

GORLIN SYNDROME

SUPPORT GROUP

News and Views - August 2005

Dear Group Members and Associates

Warm and sunny greetings to readers old and new. Its not often I can send sunny greetings from Manchester so please excuse my excitement. With the sun of course comes the extra hassle of having to slap sun cream all over, cover up and wear a silly hat when everyone else just goes for it.

One of the best things in being part of a support group is sharing information, being able to talk to people who have been through the same as you and knowing you're not the only one. Much of the work done by the Gorlin syndrome committee this year has been to influence the medical world in how it diagnoses, treats and manages Gorlin syndrome. To qualify for the charity status and the funding that follows, we have a committee; made up of a handful of Gorlin syndrome volunteers like me who feel they want to put back into the group what was there for me when I first rang the Costello hotline. All the committee members have now served their maximum time in post and need to be re-elected or you could support other group members who would like to consider election to the committee. Election of committee members will take place at the annual meeting. Please let Margaret know if you are interested and if you are unable to attend. If you fancy chatting through what we get up to then please ring me on 0161 428 8645 or contact Margaret on 01772 517624 or email gorlin.group@btconnect.com

Building on the success of last year's annual meeting, I look forward to seeing and meeting friends old and new again. The meeting as always provides us with the most up to date medical information and treatments available but more importantly the chance not only to talk to someone who wears the same T-shirt but to share our journey with members who have just received their diagnosis. We are able to support transport and accommodation costs if helpful, please contact Margaret.

Finally I thought it might be useful to share (anonymously if you prefer) sun creams and camouflage make up or any other products. I get so frustrated reading the promises on packages and wasting money. I would rather try a product that another T-Shirt wearer has recommended. Anyway this T-Shirt wearer currently recommends:-

- Ambre Solaire Factor 50 anti-aging face cream (Wear it under it under foundation as a sun screen)
- Bobbi Brown corrector – a bit expensive, lasts ages, I pick it up much cheaper at shopping outlets.

Looking forward to seeing you at the meeting. Take the very best of care.

Sally Webster - Vice Chair

Annual Conference

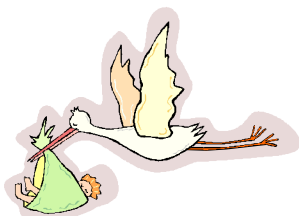
After the disappointment of there being no meeting last year we are pleased to advise that this year's event will take place on **Saturday, 22nd October** at Park Hall Hotel and Conference Centre in Chorley, Lancashire with doors opening at 9.30 am for tea and coffee and starting at 10.00 am. The day will run through until 4.00 pm and lunch will be provided. The cost of attendance is subsidised at £10.00 per adult and £5.00 for a child. Funding has been set aside to enable patients on low income or benefits to attend. Further information regarding financial assistance can be obtained by contacting Margaret Costello on 01772 517624 between 6.00 pm – 9.00 pm daily.

A full and interesting programme is planned with excellent medical speakers who will update us on research and treatments for the condition. Confirmation received Professors Farndon and Evans, Dr Allen and Mr Cornah will be attending, all with a vast experience of Gorlin Syndrome. You will have the opportunity to meet old friends, and for new comers to meet people and families to discuss common concerns. For those staying over at the hotel the evening social session extends the warmth of the day. For families attending there will be an art and craft workshop for the children, alternatively the theme park will be open for children young and old as will the swimming pool.

Anyone wishing to attend should complete and forward the attached form to Margaret along with a cheque made payable to 'Gorlin Syndrome Group'. **Closing date for applications no later than Friday, 7th October 2005.** Anyone wishing to donate a **raffle prize** please contact **Anne Mills on 01386 853094**

Skin Information Day – Saturday, 24th September 2005 10.00–3.00. Queen's Park Hospital, Learning Centre, Park View Offices, Haslingden Road, Blackburn. Admission free. Come and see us there!

International news



It was pleasing to hear from Inger of Oslo, Norway and to offer congratulations to her and the family following the birth of a second granddaughter Amalie, who weighed in at 3780 g. Amalie is the second child and daughter to Tonje and partner Johan. A welcome sister for Natalie.

Caring in Canada

I am writing from my home in Ontario, Canada after finding your email address on my search about Gorlin Syndrome. My name is Donna Allen and I am 45 years old. I was diagnosed with Gorlin Syndrome at the age of 8 but had shown many symptoms 4 years prior to diagnosis. A generation study of my family found no cases of Gorlin or any related problems in 5 generations.

I have a great interest in the disease and have always been at the leading edge of any Canadian studies/solutions. I have seen the famous Gorlin mummy that is now in the National Museum in Turin, Italy and was used as a comparative 'specimen' in a study of the mummified man and myself when I was about 17 years old. What an experience! I had the pleasure of meeting Dr Gorlin when I was 9 years old. He was quite a character as I remember and I still have notes that my parents kept from that meeting in 1968! My pictures/x-rays/findings are in many articles written in Canada and I am also noted to be one of those folks who has tolerated and experienced many of the issues related to Gorlin while managing to 'stay above water' for 42 of the 45 years of the condition. I did not display any of the disfiguring or blatant physical features at birth and have been blessed with a fairly pleasing countenance for most of my life. This is by no means a statement of vanity but instead one of perspective for those who read this note. My current issues are, of course with recurring BCCs, eyelid replacement surgery due to BCC invasions that repeated themselves at an outrageous rate and chiefly the chronic pain that results from the removal of more than 30 jaw cysts measuring 10 cm to 25 cm in length when an undetected jaw cyst destroyed a full half of my lower mandible. The 'state of the art' surgery to rebuild the jaw and remove the cyst(s) was done 33 years ago and was the biggest (16 hour) operation that I have ever encountered. We did not know if I would survive what was ground breaking surgery at the time. I was in a drug induced quiet state (asleep) for 5 days and woke to a fractured (wired) jaw and the equivalent of a fractured hip (graft site) that was fully encased in sand bags. By the end of June I was able to speak at my Grade 8 graduation at the age of 12. I was in a wheelchair until mid August and weighed only 40 kilos at the graduation (I was 105 cm tall).

I am interested in any information I could share to help or could benefit from. I am currently in an experimental group in Canada using Aldera (Imiquimod) ointment to treat BCCs on my head and face. I am doing the treatment when I can tolerate it in a fairly aggressive way but can reverse cells to the microscopic state if I am vigilant. Since most cells are slow growing it means that laser surgeries excisions and the like are somewhat reduced. I recommend this treatment for people who are not concerned about the appearance issue that often is questioned by others.

A gross and unfortunate 'routine' surgery to remove a 3 cm BCC wound up in the removal of a 12 cm lesion, 150 stitches and more than 25 staples to my skull. The incisions from the surgery were 20 and 18 cm respectively and healing was slow and very complicated. This surgery, done 2 years ago coupled with eye surgeries to replace my lower eyelid with tissue from my upper lid, roof of the mouth and behind the ear has left me with chronic pain and the need to stop the work I love (I am a primary school teacher). The eyelid replacement has been done twice in the last 7 years with 7 or 8 other procedures required to keep things working well. This site was originally radiated and the calibre of tissue left behind was compromised so that repairs were challenging at best.

I now support a programme that you may be familiar with. It is called ORBUS and is a flying operating room; classroom and clinic that flies to 3rd world countries offering free restorative eye surgery to those who would otherwise go without sight or help for severe eye cancers or eye disease. Nurses and doctors come to the aeroplane to learn new techniques, observe after care and learn preventative for some conditions. My eye surgeon volunteers his time to the organisation and travels at least once a year to do 2 weeks of pro bono work with the group. My doctor does cosmetic surgeries that are not covered by our health plans. He uses this money and much of his own to be able to make these trips. They do 2 or 3 hundred surgeries at a visit and the stories are so compelling. If you are interested in information about this group I would be pleased to provide it for anyone.

I have a great deal of time on my hands and would love to help, encourage and support anyone dealing with Gorlin Syndrome (especially those who are dealing with children). My mother and I kept many a journal about my experiences (from age 5 to 18) and the perspective for parents with children is indeed interesting and very encouraging and comforting. My concepts of pain and procedures that were done did not seem nearly so horrific to me as a child showing that it is very much in our grasp to cope with things that we as adults might find unimaginable! Please pass on my name to anyone who may like to get in touch or needs additional support. My thanks and very best to you and yours as you cope with Gorlin and the many problems and challenges that come with it. Good thoughts from 'across the pond'. I remain, Caring in Canada. *Thank you Donna for sharing your interesting and inspiring story with us, you obviously rose to the challenge! Anyone wishing to get in touch with Donna can do so at donnaallen@hotmail.com*

Jeans for Genes

The last newsletter carried information about this year's appeal. The Genetic Interest Group (GIG) has been chosen as one of the four guest charities for the Jeans for Genes Appeal. As a guest charity GIG will receive 2% of the net profits made on the actual day. GIG will use the funding to carry out Project QUICK, the patient charter project. A Project Worker will be employed for two years and work with five smaller support groups (Gorlin Syndrome Group being one of them) with a view to producing a patient charter for each.

GIG is currently looking for volunteers willing to raise awareness of their condition and the Jean for Genes appeal by speaking to local school children in school assembly or telling their story to magazines, newspapers, or television. Able to assist? Contact me by email or telephone (address and telephone no at end of newsletter) or log onto www.jeansforgenes.com/speakers/



One of our younger members, Holly Hunt has contacted me with an exciting opportunity for all teenagers affected by Gorlin Syndrome. Holly has set up a site so that you can all be in contact to share experiences of living with 'Gorlin', or to be as blunt as Holly, to get away from 'boring adult talk' about Gorlin Syndrome. If you have queries about the condition or about treatments there will be a link into the Gorlin website and email address. Of course, anything you wish to ask will be treated in the strictest confidence. Log on <http://groups.msn.com/BccnsGorlinsTeens> and have fun!

Spreading the word!

Bill from the Bristol area contacted me recently with the following comments:

'I cannot believe that people are still being given all sorts of spurious explanations for the various symptoms that this condition throws up so many years after the whole lot were put together by Gorlin. My Dermatologist at Bristol Royal Infirmary uses a good technique for spreading the word. He gets his students and groups of local GPs in to diagnose some of his patients. Last time I saw him he had some students in and asked my daughter and me to participate. We were eventually correctly diagnosed by the students allocated to us. But my message to them was that when I first showed symptoms some 50 years ago nobody had a clue and nobody was prepared to look 'outside the box' so it was not until my daughter came up with her dental cysts some 30 years later that the condition was recognised. I would urge all those who are connected with the condition to get their GPs and consultants to do what my Doctor does and maybe eventually the medical profession will finally get the message. I should also say that apart from the communications problems I have been well looked after by the NHS'. *You may wish to act on Bill's advice!*

Help for Nicky

Nicky recently contacted me via email asking to be in touch with anyone facing a similar dilemma. As a young woman of child bearing age Nicky is keen to have children in the future and would welcome the opportunity to discuss options with women who have had to make choices about child birth, particularly when there is a 50:50 chance of the child inheriting Gorlin Syndrome. Nicky can be contacted by email at nchapman5612@aol.com

In Memory of Gina and Margaret

Thank you to Brian Cooper of Leyland, his family and friends for their kind donation to support group funds in memory of Gina who passed away in December.

We also express our thanks to Margaret Young's family and friends for their generous donation following her death in September last year.

Charity Sunday Lunch - Clare Bean sent a cheque for £85.00 which had been raised by a friend of hers Pat. Pat organised a Charity Sunday Lunch. Thank you to Claire and Pat for your donation.

Hats!

A good place for hats! If you struggle to buy hats in a larger size contact Max-caps on www.max-caps.co.uk Special offer – state Gorlin (in comments box) when ordering you get one free.



Until the next time, look after yourself and take care.

Gorlin Syndrome Group Annual Conference and AGM

Saturday, 22nd October 2005

9.30 am – 4.00 pm

Park Hall Hotel & Conference Centre

Charnock Richard, Chorley, Lancashire PR7 5LP

Tel: 01257 452090

Web site: www.parkhall-hotel.co.uk

The venue is accessed via the M6 or M61 motorways (well signed posted from both- Park Hall and Camelot), and is a ten-minute taxi ride from Chorley Railway Station.

Name:

Address:

Name/s of people attending	Age (if under 16 yrs)

The cost of the conference is £10.00 per adult / £5.00 per child (under 16 years of age) and includes lunch. Please make cheque payable to Gorlin Syndrome Group and return to address below

Adult places at £	
Child places at £	
Total amount payable (cheque attached)	£

Twin or Double room x 2 guests £60.00 per person per night–dinner/bed/breakfast
(Children under 16 years £10.00 when sharing room with adults)

Single rooms £90.00 per person per night–dinner/bed/breakfast

Guests resident at the hotel have free membership to the Health and Fitness Club during their stay, which includes: indoor pools, gymnasium with weight and fitness area, sauna, spa whirlpool bath and steam room.

For those members wishing to take advantage of accommodation at the hotel, bookings should be made direct with Park Hall Hotel and Conference Centre, Chorley their website, or with Sue Lester via e-mail sue@parkhall-hotel.co.uk or on Tel 01257 452090 – quoting 'Gorlin' for preferential rates.

Gorlin Syndrome Group – Registered Charity No 1096361
11 Blackberry Way, Penwortham, Preston, PR1 9LQ, Lancashire
Tel: (44) 01772 517624
e-mail gorlin.group@btconnect.com - web site www.gorlingroup.co.uk