

News & Views

Spring 2008

INSIDE THIS ISSUE

<i>Forthcoming Events</i>	2
<i>Latest Developments</i>	3
<i>Snippets</i>	4

The last newsletter should have been with you by early December but 'all the best laid plans go to pot'. I was involved in an accident in November resulting in me breaking the neck of my left femur. Surgery and a week in Birmingham City Hospital followed before transfer to the Royal Preston Hospital. Not the 'city break' I expected! It has been a challenging time with the need for lots of patience coming to terms with limited mobility and crutches. Recovery has meant plenty of time to concentrate on GS so no excuses for lateness on this occasion!

Margaret Costello

NHS London Survey

We were invited to take part in this study on NHS care in London. The focus was on patient safety, clinical quality and the patient experience. Input from patients in the London area enabled us to make some constructive suggestions with regard to the care and treatment of GS patients. Once the report is in we hope to advise you of the findings in the next newsletter.

A warm welcome to all members comes with the Spring 2008 edition of the Gorlin Syndrome Group newsletter.

Since the last newsletter there have been many exciting developments and opportunities for you to consider.

During 2006 we became involved in a joint project with The Genetic Interest Group (GIG) to produce the enclosed Family Route Map. We offer our thanks to GIG and to all those group members who contributed to this area of work.

For the first time the annual patient conference planned for October 2007 was cancelled due to a lack of bookings. In previous years the conference has been aimed at providing information and a forum for social exchanges with fellow GS families. We are very keen to understand your needs and how we can best serve them. Your honest completion and return of the enclosed questionnaire would really help us to plan for future events.

Wishing you all the very best of health.

Sally Webster - Chair

Annual General Meeting – 26th January 2008

Cheltenham was the setting for the 2007 AGM following a postponement in October. Our thanks are extended to group members who came along and supported us at the event. The minutes of the 2006 AGM were accepted as an accurate record and the accounts for 2006/07 were presented.

With the introduction of the Charity Act 2006 came new reporting requirements meaning that smaller charities with income and expenditure less than £10,000 per annum no longer need to seek independent examination of accounts. However, in accordance with the GS Constitution independent audit remains a must. Agreement was reached that the Treasurer pursue and locate an auditor for approval by Committee.

Two additional committee members were elected to post. We are delighted to welcome Robert Webster and Helen Costello on board. Both will serve for a three year period.

Walk for Skin 2008

Walk for Skin is a series of walks organised by the British Skin Foundation (BSF) to help fund research into skin diseases. Nine events will take place across the UK between April and June 2008. All Walk for Skin sponsorship is used by the BSF for research unless walkers choose to donate 50% to a patient support group.



Why not take in some fresh air and exercise whilst raising money for research into skin disease? By taking part and donating 50% of your sponsorship to the Gorlin Syndrome Group you are ensuring that funds can be channelled into research for Gorlin Syndrome. Information about the walks and registration details are included in the enclosed British Skin Foundation leaflet. Register by completing the form and returning to the BSF or go online at www.walkforskin.org.uk

We offer sincere thanks in advance to those people 'Walking for Skin' who intend to pledge 50% of their sponsorship to the Gorlin Syndrome Group. We hope the weather is kind to you and that you enjoy the event. Why not take along your camera and email us a photograph of the event so that we can include a picture in the next newsletter.

An Evening of Music in Southampton



In December we were contacted by the Charity Symphony Orchestra of Southampton with an offer to support the Gorlin Syndrome Group. The orchestra was formed in 2006 and since their first performance in London they have performed three events annually to raise funds for charities. The players are drawn from colleges and universities across the country and the concerts serve as a chance for players to get together and make music.

On Sunday, 13th April 2008 at 6.30 pm in the Cantell Maths and Computing College, Violet Road, Southampton the orchestra will be performing what promises to be an enjoyable evening of classical music with pieces from Brahms, Dvorak and Saint-Saëns. During the interval there will be an auction for a luxury holiday at Gwel an Mor in Cornwall kindly donated by the owners. Information about the 5 star luxury holiday village can be accessed at www.gwelanmor.com Tickets for the concert can be obtained by telephoning 02380 528193 and priced at £6.00 for adults and £4.00 for concessions and students.

Committee members Sally, Helen and Margaret are attending the concert and are hoping that those living in and around the Southampton area will come along and offer their support.

In addition, Sally, Helen and Margaret will be hosting a small social event at the Ibis Hotel in Southampton on Sunday, 13th April between 3.00 – 4.30 pm. Patients and their families in the area are invited to come along. This is an opportunity to have a chat over a cup of tea or coffee and meet others whose lives are touched by Gorlin Syndrome. There will be no charge to attend so if you wish to join us kindly confirm your attendance to Margaret on 01772 517624 or email her at gorlin.group@btconnect.com

Your support is valued. All funds raised from the above events will ensure the future development and work of the Gorlin Syndrome Group.

Wellcome Library part of the Wellcome Trust is a founding member of the UK Web Archiving Consortium consisting of the British Library, JISC, The National Archives, and the National Libraries of Scotland and Wales. Web sites are selected to represent aspects of UK documentary heritage ensuring they are available to researchers in the future. A copyright licence approved by the Gorlin Syndrome Group website authors will enable the Consortium to archive and maintain the site whilst ensuring future accessibility and integrity of the website.

MIMS Dermatology is a specialist health care journal aimed at primary care and staff working in dermatology settings in secondary care. It has a readership of 8000-10000 per issue. We were approached for an article on Gorlin Syndrome for the May issue. The focus will be on diagnosis, pathology and identification of the condition.

We are grateful to Professor Peter Farndon for producing the article on behalf of the Gorlin Syndrome Group. What better way of further raising the profile of the condition amongst healthcare professionals.

Making Every Disabled Child Matter (EDCM) – campaign workshops for parents

Following the EDCM workshops held in the autumn almost all who attended requested update events as the campaign progresses. Contact a Family has teamed up with the campaign to run more workshops for parents this spring.

The workshops give parents a chance to find out about the government's programme to transform disabled children's services. A total of £430,000,000 will be spent by English local authorities on improving services, starting in April 2008. Additional money will also be available from Primary Care Trusts (PCTs). The workshops will explain how money will be spent and give people the chance to learn how to influence funding, with a focus on how parents can help make sure that local authorities and partner agencies are measured against new targets on disabled children's services.

This is an opportunity to learn about local and national campaigning, including how to get local authorities and PCTs signed up to the campaign and deliver on Charter commitments. The workshops will enable networking and sharing of experiences with parent campaigners within regions and to share them with the EDCM staff team. Six events are planned across the country and information can be obtained at www.cafamily.org.uk/influenceevents or by telephone: Liz Ranger on 020 7608 8784, email <mailto:liz.ranger@cafamily.org.uk>

Skin Care Cymru

SCCymru represents the interests of people with skin conditions in Wales. They seek improvements in care and work with relevant professional bodies, the public and media to educate and inform them about the needs of those affected by such conditions. Current areas of work include:

- Psychological effects of skin conditions.
 - Quality of services.
 - Access to services.
- Information can be obtained from Skin Care Cymru on Tel 07810 094568 or email info@skincarecymru.org the website is currently under construction but due shortly www.skincarecymru.org

NHS24 Scotland

Contact with Support Group Project at NHS24 Scotland will result in our details being included in a support group directory. We have a number of members north of the border but we expect a rise following release.

Rare Disease Day

29th February was Europe's 1st Rare Disease Day. Over 150 patients travelled to Westminster to meet MPs to raise awareness of the needs of patients. Alistair Pink of GIG said, 'Raising awareness of genetic disorders is vital. Although alone they are rare, together over 3.5 million people in the UK are affected. Many patients have similar issues and concerns and together we can help patients to access the NHS in a fair and equitable manner'. Full text www.rarediseaseday.org

Gorlin Syndrome Group

11 Blackberry Way
Penwortham
Preston PR1 9IQ

Phone: 01772 517624

Email
gorlin.group@btconnect.com

Website
www.gorlingroup.co.uk

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

Maureen Gregory – Treasurer

Margaret Costello – Secretary

Carolyn Deveney

John Doohar

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.*

We were saddened to hear of the death of Thomas May of Liverpool. Family and friends collected £60 in memory of Thomas. Our condolences and thanks for the kind donation.

Grant-giving charity on line

Turn2us is a new charity launching an online service to help people access information on all benefits and grants available to them from both statutory and voluntary organisations in the UK. Applications for support can be made directly from the website and people can be kept informed by email or by text to their mobile phone. www.turn2us.org.uk

South Birmingham PCT

This forward thinking and patient involvement leader are desperately trying to involve patients in their work – if you are located in the South Birmingham area and feel you can assist contact Rhona Woosey, Primary Care Development Manager, at rhona.woosey@southbirminghampct.nhs.uk or call on 0121 472 8781 to see how you can get involved.

Gorlin Syndrome Group Family Route Map

With work complete on the Family Route Map we are pleased to enclose a copy with this newsletter. Issues and concerns raised during a series of patient focus groups in 2006 identified a number of themes and these have been used as a basis for developing this resource. Thanks are extended to all members involved in the work and to the Genetic Interest Group (GIG) and staff Anna Allford and Melissa Hillier. Without their funding and support this project would not have been possible.

Sunbeds Increase the Risk of Skin Cancer

Cancer Research UK advises against the use of sunbeds. Young people and GS patients are particularly at risk. The use of sunbeds accelerates the skin's natural ageing process and the development of skin cancer.

<http://info.cancerresearchuk.org/healthyliving/sunsmart/skincancer>

Thank You

Festive lights again adorned the Knuckey home in Newquay at Christmas and thanks to the generosity of local people, friends, neighbours and businesses in the area Jason and Sandra raised £152.64. Thank you to Sandra and Jason for your efforts and to all who offered donations and raffle prizes.

Sandra undertook a sponsored slim over the festive season and despite all the festive treats to tempt her Sandra lost 16½ lbs in 12 weeks. Sandra's sponsorship amounted to approximately £250.00 and once all funds are in Sandra will donate them to the GS Group. Well done and thank you Sandra, we are extremely grateful.

Don't forget – your articles for future newsletters are welcome and let us know if there is a topic you would like to see included.

