

News & Views

November 2007

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The Gorlin Syndrome Group is eager to recruit additional committee members and/or Trustees to assist in the development and work of the charity. People need to be willing and able to give time to actively participate in the efficient administration of the charity and the fulfilment of its aims and objectives.

Committee members are volunteers; many work full time and have family commitments. Geographical spread of members means a good deal of our work is carried out electronically or over the telephone, with the exception of attendance at approximately 3 meetings a year for which expenses are paid.

The group is now accepting expressions of interest and nominations ahead of the AGM to be held at the George Hotel in Cheltenham on 26th January 2008. If you feel you would like to be involved or require further information, please contact Margaret Costello via email or telephone.

Warm greetings to all.

Hope this newsletter finds you keeping as well as possible, enjoying the crisp winter days and not too many wet and cold ones.

Reflecting on what we have achieved in 2007 feels strange as the year seems to have gone so quickly. Much work has taken place to promote awareness of Gorlin Syndrome with Dermatologists, Plastic surgeons, specialist skin nurses, and other health and social care providers, to ensure prompt diagnosis and choice of appropriate treatments and care are available to all as far as possible. The work is underpinned by the extensive and comprehensive website that serves to inform individuals and their healthcare professionals of the current research and treatment options and considerations.

Despite NICE guidance recommending standards for treatment we continue to hear of totally unsatisfactory treatment and care packages. We continue to voice these issues and are working with the Skin Care Campaign to highlight these issues and lobby for improved service delivery. Please continue to let us know if you are unhappy with your care or treatment for Gorlin Syndrome.

From inception of the group there has always been an annual conference to provide information, and enable individuals to network and share experiences. Historically these were held in the North West. Last year we held a successful meeting in Oxford and were planning to be back in the North West in October 2007. Unfortunately not enough people booked on to make the conference viable, so we had to cancel. We are not sure whether you feel annual meetings are no longer necessary given the information available on the website or whether you prefer more meetings should be held in the Midlands or South? In order for us to provide for your needs we will send an anonymous questionnaire in the new year to help direct us.

On behalf of the Committee, we wish you all the very best at Christmas and a peaceful New Year. Take the best of care

Sally Webster
Chair

“A Life Sentence”



Tramuntana Mountains, Mallorca 07

A couple of years ago, when I was going through a bad patch my GP told me “Sharon, Gorlin Syndrome is not a death sentence, it’s a life sentence, how you live that life is up to you”.

Although I didn’t think so at the time, he was right. A lot of people wouldn’t agree with how I live my life, some of my doctors and specialists included, but for me it’s the best way I know how. I would die cooped up in an office, doing what I do helps me to deal with the never ending checkups, treatments, and operations and all the emotional turmoil that goes with it.

So, what do I do??? Well, as of April last year (2006), I run my own business. I decided to combine all of my skills and put them to use doing things I enjoy and getting paid for it (every kid’s dream). I work as a Mountain Guide, leading adult groups on walking holidays, as an Overseas Expedition

Leader, doing personal development with young people. When I’m in the UK, infrequently these days, I teach and assess first aid and work with disaffected youth.

In between all that I fit in checkups, treatments, and one operation a year where they remove multiple BCCs. I decided a couple of years ago that Gorlin would have to fit into my life not the other way around. This was not the case and I had five operations in one year and was going down hill mentally and physically. I had a choice, fight or lie down and apart from one stupid occasion I have never been one to lie down.

Like anyone, especially those with long term conditions, I have my good and bad days. Things get me down, financial worries (being self employed is no bed of roses), another operation coming up, the usual stuff. But I’m lucky, not everyone can say they enjoy their work, but I feel very passionate about what I do, whether leading an adult group in the mountains, guiding a group of young people on expeditions worldwide, teaching first aid, or showing a young person with “issues” new ways to deal with those “issues”.

I also have some good friends. When I was young I was always a bit of a loner but I’ve learnt that I need people like anyone else and I cherish the few close friendships I have now.

So, what am I trying to say??? I guess it’s that however you choose to live your life, live it to the full and enjoy. Don’t ignore the Gorlin, tried that, it won’t go away but neither let it control you. It is part of you, not all, and with the right treatment and a good relationship with the people treating us we can all live out our “life sentences” to the full.

Sharon Hobson
October 07

Thank you for sharing your story with us Sharon and every credit to you! We are extremely grateful for your contribution. If others out there have a story to tell, kindly forward to the Gorlin Syndrome Group.

Genetics Education

The results of the National Genetics Education and Development Centre study to find out about people's experiences of receiving genetic information from health care professionals are now available. The findings from the study are that the people interviewed for this project:

- Believed that there is a need for greater awareness of genetic aspects of conditions amongst healthcare professionals, who should be more willing to consider the possibility of a genetic condition, refer patients appropriately and take their concerns seriously.
- Wanted healthcare professionals who provide genetic information to do so without judgement; to be mindful of their use of terminology; to tailor the information to the preferences of individuals; and to inform people where they can access further information. They felt that healthcare professionals should be aware that genetic information can have an emotional impact on individuals and may affect the wider family.
- Saw the GPs role as referring patients appropriately and providing ongoing support and coordination. They felt consultants in different medical specialities could play a greater role in providing genetic information. More support from healthcare professionals in gaining access to appropriate genetic information would be welcomed.

The report ISBN 978 0 9556680 0 5 can be obtained from:
The NHS Genetics Education and Development Centre
Morris House
c/o Birmingham Women's Hospital
Edgbaston
Birmingham B15 2TG

British Skin Foundation – Walk for Skin

The GS Group is teaming up with the British Skin Foundation Walk for Skin events taking place April - June 2008. Nine walks are planned. The aim of the events is to raise funds for British Skin Foundation Research Projects and for Patient Groups taking part. Information is expected in January and will be included in the next newsletter. This is an opportunity to raise funds for research and to ensure the continued work of Patient Groups supporting patients.

Thank You

Special thanks to the Thorndale family of Northampton and Ms Robertson of London for recent donations. Thanks also to John Pismeny and Yorkshire Water WaterWheelers for the donation of £100.00. A Sunday Lunch event hosted by Pat, friend of Clare Bean (group member) of Middlesex raised £129.04. Thank you Pat and Clare! We are grateful for all donations.

Newsletter Feedback

Following inclusion of the article 'A Matter of Choice' in the August newsletter two people have responded with their views.

The first wrote "I too am diagnosed with GS and had numerous operations on jaw cysts and BCCs. I am also pregnant with our third child. The thought of not having any of my children based on the notion that they may or may not have the condition is incomprehensible".

The other wrote "I have a comment to make about the gentleman who wrote a piece about trying for a family. I was diagnosed with GS at age 11, and have had many operations for jaw cysts and BCCs. I had consultation with the Geneticist about starting a family...This whole thing makes me feel strange to think that had the technology been around at the time I was in the womb and my mother aborted me, I might not be here to tell the tale. I'm in a job I enjoy, doing an Open University degree, and consider myself lucky. I'm not saying this man was wrong I just wanted to air my view!"

The article related to choices available and the decision the couple made. It is recognised their choice would not suit all. The Gorlin Syndrome Group remains impartial and respects individual views and choices made.

Sandra's Sponsored Slim

In the weeks to 29th Jan 2008 Sandra of Cornwall looks to lose 3½st prior to surgery and is seeking sponsorship. Her weight will be monitored at Slimmer's World as she sheds 'pounds' off her target weight. Update in next newsletter. Good luck Sandra and thanks in advance for sponsorship.

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

Maureen Gregory – Treasurer

Margaret Costello – Secretary

Carolyn Deveney

John Doohar

Vicky Gill

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

We are grateful for their continuing support.

Annual General Meeting

The Gorlin Syndrome AGM will take place at The George Hotel, St. George's Road, Cheltenham GL50 3DZ on Sat. 26th January 2008 3.30 pm. The Agenda will be as follows:

1. Opening of Meeting
2. Apologies for Absence
3. Minutes of the 2006 Annual General Meeting
4. Annual Accounts
5. Appointment of Auditor
6. Trustees' Annual Report
7. Election of Trustees
8. Any other business

An open invitation is extended to group members with an interest in the work of the group and to those who have been nominated for election.

Human Genetics Commission

A recent consultation by the Human Genetics Commission found that a number of people had personal experience of discrimination because of their genetic status and more feared such discrimination in the future. The Government is committed to introducing legislation to consolidate discrimination law in a new Single Equality Act. Following consultation, reflection and discussion the Commission will contribute to the Review of Discrimination Law and call for the Bill to include a prohibition on unfair discrimination on grounds of genetic difference. The full response to the review can be read of the HGC website www.hgc.gov.uk

Questions to ask: getting the most out of your appointment

The Department of Health has produced a leaflet to help you get the best out of your appointments. Receiving and understanding the right information during an appointment is key to involving you in decisions about your treatment and care. The leaflet supports patients by helping with general questions during a consultation. Pick up a leaflet at your local medical centre or GP Surgery. View at: www.dh.gov.uk/en/Publicationsandstatistics by searching 'Questions to Ask'

Changing Faces Survey

Changing Faces supports and represents people affected by disfigurement. In November they undertook the biggest survey that has taken place in the UK to find out what it is like for people with a disfigurement at secondary school and work. The findings will give the charity the evidence it needs to make teachers, employers and policy makers in the government aware of the way that school pupils and employees are treated. www.changingfaces.org.uk

Gorlin Syndrome Family Route Map

The work on the Family Route Map in conjunction with GIG is progressing nicely. It is anticipated that the completed document will be launched and distributed in the New Year. This will be a valuable resource for patients, their families and carers.

