

BCCNS Life Support Network

Quarterly Advocate

Winter 2002

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Midwest Regional Meeting

On December 7th, 2001 the BCCNS Life Support Network hosted its first regional meeting with great success. The meeting was held in Elmhurst, Illinois just west of Chicago. The main purpose of the regional meetings is to afford those who would not normally be able to attend a National meeting to share in the opportunity to meet fellow members and for us to have the opportunity to meet more of our members.

The attendees were able to get to know one another and some were putting faces with the screen names they had been communicating with. The day consisted of an information session describing many of the features, cause and effect of BCCNS/ Gorlin Syndrome. Also the group was among the first to see tidbits of the BBC films including an interview with Professor Gorlin and a very open and emotional interview with our founder Kristi Schmitt Burr.

Members ranged from veteran patients with years of experience and knowledge to those just becoming acquainted with BCCNS. Members were mostly local yet some traveled from as far away as New York, Ohio, Wisconsin, Indiana and even Georgia! We hope this will also be the beginning of many less formal outings for the local group. Future plans include a picnic and a baseball game.

Special thanks to Jon, Carol and Susan Johnson for their help in executing the meeting. HAPPY BIRTHDAY SUSAN!

State of the Organization Address

HAPPY ANNIVERSARY! On February 8th, 2002 the BCCNS Life Support Network turned two years of age! Horary! Here is a short list of some of our accomplishments since our creation.

Established Non Profit Status
Became Incorporated
Became Member N.O.R.D.
Joined Alliance of Genetic Support Groups
Recruited and Appointed Officers, Directors and Trustees
Retained Internet Domain (www.bccns.org)
Developed Website
Became Listed as Support for BCCNS on Dozens of Medical Internet Sites
Established Internet Bulletin Board (Patient Forum)

Initiated Sunday Night Web Chats
Retained and Furnished Office Space
Obtained Toll Free Number
Established International Liaisons and Partnerships
Traveled Twice to England to Attend the Gorlin Group UK Meetings
Hosted First BCCNS Life Support Network National Member Retreat in Ohio
Established our Esteemed Medical Advisory Board
Publication of our Quarterly Newsletters
Development of Organizational Brochure
Establishment of our “Care Bear” Build A Bear Program
Developed Information Binders for Requesting Members and Meeting Attendees
Mail Campaign Promoting Awareness of BCCNS and our Organization
Presence at the Annual American Dermatology Association Convention

These are many of our recent achievements. Many more could be listed. Probably our most valued item would be our service. Over the past few years we have provided information that has helped Doctors with the care of BCCNS patients. By educating and communicating our members are better able to understand and cope with their circumstance. BCCNS Life Support Network has helped win court battles of our members who were wronged by their insurance providers. We have assisted educators with special needs of some BCCNS children. We have comforted parents concerning their children’s future, assisted young couples on birthing issues, helped young persons with how and when to tell their dates or fiancé about BCCNS.

Sadly, we have been there for our friends to deal with end of life issues and most of all we have opened up the lines of communication for BCCNS patients around the world. How many BCCNS patients did you know two years ago? How many will you know two years from now? The caring and sharing that has resulted is priceless. Our mission has just begun.

Our Future Goals Include:

Establishment of a National Medical Professionals Referral Network
Enhancement of our Young Persons Activities
Hiring a Social Worker / Grant Writer
Continuing Regional Member Meetings
Developing a Presentation for Medical Trade Association Meetings
Redesign of Newsletter for Postal Mailings
Appointing Additional Regional Trustees
International Coalition of BCCNS Advocates

A long-term goal would be to host an annual clinic for BCCNS patients who could not otherwise obtain Medical Care.

Membership Dues

We can achieve all of these goals and more. But, the fact is we need your help. To date approximately 98% of our funding has come from a few generous donors and out of the pockets of Kristi and Bud. There are several problems with this. The most obvious is that funding is limited and therefore so are we. Legally it poses a problem, that in order to maintain our non-profit status, as a public corporation there is a limit to the percentage of income to the organization from individual donors. We must have participation from our members and the public at large. In soliciting grants, we also need our members to be bona fide members in that we have name, address, phone #, and not just a screen name. A list of hundreds of screen names doesn’t do anybody any good. Certainly by paying dues we would be considered bona fide members.

The success of the grant writing process also weighs strongly on how your organization is funded. Most donors expect there to be significant sponsorship from the members of the organization. The feeling is that if the members do not care about the fiscal fitness of their own organization, why should they.

Here is an example of some of our expenses* over the last two years:

Rent and Utilities	\$12,000.00
Travel to Meetings	8,500.00
Salary (Dave Calfee)	15,000.00
Member Retreat (April)	16,000.00
Chicago Regional	1,100.00
Web Development and Maintenance	1,100.00
Care Bear Program	1,500.00
Supplies, Printing and Postage	3,400.00
Computer, Furnishings and Equipment	4,600.00
Travel & Meals (local)	1,300.00
Advances on 2002 Retreat	2,000.00
Total Expenses	\$67,500.00

* Closely approximated figures

Beside the generous monetary contributions to the BCCNS Life Support Network we have been fortunate to have received in excess of \$30,000.00 in "in kind" donations. These are documented volunteer man-hours and non-reimbursed expenses from our members over the two-year period.

With a dues structure of \$35.00 per individual or \$50.00 per family the organization would project the following income:

100% Member participation would be approximately \$8,500.00 in income to the organization.

75% Member participation would be approximately \$6,375.00 in income to the organization.

50% Member participation would be approximately \$ 3,187.50 in income to the organization.

As you can see, we would all still have our work cut out for us in the fund raising department. Being involved in volunteer organizations in the past I would expect we would be lucky to hit the 75% mark. Based on these figures it leaves us with an annual deficit of \$27,300.00 to generate each year. We also expect our expenses will grow as our membership does each year.

We value each and every one of our members. No member will be denied services based on inability to pay membership dues. We hope you find value in being a part of our organization.

You can send your much-appreciated tax-deductible donation to:

BCCNS Life Support Network
14606 West Park Street #201
P.O. Box 321
Burton, Ohio 44021

Thank you.

Eastern Regional Meeting

The date has been set for our Eastern Regional Meeting of the BCCNS Life Support Network. The event will be held on March 23rd, 2002 at

Columbia University Department of Dermatology
161 Fort Washington Avenue (Corner of 165th and Ft. Washington)
12th Floor
New York, New York

Meeting will run from 9:00 AM to 4:00 PM EST.

We are extremely fortunate to have Dr. David Bickers as our Host. Dr. Bickers is the Head of Dermatology for Columbia University and is contributing member of our Medical Advisory Board. Dr. Bickers and Columbia are also providing lunch on that day.

Cost for the meeting will be \$7.50 for BCCNS Life Support Network members and \$15.00 non-members.

Those of you who attended our member retreat in Cleveland last year remember Dr. Bickers is conducting the Celebrex Study. This would be an excellent opportunity for you to obtain all the information. You will also be able to sign up for the Celebrex Study that day if you desire and meet all the criteria.

The day will begin with a presentation from Dr. Bickers on BCCNS. We will be airing the BBC Special "Bitter Inheritance" that featured the Costello family and their lives with BCCNS / Gorlin Syndrome.

Break for lunch

Afternoon session will start with Dr. Angela Christiano PHD of Microbiology and Genetics at Columbia University.

Presentation by Bill Costa and Bud Caruso on our organization

To register, simply copy and paste this form to your word processor and print. Mail to:

BCCNS Life Support Network
P. O. Box 321
14606 West Park Street #201
Burton, Ohio 44021
Phone# 1-866-834-1895
Fax# 1-440-834-1894

BCCNS Life Support Network
Eastern Regional Meeting
March 23rd, 2002
9:00 AM - 4:00 PM

I am enclosing \$ _____ .00 for _____ members of the BCCNS Life Support Network and \$ _____ .00 for _____ non members to attend the Eastern Regional Meeting at:

Columbia University Department of Dermatology
161 Fort Washington Avenue
12th Floor
New York, New York

BBC Programme “A Bitter Inheritance”

The last of a four-part series on genetic defects and their effect on families aired on January 31st, 2002 at 9:30 PM GMT. Within hours of the broadcast Jim Costello, the star of the special, received over 200 e-mails from people wishing to express how moved they were by seeing a bit of his life journey with Gorlin Syndrome and that of his family. Jim and Margaret have already been in touch with over half a dozen new families who didn't know a support group existed. Jim and Margaret were kind enough to share some of the e-mails with us.

Dear Jim,

I have just finished watching the BBC program regarding Gorlins syndrome and was moved to email you. I'm a 31-year-old doctor, working with HIV patients in the London area. In some ways there are similarities in that in both cases there is no cure, they are chronic conditions, and can have a major impact on both people's health and social lives. I would hope that these days doctors are more holistic in their relations with patients, not just treating illnesses but also trying to minimize their impact on peoples lives.

But let me come down off my doctor's podium and speak as a human being. I lost one of my brothers 5 years ago, and like many people, began to question why life deals out such blows. It made me, more than ever before, resolves to try to make others suffering a little less if I could. Don't get me wrong: like everyone else, I'm no saint. Sometimes you begin to wonder if anything you do really makes any difference. But perhaps its one thank you from a previously withdrawn or angry patient, one smile on someone's face that keeps you going. Sometimes its the courage in another human being that awes you and makes your own problems seem so small. And I was awed tonight.

Your courage and determination is an absolute inspiration. What you have done in forming the support group cannot now be undone, and will continue to be a force for good as it ever expands. Many would be envious of such a lasting legacy.

What can I say further Jim, you, your family and all those with Gorlins or other chronic illnesses are the true heroes.

Best wishes for the future,

Dr Gerry Gorman

If you would like to view more of the responses they are available from our website at:

<http://www.bccns.org/bbcfeedback.htm>

National BCCNS Life Support Member Retreat

On June 7th, 8th, & 9th 2002 Punderson Manor Resort and Conference Center in Newbury, Ohio will be home to the BCCNS Life Support Network 2nd Annual Member Retreat. Based on our attendance and feedback from last years meeting we are sure to have a great turnout. Once again we will be bringing in some of the top clinicians and researchers in the country. We will have the latest information on clinical trials and studies. You will actually have the opportunity to meet the people responsible for the research and sign up if you desire and fit the protocol.

Being a state park atmosphere there are many more family oriented activities. The park features a fishing lake, hiking trails, indoor and outdoor pool and an array of activities. Accommodations vary from the Manor Lodge, which has an excellent restaurant and bar. There are also family cabins that can be shared. Cabins are two

bedrooms, living area with fireplace and kitchen. For the more adventurous there is also a campground. Punderson is located about 20 minutes from Six Flags Amusement Park and 40 Minutes East of Downtown Cleveland.

Here is a link to Punderson Manor Resort:

<http://www.pundersonmanorresort.com/>

Here is the link to Six Flags Worlds of Adventure Theme Park:

<http://www.sixflags.com/parks/worldsofadventure/home.asp>

Here is a link to Ohio Tourism:

http://www.ohiotourism.com/default_f.asp

There are a limited number of rooms and cabins available we suggest you book as far in advance as possible. To reserve your room call 1-800-282-7275 which is the number for Ohio State Parks Reservations tell them you would like to reserve a room or cabin at Punderson Manor and mention reservation code G-958963

If you prefer to stay at the Bertram Inn and Conference Center where we were last year it is about a 25 minute drive to Punderson here is the link to their website:

<http://www.thebertraminn.com/index2.htm>

There are several towns that are within thirty minutes drive including Mentor, Bainbridge & Solon if you would like to search on www.travelocity.com or www.orbitz.com

More information to follow, as details develop. Be sure to plan to attend!

American Dermatology Association

The BCCNS Life Support Network will be represented by Kristi Schmitt Burr at the annual convention and trade show of the American Academy of Dermatology. We are very fortunate to have the opportunity to display our brochures at the booth of the Dermatology Association. This is a savings of about \$10,000.00 an amount we could otherwise not afford to pay. If not for the kindness of Dr. David Bickers, Dr. William Lynch and the Dermatology Association it would not be possible. We hope this activity will take great strides toward creating awareness for BCCNS and reaching out to even more BCCNS patients throughout the country. So as they say, "Who dat?" Dat Kristi! Hopefully Kristi will be traveling with Louisiana native Dr. William Lynch, so Le Bon Temps Rouler!

BCCNS Life Support Network

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