

Quarterly Advocate

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New Topical Treatment

A cream developed primarily for use on genital warts is being tested for use on BCC's. It is called Aldara (Imiquimod) and clinical trials are now under way. I have read the literature and have seen the results of its effects on one of our members. The cream is applied daily and over a period of time the BCC is removed in the form of a scab. The result is believed to leave a cleaner margin in that the cream does not discriminate, nor does it depend on the feel of scraping or ability to determine a clean margin microscopically. The entire region around the BCC is affected and any cells should react with its application. Scarring is also less. The ongoing trials will determine if there is sufficient penetration to remove the BCC entirely. Those of you who have had the experience of Effudex Cream know that even though the reaction seemed to remove the BCC but had a high recurrence rate due to lack of penetration. We will wait in anticipation of the results.

If you would like to learn more about Aldara Cream

Click Here [Imiquimod \(Aldara\) Drug for Warts: Use, Side Effects, Interactions](#)

November Meeting

The UK group led by Jim Costello is having its Annual Meeting on November 11th, 2000 to be held at the Wendover Hotel in Manchester, England. I will be attending this meeting along with several other members from the United States. We are trying to put together an Icebreaker session for the evening of the 10th to get together over a few cocktails or a cup of tea at a location to be determined. The Saturday meeting will consist of a presentation on the advancements in genetic research and will include a Q & A session afterwards. There will be a lunch served and then the afternoon is more of a reunion type atmosphere where you will have the chance to meet with probably over 100 attendees! I feel this could be a once in a lifetime opportunity for some of our members! Where else could you possibly learn so much in one day! The UK group really has it together thanks to the continuing efforts and commitment of Mr. Costello. The meetings have grown considerably over the years and I am told are certainly not all doom and gloom in fact they have quite a lot of fun! I know that cost is always a consideration. I have taken the time to do a little shopping for you. The airfare round-trip from Chicago to Manchester is about \$475.00 round trip right now I understand the rates generally come down in October. I anticipate the rates could be as low as \$350.00 round trip by the time of travel, depending on where and when you depart.

The best rates so far seem to be from Virgin Atlantic Airlines. They also only require 7 day advance booking where most require 14 days. You can find them here [Virgin.com](#)

You can register @ priceline.com and be notified by e-mail of price reductions as they occur You can find them here [Priceline.com](#) - Name Your Own Price for airline tickets, hotel rooms, groceries

Mr. Costello has made arrangements for special rates at The Wendover Hotel the choices in rate are a King Room @ \$66.00 per night (depending of course on the rate of exchange at the time) or \$49.00 for a single room. You can go to the website and contact Ms. Ann Graves who is in charge of the function.

Find the Wendover here [Wendover Hotel Manchester](#)

All told you can probably do the trip for about \$750.00! What an opportunity. This of course, would make a great early holiday present from someone who loves you! OK! Maybe a group of people who love you but what a great gift nonetheless! I strongly encourage your attendance. If you are interested in attending please contact me.

To learn more about the UK group or the meeting go here:

<http://www.gorlin-group.pwp.blueyonder.co.uk/>

Growth

Since our creation just a short time ago our group has grown with incredible speed! The Internet has been a tremendous vehicle for us. We are also listed with the National Organization for Rare Disorders (NORD) and the Alliance of Genetic Support Groups. This coming year we will be doing some marketing at the American Academy of Dermatology Meetings. (My Mohs Surgeon happens to be running for President. I am sure this could be helpful to us). We hope to do the same for the College of Mohs Surgeons. A large part of our goal is to try to help educate primary health care providers about the syndrome as they are in a position to diagnose the symptoms early. We are working on this objective. Mr. Jim Costello from the UK Gorlin Support Group has been both a tremendous resource for us as well as very helpful in referring new members. Most of all, our existing members for the referrals of their friends and family.

The holidays are coming and this seems to be a time when numbers really increase weather it is related to time available for Dr. Visits leading to a new diagnosis or people having the time to reflect and feeling a need for information or a sense of community.

Most people find us when desperate for information and end up benefiting both from the education they receive and ultimately from a feeling of belonging. All of our new contacts are glad to find us out there. There is almost an unanimous feeling of; I'm not alone in this! If you are not currently active in the discussions on the Patient Forum <http://www.delphi.com/gorlinsyndrome/start> I strongly encourage you to do so. This may not be a time when you are feeling a need to reach out for your own sake, but there is always someone who could use a friendly ear. Wont you please help? Feel free to start new topics. It is quite all right to have fun here and the talk does not have to be about the syndrome although we would love to hear your story as to how the syndrome has affected you as a patient or as a family member or loved one to those affected. I thank you in advance for your cooperation. Have Fun!

Holy Cow! A New Affiliation!

What else has this guy been up to? And by the way, how come I didn't get the Summer Issue of the Quarterly Advocate? Well, the answer to your questions is this. I am absolutely overwhelmed with request and new ventures. I love it! I am a Real Estate broker by profession and have just gone through my first busy season of business while trying to run this organization! Oh, and of course, all my usual medical treatments and a few new ones. All I can say is whewww! The Summer Issue was ready for publication and included information, primarily on being careful in the Sun during the summer months & what you can do to protect yourself, including differences in sunscreen products and where to get the best ones for our needs, Information on sun protective clothing & accessories and the issue of the depletion of our Ozone & global warming and what you could do to help. Including links to all the related websites on these issues. During my research I discovered the controversy in the Scientific community on both issues as to the Ozone depletion (or not) and the effect of the sun on BCCNS patients! I do not want to put out inaccurate information. There is enough unfiltered information out there for you to have to sort through without me adding to it. All of this combined with the overwhelming growth of our group brought to surface the need to take this group to the next level!

So what about it? Well, I recently had the opportunity to travel to Cleveland where I had the privilege to meet with one of our members who many of you know. Her name is Kristi Schmitt Burr. I have communicated with Kristi for some time and have long awaited meeting her. All I can say is WOW what a dynamo! Kristi is actively involved in many things including her local chamber of commerce, Public radio, and land conservation among them. Kristi is the owner of Beecap a food supplement distributor and a very large modern dairy farm. Kristi is also the founder of The Nevold Basal Cell Carcinoma Life Support Network and has been working on this project for about 2 years. I was electronically introduced to Kristi from a member who was introduced to me by Jim Costello of the UK group. Kristi has taken all the appropriate steps to establish an organization that can provide real support to its members. Some of her accomplishments towards this include retaining Legal Council to obtain the not for profit status and become a corporation. Retain the services of an administrator for the group. Recruit the assistance of medical professionals for a medical advisory board. Compile lots of data regarding our Syndrome and has been spreading the word. I realize the task at hand and am aware of the restrictions on one person working alone. I have decided that it is best for all to merge my efforts with Kristi in order to provide the best possible, consistent quality service to our members. We both share the same goals and desires for the group's long-term ability to survive and provide these services. We had quite an exciting weekend. In attendance were Kristi Schmitt Burr, Hans Muller, Jenni Werkmeister, Bill Ginn (Legal Council and great friend), Dr. William Lynch of University Hospital in Cleveland (Dr. Lynch has agreed to head the Medical Advisory Board), Sharon Burger and myself.

I have to admit it was an unusual experience to travel and meet with people I have never met. What if you don't like them or worse what if they don't like you? What will we say? What will they ask me? I am pretty outgoing and adjust to these situations well. My wife does not. We both felt at home immediately upon arrival. What great people. I feel like I have two new sisters. The area was beautiful and the accommodations were fantastic. I would like to thank Kristi, her friends and family for taking time from their very busy schedules and being such tremendous

host to my wife and I. We certainly felt like visiting dignitaries. I highly recommend that you seek out fellow Gorlin Syndrome patients and get to know them. What an experience we had a great time. It was so cool to sit at a table with three other people who have the syndrome and have an idea of what you go through. There were no tears unless it was from laughing so hard. Give it a try.

Many great ideas came out of this meeting. Here is a small sampling of them.

- Educating our members and their families.
- Care packages for young children recently diagnosed or having a difficult time.
- Regional Representatives and meetings.
- National and International Meetings.
- Net meetings.
- Weekly web chat.
- Expanded Forums and Bulletin Boards.
- Children Pen Pal program.
- Contact Lists of members willing to talk to people about the syndrome.
- Additional efforts to educate primary care providers regarding the syndrome.
- Public awareness programs.
- Medical advisory board.
- Assistance in dealing with legal issues such as discrimination, living wills, disability and bankruptcy.
- Website design.
- Finding and recruiting members.
- Asking our members to take advantage of free home pages widely available on the Internet and link to a main page.

Of course, all of this worked needs to be carried out and funded. It was discussed that we may be able to call on the talents and dedication of many of our existing members. Funding may come from charitable donations and grants. We will also solicit drug manufacturers, equipment manufacturers, large corporations, associations and organizations that may budget such items, fund raisers put on by our members and/or their families.

So being in sales, here comes the close. Do you feel you have a talent e.g.: webmaster, councilor, research skills, fund raising that would contribute or just an interest in helping others with BCCNS/Gorlin Syndrome? Well now is the time to act! Just let me know and we will get started there is much to be done. We realize we must crawl before we walk but lets crawl fast! I came away with the echo of the words of famous architect Daniel Burnham who is responsible for Chicago's nickname City of Big shoulders "Make no little plans for they have no magic to stir men's blood" Let's stir some blood.