

## Welcome to all newsletter readers

So much is now happening in the advance of new treatment options for individuals with Gorlin syndrome. In the last newsletter we announced the launch of phase 2 clinical drug trials for LDE225, to assess the effect and safety of this drug in individuals with advanced basal cell carcinoma. In addition phase 2 clinical trials are also taking place for GDC049. This drug works in a similar way and so far has been tested for advanced basal cell skin cancers that have spread other parts of the body, have come back after surgery and cannot be removed, or are in a position where they cannot be removed surgically. Presently these drugs are restricted for those over 18 years of age.

Results so far found that the cancers shrank in about 3 out of 10 people (30%) whose cancer had spread to another part of the body. They shrank in 4 out of 10 people (40%) whose cancer had spread into nearby tissue (locally advanced disease). In about 2 in 10 people (20%) with locally advanced disease there were no cancer cells when researchers took a sample of tissue. For more information on UK clinical trials see [http://clinicaltrials.gov/ct2/show/study/NCT01367665?term=vismodegib&cntry1=EU%3AGB&rank=2&show\\_locs=Y](http://clinicaltrials.gov/ct2/show/study/NCT01367665?term=vismodegib&cntry1=EU%3AGB&rank=2&show_locs=Y). The drug, Vismodegib is now licensed for use in the US following extensive drugs trials and following completion of successful drug trials in the UK it is hoped that the full range of drugs become available soon in this country.

The latest news and updates from these drug trials and progress with other treatments will be presented at our patient conference to be held on the 3<sup>rd</sup> November 2012 at the Novotel in Birmingham. Details of the conference are included in this newsletter. With all the advances in new emerging treatments, it would be lovely to welcome new and current members to learn more about these exciting treatments, find out about the condition and talk to others and share thoughts and experiences.

At conference Margaret and I will also update you on our progress to become compliant with the Information Standard. This standard is a mark that that our web based and published information is evidenced based and a reliable and credible source.

In July Margaret and I attended a meeting of global skin cancer patient support groups. The main objective was bringing together global basal cell carcinoma and melanoma patient support groups to share disease experience and challenges and learn from each other bringing across the needs and problems of small patient group organisations. We met with Geoff Olsson from the Australian and Kristi Schmitt Burr from the US respective Gorlin Syndrome groups. It is hoped that more collaborative patient support group work will follow.

We look forward to welcoming you at the conference. With very best wishes.

*Sally Webster  
Chair*

## Donations and Fundraising

In our last newsletter we reported on the death of Victoria Crampton-Barden in November 2011. Victoria bravely battled with complications associated to Gorlin Syndrome for many years. We would like to express sincere thanks to Victoria's family and friends for the very generous donation of £1055.00 in Victoria's memory.

### A Big thank you to

Zenshin Karate Club of Bristol for your continuing support. Thank you for another donation, this time £200.00 to group funds. We appreciate all you do in support of our work.

### Manchester 10K – 20<sup>th</sup> May 12



Dennis the Menace and Minnie aka Nigel & Maureen of Burnley donned their running gear to raise funds in the Manchester 10K in May. Maureen became aware of the group through a work colleague, sister-in-law of Margaret Costello. Maureen states 'since then we haven't looked back, Nigel was referred to professionals able to deal with the condition. We value the support, latest information and friendship. We had the privilege of meeting Jim Costello – a truly inspirational man! This is our way of saying 'thank you' and giving something back.' And thanks to Maureen and Nigel from all at the GSG.

## 20<sup>th</sup> Anniversary Patient Conference

Those of you with internet access will already know that this year sees the 20<sup>th</sup> anniversary of the Gorlin Syndrome Group. To mark this milestone a patient conference is planned and will take place at the Novotel, Broad Street, Birmingham B1 2HT on Saturday, 3<sup>rd</sup> November 2012 between 9.30 am – 4.00 pm.

We have an interesting programme planned with confirmed attendance from a number of healthcare professionals with expertise and a special interest in Gorlin Syndrome. The focus of the day will be on genetics, surveillance and management of the condition, new advances in treatment and clinical trials. Final details of the programme will be circulated to attendees prior to the event.

The conference is heavily subsidised as a result of successful grant applications and sponsorship. A limited amount of funding is available to support attendance, i.e. cost of stay and/or travel subject to demand for those who would otherwise struggle to come along. However, we are requesting a non-refundable deposit of £10.00 per adult payable in advance to secure bookings, there is no charge for children under the age of 16 years.

As in previous years there will be a fully supervised crèche provided by the Safehands Network, which will enable parents to concentrate on the content of the day knowing that their children are happy, having fun and fully occupied in a safe environment.

Anyone wishing to book accommodation at the Novotel for Friday 2<sup>nd</sup> and/or Saturday 3<sup>rd</sup> should contact the hotel direct on 0121 643 2000 and quote 'Gorlin'. Rooms are priced at £85.00 per night and include breakfast.

Should you require further information about any aspect of the event then do please get in touch with Margaret or Helen on 01772 496849.

A booking form is enclosed with the newsletter. Kindly ensure the form is returned along with booking fee at the earliest opportunity to assist us with planning and final organisation of the event. Closing date for bookings is 3<sup>rd</sup> October 2012.

**We look forward to welcoming you to our 20<sup>th</sup> anniversary patient conference.**

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## Genetics and Insurance

Have you ever had problems or struggled to access insurance because of your genetic condition?

Genetics Alliance UK recently completed a project based around insurance for their members. The project looked at the problems people with genetic conditions, particularly rare conditions, faced when applying for insurance. As a result of the project Genetics Alliance UK has produced a number of helpful information booklets that contain accurate and clear answers on insurance related topics. To access the booklets visit the Genetics Alliance website.

## HealthUnlocked Gorlin Syndrome Group

The Gorlin Syndrome Group has linked up with HealthUnlocked to create a new on-line community that connects people, volunteers and professionals to help learn, share and give practical support to one another. A number of people affected by the condition are signed up to the community already and can access blogs and polls, ask questions about the condition and catch up on health issues and debates relevant to them.

Additionally you can add a location by including your postcode and find people near you, subject to them also having specified their location, and perhaps share experiences of local health issues. It is worth checking out at <http://gorlinsyndrome.healthunlocked.com/>

## Congratulations



We were delighted to hear earlier this year that Gorlin Syndrome Group medical advisor and Professor of Clinical Genetics at the University of Birmingham, Peter Fardon was awarded the CBE for his service to Medicine in February 2012.

Professor Farndon has a long standing interest and experience in genetics and he gained an MD for research in Gorlin Syndrome.

We offer our special congratulations to Peter and express sincere thanks for his support over the last twenty years. Without Peter's input and that of other medical advisors the support group probably wouldn't be here today.

## Facebook

The Facebook page for the Gorlin Syndrome Support Group

<https://www.facebook.com/#!/groups/12723259010/>

continues to attract new members and is proving to be a popular resource for those wishing to network with others affected by the condition. It's a great place to share experiences about the condition and the various treatments for many of the symptoms associated with Gorlin Syndrome, even the rarer ones.

However, there have been occasions when inappropriate content has been posted. The site is monitored on a regular basis and posts deemed not suitable are deleted so a gentle reminder to all, kindly ensure content is appropriate. Thanks for your co-operation.

## Patient Stories/Articles

It's been many, many months since we have featured any patient stories or articles in the newsletter. Such items are always welcomed and are appreciated by others living with Gorlin Syndrome.

If anyone feels that they would like to share their particular experience/s with others then we would be delighted to hear from you or receive items via email at [info@gorlingroup.org](mailto:info@gorlingroup.org) or by post.

## Gorlin Syndrome Group

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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 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.*

## Say no to children being sunburnt in schools

The British Skin Foundation (BSF) has launched a campaign and they need your voice to say no to children being sunburnt in schools.

The BSF are after **100,000 signatures** to have the issue of sun safety in schools debated and clarified in the House of Commons. Nurseries, primary schools and secondary schools in England currently have no standardised policies in terms of the responsibility of sunscreen re-application amongst staff, pupils and parents. Each school or local education authority decides for themselves on an ad-hoc basis what they want to action - if anything.

Every year the BSF receive numerous calls from concerned parents about this issue, so they are want the government to clarify who is responsible for what aspect of a child's sun safety during school hours.

The campaign is supported by Sian James MP, chair of the Melanoma Taskforce, on the issue, but your help is needed. Help the BSF reach 100,000 signatures and get this issue raised at the House of Commons - sign the petition at <http://epetitions.direct.gov.uk/petitions/32565> closing date April 2013.

## Cancer Research UK partnership with Nivea

Cancer Research UK is set to raise millions to fund skin cancer research and raise awareness of sun safety awareness.

Find out more about the partnership with Nivea at [http://www.nivea.co.uk/about-us/beiersdorf/sos-kinderdorf-at?utm\\_campaign=TogetherJul12\\_S2&utm\\_content=36780587937&utm\\_medium=email&utm\\_source=Emailvision&cid=deeplink-cruk](http://www.nivea.co.uk/about-us/beiersdorf/sos-kinderdorf-at?utm_campaign=TogetherJul12_S2&utm_content=36780587937&utm_medium=email&utm_source=Emailvision&cid=deeplink-cruk)

Further information about safety in the sun can be found at the following websites, <http://www.sunsmart.org.uk/> and <http://www.nivea.co.uk/Experience/sun-care/SUN-Advice-> all three sites give lots of good information about skin care protection in the sun.

*Don't forget about those booking forms for the patient conference. Closing date is 3<sup>rd</sup> October 2012.*

*Until the next time!*