt, Mr. & Mrs. Bill Ginn and Mr. Edward Nord for their extreme generosity as our first financial donors to the group. Without their help none of this would have been possible for us. In attendance from the

USA group were Kristi Schmitt Burr, Hans Muller, Sharon Burger, Jon & Jennifer Werkmeister and my family.

I strongly recommend any of our members to attend future meetings in the UK. You owe it to yourself to make this trek at least once in your lifetime. I hope to attend each year. For information on future UK Gorlin Group Meetings watch for details on their website. <http://www.gorlin-group.pwp.blueyonder.co.uk/>

Merger Update

Kristi Schmitt Burr founder of the Basal Cell Carcinoma Nevus Syndrome Life Support Network, Sharon Burger the group's administrator and myself have worked diligently to finalize all the details of our merger. The group has obtained and furnished office space, selected computer equipment and have hired a full time assistant. Just a few small details remain before the full transition will occur. I traveled to Cleveland over the holidays to see Kristi and all the staff there. We spent our time researching and planning our retreat now set for April 2001. We have also interviewed an Executive Officer who will conduct the day to day operation of the organization and assist in packaging and selling presentations on BCCNS / Gorlin Syndrome for whoever may have interest. The Executive Officer will also be in charge of grant writing and soliciting funds.

Member Retreat April 2001

The Basal Cell Carcinoma Nevus Syndrome Life Support Network Retreat will be held April 20th, & 21st 2001 in Aurora, (Cleveland) Ohio at the Bertram Inn & Conference Center 600 North Aurora Road, Aurora Ohio 44202. The two day retreat will feature speakers on the genetics of NBCCS / Gorlin Syndrome and Mohs Surgery for BCC removal. We are still awaiting response from speakers on clinical trials and Photodynamic Therapy. We will also be hosting member sessions with group discussions or roundtable discussions on such topics as:

- Discussing NBCCS / Gorlin Syndrome with affected children and their siblings.
- Should I have children?
- What can I expect as I get older with NBCCS / Gorlin syndrome?
- At what age will I stop getting treated for the syndrome or will I ever?
- Coping skills.
- Look at the bright side. Positive aspects of the syndrome.

You should plan to arrive on Thursday April 19th, 2001. We will host a getting to know you reception at 7:00 PM. Meetings will start promptly at 9:00 AM and will continue through the day including lunch.

We will also have arrangements with a nearby spa for a variety of services including facials, manicures, massage and makeup and hair technicians. We want to strongly encourage you to bring your children to the meeting. We will have plenty of special activities for all ages. The Bertram is just 5 minutes drive from Aurora Premium Outlet Center, Six Flags and Seaworld.

There are many more attractions such as Cedar Point Amusement Park, the flats, and the Rock & Roll Hall of Fame. Lake Erie is also the Walleye Fishing Capitol of the world.

The Bertram Inn is a brand new facility and perfect for our needs. We are still in the process of negotiating rates for such things as meeting rooms, food and refreshments for attendees and equipment. We have negotiated reasonable rates of \$90.00 per night reduced from \$155.00 for a large room with either 1 King or 2 Queen beds. Each room features high speed Internet access, coffee service, hair dryers and robes. Movies, WebTV and video games are also available. The facility also features a complimentary business center, A sushi bar, Fine Dining, T'Go breakfast bar and a coffee shop. Fully equipped exercise room and an outdoor heated pool that may be open depending on the weather. Please do not call for reservations until we have finalized our negotiations with them. A retreat registration form will be sent out shortly and will have all the information for reservations. We are also in the process of soliciting corporate sponsors for this event in effort to try to offset the cost of the meeting rooms and miscellaneous expenses. If you know of a potential sponsor please ask for their assistance or pass the contact information along to me and I will follow up with them.

We would also like you to invite your family to attend the retreat. This is the perfect way to have them understand the genetics and the full possible impact of this syndrome. We have had a very positive response to the idea of a retreat. You could be of great help to other families with the syndrome by printing a copy of this newsletter and bring it to each one of your health care providers to invite their other NBCCS/Gorlin Syndrome patients to attend.

Winter Fun, Winter Sun

Just a reminder as you shovel out of two feet of snow that the Sun's rays can be almost as damaging in the winter as in the summer. Possibly even more so when there is snow on the ground causing reflection of the Sun's rays. So as you enjoy the winter weather Skiing, Ice fishing, Sleding, Snowmobiling or everyone's favorite Shoveling, be sure to wear protective clothing, sunglasses and sunscreen. Have fun and stay healthy. Here is a good article on Sunscreen: <http://www.aubreyorganics.com/articles/healthy10.html>

Green Tea and Skin Cancer

Green tea, widely promoted for its antioxidant properties, may possibly have a role in preventing skin damage from solar energy, reducing sunburn, wrinkles and even perhaps skin cancer. Green tea is prepared from fresh dried leaves, which are not allowed to oxidise as in black tea. It is rich in polyphenols, which are believed to be the active agents. In mice green tea by mouth or applied to the skin can prevent UV light damage to the skin. It also reduces the carcinogenic effect of topically applied chemical carcinogens. Unfortunately evidence in human subjects is currently lacking.

Mukhtar H et al: Arch Dermatol 2000;136:989-994.

Fluke or Fate

While traveling to Manchester for the UK Gorlin Group meeting my family and I had the opportunity to take in a bit of Holland and Belgium. While at an Internet Café in Amsterdam during the start of our trip, I was checking my e-mail and doing a posting on our Patient Forum I received an e-mail request for information from a Husband and Wife from the Netherlands who have a son affected by NBCCS / Gorlin Syndrome. I immediately replied informing the couple that I was in the Netherlands at that time and the purpose of my trip. I also included the information for the UK group and how to contact Jim. The couple responded with much amazement and said I was no more than 100 meters away from them when I got their message. To my surprise when we arrived in Manchester Jim Costello informed me that in fact the Couple had made contact and decided to attend the meeting as well. The couple was so moved by the experience that within a week or so of making their initial request for information they now were leading a cause for awareness in the Netherlands! In fact they have established a website in two languages and have been in contact with local families! Great Job Willem & Betty! Here is their new website: <http://members1.chello.nl/~wf.breurken/Persoonlijke%20webpagina.htm>

Can it get anymore coincidental? Upon arriving home from the UK, I played a message on our home answering machine from a very excited member. She had received a call from the school councilor who stated that she thought her son's syndrome sounded familiar and that she remembered having a student the previous year with the same syndrome! As it turns out the other family lives in the same neighborhood and the two boys attend school together! They were even intending on attending the same Karate class! The new family has been searching for a support group for three years! Even though the Mother is a health care professional there was no luck in locating a support group. They are very excited to be part of our group. We are equally excited to be here for them.