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## **Annual Patient Conference**

As indicated in the last newsletter the event this year will take place at the Britannia Hotel in Birmingham on Saturday, 24<sup>th</sup> October 2009.

A significant number of bookings have already been received. For those of you who have not already done so there is still time to book your place. Don't worry if you mislaid the original form as a further copy is attached for convenience. Kindly ensure the form is completed in full and returned to us with the appropriate fee and cheques payable to Gorlin Syndrome Group.

Room bookings should be made direct with the Sarah in the Conference Office at the hotel on 0121 631 3331 but please do be sure to quote 'Gorlin' to take advantage of the special rates quoted.

We look forward to welcoming each of you to this informative and enjoyable event in our calendar.

*Margaret Costello*

Welcome to our summer newsletter

Further to the announcement of the annual patient conference we have been busy securing the speakers and information resources to provide a forum that meets the needs of both new and existing patients, their families, friends and health or social care professionals.

We currently support about 350 patients and families in the UK. This year so far, we have 38 people booked on the conference and we are really pleased to welcome a number of first time attendees.

Whilst the web sites and medical consultations can provide a wealth of information, when you have or support someone with Gorlin syndrome, there is nothing in my opinion like sharing with another person or family affected by Gorlin syndrome. My family have been involved with the group for 14 years and still find comfort in discussing the impact of treatments, however value and treasure the friendships we have developed.

It would be fantastic to see as many people as possible attend to share and support, check out the current information and take benefit of the medical advisers available on the day. For those unable to attend we will produce a summary of any new key developments and report back in the next newsletter.

Looking forward to meeting up at the conference and to wish everyone an enjoyable summer break

With best wishes

*Sally Webster*  
*Chair*

Look out for the feature on Gorlin Syndrome in  
**Pick Me Up – Summer Special**  
on the 17<sup>th</sup> July 2009. More detail on page 3.

## Walk for Skin 2009

The events organised by the British Skin Foundation (BSF) offer an opportunity for people to show their support for the work of the BSF and their commitment to funding research into skin conditions.

Jane Costello accompanied by her partner Paul and daughter Aimee participated in the Kensington Gardens walk in May and opted for their sponsorship to be split equally between the BSF and the Gorlin Syndrome Group.

### Jane, Paul and Aimee's Walk for Skin – 10<sup>th</sup> May 2009



The day of our walk had finally arrived. After months of fundraising, I was filled with anticipation, warmth, and pride, whilst predictably emotional with thoughts of my dad. It was an early start (but then it always is with a 2 year old!) and a gloriously sunny day, which made everything seem even more special.

Aimee looked adorable in her homemade baby pink Walk for Skin t-shirt, and after applying sun cream and packing necessities, such as sunhats and refreshments, we set off on the short journey to London. Aimee insisted on walking from South Kensington tube stop to the park entrance at the Royal Albert Hall (quite a hike for little legs!) and was very excited after registration, when she was given a sticker and a balloon.

We joined the crowds at the starting line at the Albert War Memorial, along with the press, and Denise Van Outen, who was to start the walk. The walk itself was quite short, but as long as we were raising awareness and money for the British Skin Foundation, and Gorlin Syndrome group, this was irrelevant. Aimee was struggling with the heat so for her, it was a mixture of walking, her pushchair, or being carried (alright for some!).



The hustle, bustle, and stress that usual comes with a trip to London was absent today, being in such a beautiful park, for such a good cause. The park seemed endless, as we passed the Peter Pan statue, the serpentine, fountains, Kensington Palace, and the Diana Princess of Wales Memorial Playground. Three miles later, as we finished our walk we were again met with a wonderful atmosphere of music, jugglers, laughter, and goody bags. I had prepared a well deserved picnic which we enjoyed in the shadow of the Royal Albert Hall, whilst taking everything in.



We raised £1424 for the British Skin Foundation and Gorlin Syndrome group which will be matched by my employers. To everyone who sponsored us, we are eternally grateful.

*Jane Costello*

On behalf of all at the Gorlin Syndrome Group we offer our sincere and grateful thanks to Jane, Paul and Aimee, and a special thank you to all those who sponsored them.

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### Pick Me Up Summer Special

As a result of Jane registering for the London Walk for Skin she was approached by the British Skin Foundation Press Office with a request for her to become a case study to raise awareness of skin conditions. With Jane's agreement she was then contacted by the Press Association and interviewed with a view to an article being published about Jane's experience of living with Gorlin Syndrome.

Jane's interview will feature in the Summer Special edition of Pick Me Up Magazine.

We are grateful to Jane for sharing her experience of living with Gorlin Syndrome and hope that this goes some way to raising awareness of the condition and skin conditions in general.

For all those of you out there wishing to see the article just pick up a copy of the Pick Me Up Summer Special from 17th July 2009.

### BAD Annual Conference

This year John Doohar and Margaret Costello travelled to Glasgow to be at the British Association of Dermatologists and the British Dermatological Nursing Group Annual Meetings which took place at the Scottish Exhibition and Conference Centre on 7<sup>th</sup> – 10<sup>th</sup> July 2009.

We were one of 21 patient support groups and almost 50 pharmaceutical exhibitors represented at the event.

Healthcare professionals working in Dermatology settings across the UK attend the event and it is a great opportunity to raise awareness of Gorlin Syndrome and the needs of patients. As in previous years we took the opportunity to network with Doctors and Nurses visiting our stand and were able to offer information about Gorlin Syndrome.

It was pleasing to hear that a number of patient studies are currently underway in the UK with regards to the treatment of Gorlin patients and we are hoping to gather and feedback information at a later date.

We are grateful to the British Association of Dermatologists and organisers of the event for enabling patient support group attendance and their continuing commitment and active encouragement of the work we undertake.

### Rare Disease UK Update

On 10<sup>th</sup> June Rare Disease UK, the national alliance of patient charities, medical professionals and industry representatives, issued a press release welcoming the adoption by EU Health Ministers of a Council Recommendation calling on Member States to develop and implement plans for the treatment of rare diseases.

Alastair Kent, Chair of Rare Disease UK, said: *"This is an important step forward for the estimated 3.5 million people in the UK who are affected by rare disease. We are also delighted that this initiative has received wide cross-party support. It now needs to be taken forward in all the nations of the UK."*

He added: *"It is important that families affected by rare conditions are offered a strategic approach to the provision of their healthcare. We are still hearing frequently that patients are having difficulties accessing high quality care and services."*

Dr Peter Corry, a leading Paediatrician at St Luke's Hospital, Bradford, said: *"Diagnosing rare diseases is often difficult and the complex treatments required may involve several specialists. A national strategy that integrated rare disease services would enable patients and health professionals to provide and use best practice care and the health services to make best use of scarce expertise and improve outcomes for patients."*

Good news and a move in the right direction!

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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 Dooher – 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.*

## Care in the sun

Summer is here and already we have seen temperatures rising into the 90s in some part of the country.

Sun damage can cause premature aging, wrinkles and skin cancer. Sunlight may be one of the environmental agents promoting the appearance of BCCs in Gorlin Syndrome. It is highly recommended that patients:

- Stay in the shade whilst the sun is at its highest, usually between 11.00 am and 3.00 pm.
- Wear wide brimmed hats and protective clothing.
- Wear 100% UV sunglasses to protect the area surrounding the eyes. Be sure that sunglasses carry quality marks such as BS Kite and CE marks. These will guarantee that they are giving you a high level of protection against UVB and UVA rays of the sun.
- Use sun-block or high factor sunscreen, the higher the number the better the protection. Look at the label and ensure that the product protects from UVA and UVB and that it carries a 4 star rating.

## News from the United States

The BCCNS Life Support Network (American group) has alerted us to a number of trials taking place in the US. They are continuing to recruit for a National Cancer Institute funded trial of the chemo preventative efficacy of the topical agent Tazorac vs. the development of BCCs, a vitamin A derivative that has been used in the treatment of acne for over a decade. The goal of the trial is to ascertain whether the cream is safe for GS patients and to see if it will reduce the numbers of BCCs on the face and chest.

A good deal of research has been going on focussed on Sonic Hedgehog (SHH) Signalling Pathway Inhibitors (when the pathway malfunctions it leads to diseases like basal cell carcinomas). This trial is available to patients with aggressive BCCs or those where BCCs have invaded other structures, making the results of surgery unlikely to be satisfactory. The results of the first stage trials look promising with patients reporting tumour stabilization or shrinkage.

We are hoping to be in a position to offer further information about the trials in the next newsletter.

Till the next time!

We welcome your stories, articles and items for inclusion in newsletters. All contributions are gratefully accepted and can be submitted by email or post.