

GORLIN SYNDROME

SUPPORT GROUP

News and Views - July 2006

Dear Group Members and Associates

Hoping this newsletter finds you all as well as possible. Just to add special thoughts for those going through or supporting during the stages of treatment.

The last newsletter was January 2006; I remember being all wrapped up as it was so cold. What a contrast to the warmth June has offered us so far. Apart from not being able to squeeze into last years clothes, the only downside is to remember to be more thorough with the old sun block. I have really found the Sunsense Ultra SPF 60 to be effective. I had no problem obtaining it on prescription from my GP. The bottle is a bit piddly with only 125mls in, so I just keep it on constant repeat prescription. Not available on prescription is the Sunsense Daily face SPF 60. This combines with a moisturiser and has a mild tint. I wear it alone or under normal makeup. It sinks in quickly and is not greasy. A tube costs £12, I wear it all year and it lasts 3-4 months. I was advised to layer the cream on not rub it in, this allows it to be adsorbed into the skin. Please let us know how you get on with all the products available so we can share with other members.

Moving on to the autumn, we are holding the next Gorlin Group meeting in at The Holiday Inn, Oxford on Saturday 21st October .We hope by making the meeting more geographically accessible, more members from the southern part of the country can attend. We are again really lucky our medical speakers have volunteered to attend and share the current treatments and options. Attached with this newsletter is the application form and further details. After this meeting we will evaluate members' views with a view to alternating the meetings north and south each year.

We are really looking forward to seeing members old and new in Oxford. Take good care

Sally Webster

See inside this issue for details of this year's annual patient conference. For the first time we will be moving South to Oxford in the hopes that we will attract patients and their families who haven't had the opportunity to attend before. We hope this does not put off people from further North. As is usually the case everyone is welcome. We look forward to your continuing support.

Places are limited so you will need to get your forms back to us as soon as possible.

We look forward to seeing you!

Sat, 21st October 2006 at the Holiday Inn in Oxford.

Thank you to John Pismeny and colleagues at Yorkshire Water. A collection during Skin Foundation Awareness Week raised £261.45 for group funds. John and colleagues at Yorkshire Water hold a number of regular fund raising events each year and this is not the first time that we have benefited from their efforts. On behalf of the Trustees and members I would like to express our sincere thanks for another generous donation.

Family Route Map Project and Gorlin Syndrome Group

This project has been jointly funded by Jeans for Genes and an educational grant from Genzyme for two years. Anna Lane is the Project Officer from the Genetic Interest Group (GIG) who will work with families belonging to the Gorlin Syndrome Group plus five other associations which support genetic conditions. Together with you and healthcare professionals, Anna will build up a picture of the services families receive. The process will be staggered so that each of the six genetic conditions, including Gorlin Syndrome, is focused upon. The project will develop ways to gather and disseminate the findings to support Gorlin Syndrome patients and their families. The aim of the project is to help patients and families to access services and information.

This approach is new and innovative so what is learned will be important for other charities. They will be able to use the framework to develop their 'Family Route Map'. An Advisory Group will oversee the developments and progress throughout the project.

Anna is inviting you to help with the project in the following ways:

- Complete a short questionnaire either online at <http://www.gig.org.uk/family-routemap-survey.php> or by post.
- Tell her about your experiences of accessing services.
- Take part in a group meeting (Focus Group) to discuss your experiences.
- Help to pilot and develop the Gorlin Family Route Map.
- Provide Anna with copies of information leaflets that have helped you.

This project is part funded by the Jeans for Genes Appeal. J4Gs is an annual campaign in its 11th year and relies on media coverage, to raise awareness and encourage people to pay £1 and wear jeans for a day. To help generate publicity for this day J4Gs work closely with the charities involved, of which GIG is one, to tell the stories of families and individuals affected by genetic conditions. This forms a large part of the campaign and enables charities to appear in the media. It's a great way to raise awareness of Gorlin Group and the families it supports.

Could you help raise awareness of your support group to a wider audience?

Through speaking to newspapers and magazines. J4Gs has annual coverage in national and local papers with stories of families affected by genetic disorders.

- Through speaking to radio and TV – each year J4Gs events appear on local news stories as well as on radio stations around the UK.
- Speaking at local schools with Jeans for Genes presentation packs.

A leaflet containing further information about the project and why the Gorlin Syndrome Group feels it is important to be involved, is enclosed with this Newsletter. If you would like to complete the questionnaire by post or want more information about ways you can get involved, contact Anna by emailing anna@gig.org.uk , phone 01562 885792 or complete the form on line at <http://www.gig.org.uk/family-routemap-survey.php>

If you would like any further information about how you can help with media stories and ways to raise awareness please contact Melissa Winter by emailing melissa@gig.org.uk or phone 0207 7043141. Alternatively, write to GIG, Unit 4D, Leroy House, 436 Essex Road, London, N1 3QP.

Have you checked out the website?



Take a look. This is a chance to share your experiences of living with Gorlin with people of your own age.

Skin Care Campaign

The Skin Care Campaign has ceased printing and mailing their newsletter, it can now be accessed at www.skincarecampaign.org

British Association of Dermatologists

The 86th annual meeting of British Association of Dermatologists and British Dermatological Nursing Group 16th Annual Meeting took place at the Manchester International Conference Centre and G-Mex in July. Sally and Maureen attended on behalf of the group and staffed the Patient Support Group stand on Tuesday, 4th and Thursday, 6th July. This is an important forum and the ideal opportunity for further raising awareness of Gorlin Syndrome.

Web Site

The website continues to attract between 7000 and 9000 hits per month. If you don't have access to a computer at home don't forget your local library. Most libraries these days have access to the Internet and customers can log on for a small fee. If you aren't sure how to use the facilities there are always members of staff on hand to assist you.

Most of our new contacts come via the Internet and are from patients looking for more information and guidance. We would like to say hello and a warm welcome to you all. We hope that you find the information on the website useful. Further information or guidance is available on request. Just click the link on the home page.

New look site launched so check it out at www.gorlingroup.co.uk Added features are the message board and discussion forum which will commence in August.

NICE Guidance

In the last newsletter it was noted that guidance for the treatment of patients with skin cancer was launched in January 2006. Gorlin Syndrome patients are afforded recognition under special groups. These groups amount to less than 2% of the population but they are patients with a genetic predisposition to the development of multiple skin cancers earlier in life than in the general population. The guidance acknowledges that for these high-risk groups the development of skin cancer is inevitable and that services for early detection and treatment need to be tailored to their specific needs. Recognition is also given to the needs of children and young people who develop 'adult-type' skin cancers. The guidelines indicate:

- Information provision for patients in these special groups should be tailored to their specific need.
- Treatment strategies for individual patients should be made and developed in the context of multi disciplinary team meetings (MDT) at which all relevant clinical specialists, including a Clinical Nurse Specialist are present.
- Patients in high-risk groups with precancerous skin lesions should be referred early to a dermatologist for assessment, active treatment and follow up.
- Once patients at high-risk start to develop skin lesions they should be offered at least 6-monthly follow up.
- Children and young people diagnosed with skin cancer should be managed within the context of an MDT, which will include a dermatologist expert in skin malignancies....

In Gorlin Syndrome the guidance notes that patients may develop thousands of basal cell carcinomas and that topical body application of tretinoin or fluorouracil can control lesions, Photodynamic Therapy can give a high rate of tumour response, and there is evidence that radiotherapy should not be used.

Let us know how you get on with future treatments and whether or not these provisions are in place.

With Sympathy

I was saddened to hear of the death of one of our younger members, Paul Drury. Paul also suffered from epilepsy and died suddenly in the early hours of Monday, 17th July 2006. I am sure that all members join me in offering sincere condolences to Paul's parents Colin and Sue and their family.

When a loved one
has gone you feel
you will never smile
again,
But as time goes by
you will find your
loved one is still
beside you and
always will be.



May you find comfort in knowing that others share your grief.

Colin and Sue have asked family and friends for donations in memory of Paul to be offered to Gorlin Syndrome Group funds. We are honoured and extremely grateful for their generosity at this sad time.

BAD Patient Support Group Meeting

The next meeting of the British Association of Dermatologist Patient Support Groups Meeting will take place on 23rd November and it is hoped we will be sending a representative along to participate in this important forum to raise issues of concern.

Patient Involvement

In May Health minister Rosie Winterton MP announced the launch of a new resource centre promoting the value of patient involvement, service users and the public in health services. The successful bid to run the centre came from a consortium made up of the University of Warwick, the Centre for Public Scrutiny and LMCA. David Pink, LMCAs chief executive said: "LMCA is an alliance of over 100 patient organisations that believe in the importance of 'patient-led' services; we are looking forward to a fresh start in helping bring the voice of patients and

the public to the heart of service decision-making."

Travel Insurance

This summer Cancerbackup launches a campaign to highlight the problems people with cancer face when trying to arrange travel insurance. A recent survey by Cancerbackup reveals that 40% of people with cancer are forced to contact up to 10 companies to try and buy travel insurance, and over half the people went on holiday without travel insurance.

80% of people surveyed report being put through to medical screening lines on contacting insurance companies and asked standardised questions about their cancer. General feeling was that insurance staff had a poor understanding of cancer and its treatments. Travel companies are telling people they are high risk (35%) but nearly half of them are not told why. Many are refused cover or quoted very high premiums. Cancerbackup aims to work with the travel insurance regulatory body to improve access to travel insurance for cancer patients.

It ain't half hot!

What a wonderful summer we are having. I heard on the radio earlier in the week that temperatures here in the North of England were higher than those in Miami. Don't we all feel better when the sun is shining? For people with a pre-disposition to skin cancer it can be a worrying time but with extra care it can be enjoyable too. Recommendations by Cancer Research SMART campaign are that everyone needs to take care in the sun by using high factor sun creams, wearing a hat, cover up in the sun, and wear good quality sunglasses to protect the eyes from the sun's harmful rays.

And finally! Enjoy the summer! Don't forget to get your forms back for a place on the conference in October. They can be completed and sent back by post or via email. We look forward to welcoming and spending time with you to Oxford. Best wishes and enjoy the summer. Until the next time!

Gorlin Syndrome Group Annual Conference and AGM

Saturday, 21st October 200

9.30 am – 4.00 pm

The Holiday Inn, Peartree Roundabout

Oxford, OX2 8JD

The venue is accessed via the M40 motorway, leave at junction 9 heading south on A34 to Oxford and Newbury. Leave at the Peartree Interchange, also signposted for Blenheim Palace. At the roundabout, take the first exit, and the Holiday Inn in on the left. The hotel is situated 4.5 kms from Oxford Railway station. Heathrow airport is 80 kms and Birmingham airport 96 kms. There are frequent express bus links between London and Oxford.

Name:

Address:

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

The cost of the conference for the day is £20.00 per adult and £7.50 per child (subsidised) to cover refreshments and lunch.

Single, twin, double and family rooms on a bed and breakfast basis on Friday, 20th and Saturday, 21st October are £90.00 per room, per night. For those wishing to take advantage of the hotel's surroundings in the evenings, bar snacks or dinner can be booked and paid for separately. **For those people wishing to stay at the hotel, bookings should be made direct with** The Holiday Inn in Oxford. Tel No 0870 4009086 quoting 'Gorlin' special rates.

Guests resident at the hotel have free membership to the Spirit Leisure Club containing spa, sauna, gym, swimming pool and beauty treatment centre during their stay. Make a weekend of it. Limited funding is available to those patients/families who would otherwise find it difficult to attend. Contact Margaret on the number below for further details.

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