

**INSIDE THIS ISSUE**

<i>Symphony Orchestra</i>	2
<i>Patient Questionnaire</i>	2
<i>News Update</i>	3
<i>Treatment Advances</i>	4

**BAD Annual Conference**

Sally, John and Margaret attended the Annual BAD Conference in July. The event took place at the Liverpool Arena, a newly built state of the art centre, located in the heart of the city on the historic, world heritage waterfront.

An important event in our calendar and one which enables us the opportunity to exhibit over a period of three days and to spread the word about Gorlin Syndrome to dermatology nurses and Dermatologists.

**Freedom Insurance** and the Gorlin Syndrome Group form partnership to offer travel insurance policies for people living with pre-existing medical conditions. Freedom are able to provide an insurance solution to fit individual circumstances, giving peace of security and peace of mind.

For each policy sold the group will receive a donation from Freedom when 'Gorlin' is quoted. See enclosed leaflet for details.

Warm greetings to newsletter readers old and new.

Hoping you are enjoying the summer weather and the variety of leisure and social opportunities that accompany this time of year.

Committee membership changed following the resignations of Carolyn Deveney and Maureen Gregory. We were delighted to receive nominations from Helen Costello and Robert Webster who are now in post. John Dooher was elected interim treasurer pending the next AGM. We extend our thanks to Carolyn and Maureen for their contribution, welcome Helen and Robert, and acknowledge John for taking up treasurer responsibilities.

Margaret has devoted much time and expertise giving the website a facelift, adding and extending to what I hope you will agree is a comprehensive source of information. On-going problems with the internet service provider were encountered necessitating a move to a new provider. Hence a change of contact details, see back page of newsletter.

The Family Route Map developed by Carolyn, Margaret and I in partnership with GIG has been distributed and welcomed by healthcare professionals. It is designed to support newly diagnosed patients and their families to guide recommended care pathways. Copies are available on request or via the website.

Committee members attended a Symphony Orchestra event in Southampton and the BAD conference in Liverpool. (further details are included under separate headings). Work on the research guidelines is complete and John has prepared a draft travel policy to ensure we maintain financial governance where expenses need to be claimed.

Due to ongoing health problems within the committee, it may not be possible to organise a full patient conference this year. We are looking at alternatives and will endeavour to provide the most informative forum we can.

Take the very best of care,

*Sally Webster - Chair*



### Charity Symphony Orchestra Event

Trustees Sally, Helen and Margaret attended the event held in Southampton on Sunday 13<sup>th</sup> April. The audience was entertained to a wonderful evening of music which included Brahms orch. Tarrant *Scherzo from Piano Quintet in F minor, op. 34*, Saint-Saëns *Cello Concerto No. 1 in A minor, op. 33*, Dvořák *Symphony No. 7 in D minor, op.70*.

On behalf of all members of the Gorlin Syndrome Group we express our sincere thanks to the organisers, conductors, players and volunteers who gave up their time in support of the group. Thanks also to the owners of Gwel an Mor Luxury Holiday Village in Cornwall for the very generous donation of a seven day holiday in a VIP Luxury Lodge on their five star park and to all local businesses who donated raffle prizes. As a result of everyone's efforts a total of £800.00 was raised.

It was especially pleasing to meet with Victoria and Charis, both GS patients, and to spend time chatting with them and to join them at the concert. A great weekend all round!

### Patient Questionnaire

Returns of the questionnaire sent out with the last newsletter were low but of the responses received 76% confirmed the usefulness of the annual conference and indicated that attendance at the events had met their needs. Many respondents expanded on their answers and clearly indicated that attendance at the events had been a welcome opportunity to meet others affected by Gorlin Syndrome. Also valued was the input of healthcare professionals from the various disciplines who offer their expertise and advice on the many aspects of the condition. Indications are that we need to lift some of the barriers to attendance by reducing costs; accessing affordable venues, considering the timing of the event and location of venues, and allowing more time for social interaction. It was pleasing to acknowledge that 86% of those who responded saw the GS website as a valuable resource.

We now need to consider the feedback at the next committee meeting, with a view to running future events. Watch this space for further information.

### Our Sincere Condolences go to the Bruerken Family

In May we were saddened to hear of the premature death of Willem Bruerken, as a result of a tragic accident. Willem first made contact in the early 1990s and he attended a number of our events with his family. A few days after that first visit Willem had a website up offering information in Dutch and German.

Willem was a true family man and loved life, was fluent in 5 languages, a skilled musician and craftsman in woodworking, and had a passion for the sea.

Willem will be missed and I am sure that each of you would wish to join us in extending our sincere condolences to Willem's wife Betty and children Alexa (& Ted), Michiel and Maartje (& Steven). Our thoughts and prayers are with them all.



### **Low Energy Light bulbs**

Articles in the press earlier in the year indicated that concerns are being expressed by the British Association of Dermatologists (BAD) and the Skin Care Campaign about the potential risks of low energy light bulbs for people with existing skin conditions. Following the publication contact was made with British Association of Dermatologists.

Dr Holden, President quoted "Conclusions are that because the light bulbs emit vanishingly small amounts of ultraviolet, they are very unlikely to affect Gorlin Syndrome patients. Confirmation of the exact output of ultraviolet is still finally awaited, but even so it seems Gorlin syndrome patients don't have anything to worry about. It seems quite likely that a facility will be retained for people with various skin disorders to have access to the current or similar incandescent yellow tungsten bulbs if they want them. But in any case, there is a lot of activity going on to try and retain access to the current yellow bulbs if necessary".

### **National Institute of Clinical Excellence (NICE) Surgical Site Infection consultation**

As a registered stakeholder for the NICE Consultation process the Gorlin Syndrome Group were afforded the opportunity to comment on the draft guideline for Surgical Site Infection (SSI). The guideline addresses many aspects of SSI prevention but did not refer to patients requiring plastic surgery for skin cancers and the potential risk of SSI. Clarification has been sought as to whether there is evidence of SSI further to plastic surgery and if any of the prevention strategies covered in the document would apply.

### **NICE Consultation – Prevention of Skin Cancer**

As stakeholders we took the opportunity to comment on draft guidance published for consultation in June to ensure that the need for specific information for those at greater risk of developing skin cancer is included in the guidelines.

A range of medical disciplines and charitable organisations concluded that activities not included seemed the most relevant thus making the guidance extremely restrictive. NICE confirm the focus is on information provision and not environmental factors, i.e. exclusion of sunbed regulations and shaded areas in schools, work and public areas. With this in mind it is extremely likely other topics will be referred to the Department of Health for future guidance and consultation.

We feel, like the many other stakeholders that input has made a little but significant impact with NICE making various amendments to the guidance.

### **Skin Care Campaign**

Skin Care Cymru (SCC) represents the interests of people with skin conditions in Wales and is currently looking at the issue of psycho-social support for dermatology patients. There is a lack of services for patients and SCC is considering how this could be changed. The issue has been raised with the Deputy Chief Medical Officer and a meeting is planned with the Minister for Health, Edwina Hart to discuss the situation.

SCC Cymru also contributed to a consultation regarding guidance on the use of sunbeds. Although guidance is considered a step in the right direction SCC would like to see tanning parlours licensed and it made illegal for anyone under 18 to use them.

Recent research in Scotland showed that four out of five sunbed parlours fell short of current safety guidelines MPs and SCC Scotland are calling for regulation of the tanning machines as part of a public health bill going through parliament.

### **Join us on Face Book**

Trustee Helen ensures our presence on Face Book. This is a way of keeping in touch with others affected by GS. See who is on line, view pictures, take part in the discussions or start your own. Search for Gorlin Syndrome Support Group at: <http://www.facebook.com> It's definitely worth a look!

## Gorlin Syndrome Group

11 Blackberry Way  
Penwortham  
Preston PR1 9IQ

Phone: 01772 496849

Email  
[info@gorlingroup.org](mailto:info@gorlingroup.org)

Website  
[www.gorlingroup.org](http://www.gorlingroup.org)

Registered Charity No: 1096361

The Gorlin Syndrome Group was formed in 1992 by Founder and First Chair Jim Costello (deceased)

### Patrons

Professor R J Gorlin (deceased)

Professor P A Farndon

Professor G R Evans

### Trustees / Committee

Sally Webster – Chair

John Doohar – Treasurer

Margaret Costello – Secretary

Vicky Gill

Robert Webster

Helen Costello

*Backed by a Medical Advisory Board consisting of healthcare professionals covering the many aspects of Gorlin Syndrome*

*We are grateful for their continuing support.*

**PDT Hits the Headlines** A recent report by the BBC website claims that researchers have "greatly improved" the effectiveness of a skin cancer treatment by adding an extra ingredient. Work is currently being carried out at the Peninsula Medical School in Truro, Cornwall.

Photodynamic therapy involves applying a sensitizer cream to the affected area and then treating with a red light to activate the cancer fighting chemicals. Scientists have modified the cream by adding an ingredient called CP94. The research team has confirmed that by adding the CP94 treatment can take place on BCCs previously considered too thick for standard photodynamic therapy.

A member of our medical advisory team confirmed that the research team has done a lot of work with skin cultures and to ensure the safety of the preparation. The preparation is not commercially available but trials are underway at the Royal Cornwall Hospitals NHS trust to assess whether this really is an advance on standard PDT. We hope to keep you informed.

**Non Invasive Biopsies!** - The BAD Conference in Liverpool gave us the opportunity to see first hand scanning equipment used for the early detection and diagnosis of skin cancer. The new technology offers a non-invasive view into the layers of the skin meaning that a substantial number of biopsies can be avoided. Through the use of clinical photographs and laser scanning microscopes the dermatologist or plastic surgeon is able to obtain an 'optical biopsy' of the skin, which measures the extent of lesions. This will allow surgeons the opportunity to perform assessments and cut down on the waiting time for patients for the results of biopsies. As the equipment is introduced to clinics this could see an end to all those biopsies.

**Promising Results from US Trials** - A novel molecule, GDC-0449, shrinks tumours for patients with advanced basal cell carcinoma with limited side effects, suggesting a viable new treatment option for patients with the advanced form of this cancer, according to research presented at the 2008 Annual Meeting of the American Association for Cancer Research. GDC-0449 works by inhibiting the Hedgehog pathway. The Hedgehog ligands are a family of proteins that are important in tissue growth and repair. Abnormal activation of Hedgehog signalling pathway because of mutations in PTCH and SMO is the cause of most basal cell carcinomas. Data from trial suggests a good response. More information can be viewed at: [www.sciencedaily.com/releases/2008/04/080414161050.htm](http://www.sciencedaily.com/releases/2008/04/080414161050.htm) It's early days but this could be a real advance for Gorlin Syndrome patients with advanced BCCs.