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Just before Christmas we were saddened to hear of the death of Eleanor Schmitt, mother of Kristi Schmitt-Burr of US group, BCCNS Life Support Network. Eleanor was one of the founding members of the US group, providing financial support and for many years she served as a tireless advocate for those less fortunate than herself.

Our sincere condolences go to Kristi and her family.

The present economic climate continues to affect us all. A number of charities who have operated for many years are feeling the strain; some have in fact folded due to the 'downturn' in giving. Our financial situation is currently sound thanks to the many supporters who year after year continue to make contributions and raise money via fund raising events.

Special thanks go to all for your generosity and to all those who sent cards, letters and good wishes in the run up to Christmas.

A Happy New Year to all our readers.

I hope that you all enjoyed Christmas and the New Year celebrations and the variety of family, leisure and social opportunities that accompany the festive season.

During 2008, despite long term and ongoing health problems with some committee members we have managed to maintain an active involvement in working with national initiatives to ensure the needs of Gorlin Syndrome individuals and their families are included in national consultations, discussions and policy development.

Unfortunately we have been unable to organise our usual annual patient conference, but if all goes to plan we hope to be back on track next year.

We are very keen to hear from anyone who is interested in helping us run the group and arranging the meetings. If you feel you could offer the time please contact Margaret or me and we would be happy to discuss further. Our next AGM is planned for 24th January 2009 in Manchester. (See page 2 for details). Why not come along and see what is involved?

Hope you find the contents of the newsletter interesting, especially Helen's summary of the GIG conference, also if you have not already; do check out the new website so skilfully produced by both Margaret and Helen.

On behalf of committee members I wish you all the very best for 2009.

Sally Webster
Chair

Check out the website at www.gorlingroup.org
A discussion forum has been re-introduced and can be accessed by clicking on 'Forum' on the menu. Some interesting topics have been posted. If you wish to post comments or respond to any postings register on-line to get started

Employment & Support Allowance

In October 2008 a new benefit, the Employment and Support Allowance was introduced. It is a benefit for people who have a limited capacity for work, and under the previous system, would have claimed Incapacity Benefit or Income Support. ESA is paid at two different levels; at the lower rate during the assessment period, and then one of two higher rates. Jobcentre Plus assesses eligibility for ESA and if accepted people who have a limited capacity for work will receive one of the two rates.

- The 'support group' – for people considered severely disabled.
- 'Employment related activity group' – for everyone else. In this group people will attend regular work-focussed interviews aimed at improving the chances of eventually moving into work.

Employment and Support Allowance can be claimed from the age of 16 years.

Contact a Family have a free telephone helpline 0808 808 3555 – call them for information or detailed advice on ESA or contact Job Centreplus.

Annual General Meeting

The AGM will take place on Saturday, 24th January 2009 at 1.00 pm at the NOWGEN Centre, 29 Grafton Street, Manchester M13 9WU. Grafton Street is adjacent to the University of Manchester and Manchester Royal Infirmary just off Oxford Road. Pay and display multi storey car parking is available on Grafton Street.

We are very conscious that no patient meeting has taken place since 2006 and for this reason we feel this is an ideal opportunity to invite you to join us for lunch and the AGM. Once the formalities of the AGM are out of the way there will be a chance to catch up with others and meet with committee members.

We are looking to recruit additional committee members to assist in the work of the charity but don't let that put you off coming, we won't be putting pressure on anyone.

Anyone wishing to join the committee needs to be willing to give time to actively participate in the efficient administration of the charity and the fulfilment of its aims.

Committee members are volunteers; many work full time and have family commitments. With this in mind and given the geographical spread of members a good deal of our work is carried out electronically or over the telephone, with the exception of attendance at 2 or 3 meetings annually and for which expenses are paid.

We are accepting expressions of interest and nominations ahead of the AGM. Anyone interested in becoming a committee member and would like more information then email margaret.costello@gorlingroup.org or telephone on 01772 496849.

Come along at 1.00 – 4.00 pm but be sure to let Margaret know you are coming so that enough refreshments are available for all.

We look forward to meeting and welcoming you.

Tackling Disabilist Bullying

Contact a Family in conjunction with Parentline Plus have produced a new guide about dealing with bullying for parents of disabled children.

For information visit www.cafamily.org.uk

GIG – Choices and Challenges of Reproductive Health - October 6th 2008

As a trustee of the Gorlin Syndrome Group I was lucky enough to attend GIGs Choices and Challenges of Reproductive Health conference in London.

I found the day extremely interesting and informative. It was also beneficial networking with people from other support groups, genetic counsellors and health professionals.

There was also a great deal of positive feedback from the Family Route Map that I had taken down with me. I really enjoyed the day and gained a lot of knowledge of developments in this area.

Presentations were given by the following professionals:

- **Dr Lynn Chitty – NIPD (Non Invasive Prenatal Diagnosis)**
NIPD is a relatively new technique which involves the testing of fetal DNA from a sample of maternal blood. This has potential to improve various forms of antenatal testing for genetic conditions. It will come under close scrutiny over the next couple of months as the technology develops.
- **Alison Lashwood – Centre for PGD, Guys & St. Thomas' Hospital**
PGD is a process that involves testing embryos for genetic single gene or chromosome disorders.
- **Dr Ainsley Newson – Lecturer in Biomedical Ethics at Bristol University**
Ethics is a big part of any prenatal diagnosis. Her presentation was about the existing ethical debates surrounding PND and PGD.
- **Cara Scott – ARC (Antenatal Results and Choices)**
ARC has been running for 20 years and supports patients through screening and testing. They are an independent source of information that compliments the work of health professionals.
- **Dr Hilary Burton – Consultant in Public Health (PHG Foundation)**
Inherited disorders – A challenge for Health Services
Ran through the reviews they have undertaken in the last 12 months, what the new health needs are, what patients want, what we have now and what needs to happen in the future.

After the conference I wrote a report all about the presentations that were given. If you would like to read the full report it can be found on our website.

Helen Costello

Trustee

Gorlin Syndrome Group

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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

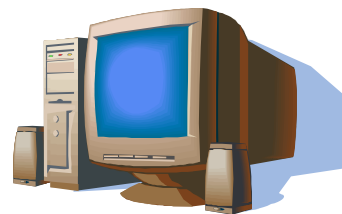
Helen Costello

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

We are grateful for their continuing support.

Raising funds with eBay

Treasurer John Dooher reports that the group's finances are in good shape. However, it is important that we look at all possible sources of income. John has set up an account on eBay which will enable people to make contributions to group funds.



By selling things on eBay it is possible to divert between 10% and 100% of the sale price to the Gorlin Syndrome Group. To register go to <http://www.ebay.co.uk/> Fill in the form (you'll need to decide on a 'User ID' and a password) and click 'Register'. This takes you through the process of setting up an eBay account and enables you to sell your goods and make contributions. A detailed explanation on how to register and sell goods is available on eBay.

Partnership with Freedom Insurance



Earlier in the year we entered a partnership agreement with Freedom Insurance. For each travel policy sold a donation is made to the Gorlin Syndrome

Group. A copy of the Freedom newsletter is enclosed for your information.

Walk for Skin

In 2008 a series of walks organised by the British Skin Foundation took place at nine venues to raise funds for research into skin disease and patient support groups. We were delighted to receive a cheque for £386.50 from the organisers. The amount was raised by those taking part and who opted for 50% of their sponsorship to be committed to Gorlin Group funds.

Planning is underway for similar events in 2009 and we have registered as an affiliated patient support group meaning that walkers can again donate 50% of what they raise through sponsorship to us.

Detailed information about these events is expected in the New Year. We'll keep you updated.

Until the next time, keep well and keep smiling!

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