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Congratulations and very best wishes to Mick and Laretta Chester. They were delighted and proud to welcome their first grandson on his arrival over the Christmas / New Year period.

The AGM on 24<sup>th</sup> Jan 2009 took place at the NOWGEN Centre, Manchester.

No nominations to join the committee were received. Sally and Margaret were re-elected Chair and Secretary respectively for a further three year period and John Doohar was appointed to the role of Treasurer having 'acted up' since resignation of last Treasurer.

Annual Report and Financial Accounts for 2007-2008 were presented by John and the minutes of the last meeting were accepted as an accurate record.

It was pleasing to welcome those who took time out of their weekends to be there. We value your participation and enjoyed the opportunity to catch up. It was good to see you.

*Margaret Costello*

Dear newsletter reader current and new

Welcome to our spring 2009 newsletter. We are pleased to announce the 2009 patient conference on Saturday 24 October 2009. This year will be in Birmingham which will hopefully enable many people to attend.

As with our previous conferences we will hear presentations from medical speakers to help us further understand the condition, treatments, the implications and treatments for the future. There is always plenty of opportunity to ask questions or leave questions anonymously for the panel to answer. Once again we look forward to welcoming Professor Peter Farndon, Consultant Clinical Geneticist and Medical Advisor for the group.

One of the most enjoyable aspects is the opportunity to meet old friends and welcome new attendees and members.

Only individuals, family members or close friends of those affected by gorlin syndrome can really understand and relate to the frustrations and practicalities of dealing with the condition. Its also great fun to catch up on life in general.

It would be fantastic to see as many people as possible.

Please see the section in the newsletter and return your booking form as soon as possible.

With best wishes

*Sally Webster*  
*Chair*

On behalf of the Executive Committee and members of the Gorlin Syndrome Group we offer sincere condolences to Professor Peter Farndon on the recent death of his mother. Our thoughts and prayers are with Peter and his family.

## NHS Constitution

Lord Darzi's review of the NHS, 'High Quality Care for All' concluded last summer that there was a case for an NHS Constitution to enshrine the principles and values of the NHS in England. The constitution puts in one place what patients, staff and the public can expect of the health service. The Constitution, the first of its kind in the world, was signed by Prime Minister Gordon Brown, Health Secretary Alan Johnson and NHS Chief Executive David Nicholson.

It brings patients existing rights together in one place so they know what they are legally entitled to, how they can exercise their rights and understand their responsibilities. It also contains a range of pledges to patients, public and staff, which the NHS is committed to achieving.

For further detail visit:

<http://www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm>

## Prescription Charges

With effect from April 2009 cancer patients in England will no longer pay prescriptions charges. At this stage it is unclear whether the exemption will apply to Gorlin Syndrome patients. We will be checking this out and keeping everyone updated but it may well be worth checking with your GP.

## Surveillance

*In recent months a number of people have been in contact to enquire about the frequency of surveillance. Recommended guidance is included below.*

**During pregnancy** – most babies with Gorlin Syndrome have large heads and so may need assistance in delivery either by forceps or by Caesarean section. An ultrasound scan may help in predicting this.

**Neonatal physical examination** – when the baby is born, it may be apparent that he / she has a larger than average head circumference which would raise the suspicion that the baby had inherited the condition. In these cases ex-rays may confirm bifid ribs or vertebral anomalies.

**Childhood** – annual dental screening should commence from about 8 years for the detection and early treatment of jaw cysts. There is also a need for at least annual surveillance from the specialist taking responsibility for the treatment of the skin.

**Adults** – should inspect their skin regularly. Annual surveillance of the skin by a Dermatologist or Plastic Surgeon is recommended and dental screening should continue into adult life, its frequency depending on the findings of each x-ray. New jaw cysts seem to slow after the middle thirties. It is unusual (but not impossible) for cysts to appear after this age.

**Treatment Priorities** – to ensure effective management of Gorlin Syndrome it is vital that patients are treated in the early stages and for this reason regular surveillance is recommended to ensure:

- Prompt treatment for best cosmetic effects
- Eradication of aggressive basal cell carcinomas
- Particular attention to individual lesions occurring around the eyes, nose, mouth and ears
- Preservation of normal tissue to prevent disfigurement
- Early detection and surgical excision of jaw cysts.

It is highly recommended that patients with Gorlin Syndrome are seen regularly by an experienced Dermatologist.

Discuss treatment options with your specialist to ascertain which would best suit your situation and give the best outcome.

**If you have problems accessing timely surveillance and treatment speak to your Consultant or GP. If the problem persists let us know as we are in a position to offer advice or guidance in this area.**

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### Annual Patient Conference

We are pleased to announce that planning for the return of the patient conference is well underway. This year the event will take place at the Britannia Hotel, New Street, Birmingham on Saturday, 24<sup>th</sup> October 2009 between 9.30 am and 4.00 pm.

The hotel is in a superb location in the heart of Birmingham city centre and is close to motorway networks and just minutes from New Street Railway Station. The Britannia has 195 bedrooms and offers value and comfort to guests. Single, double and twin rooms are available starting from £40.00 per night, with family rooms available from £50.00 per night. Room bookings should be made direct with the hotel either on-line at [www.BritanniaHotel-Birmingham.co.uk](http://www.BritanniaHotel-Birmingham.co.uk) or by telephone (44) 0871 702 9712.

The programme is yet to be finalised but there will be a range of speakers, i.e. genetics, dermatology etc. This will allow people the opportunity to listen to presentations and to ask questions about the condition.

The event also provides people with the opportunity to meet and network with other patients and families affected by Gorlin Syndrome, and to spend time with them on a social level.

A booking form is attached. Kindly ensure completed forms are returned electronically or by post (see page 4 for return address) by Friday, 2<sup>nd</sup> October 2009 so that final arrangements can be made with conference staff.

We look forward to welcoming you to this important event.

### Prescription Charges Review

In January we received notification from the Dept of Health that people with cancer can apply for a 5 year exemption of prescription charges with effect from 1<sup>st</sup> April 2009.

Additionally, we are advised that over the next few years the exemption charge will also be extended to people affected by long term conditions. The Minister of Public Health asked Professor Gilmore of the Royal College of Physicians to undertake a review of current prescription charges to consider how the exemption for people with long term conditions could be implemented. We have submitted a written response to the review supporting the principle of exemption charges for patients affected by Gorlin Syndrome.

### NICE Consultation

In March the National Institute of Clinical Excellence issued for public consultation the work commissioned on behalf of the DH to develop **public health intervention guidance** for the NHS and local authorities on the prevention of skin cancer in the general public with specific reference to the **provision of information**.

Initial consultation took place last summer and it is pleasing to note that many of the observations and comments by healthcare professionals and patient groups were taken on board and are included in this first draft scope. Other areas of work are expected over the coming months to include:

- Physical changes to the environment
- Supply of sun protection resources

We will be submitting written responses on behalf of Gorlin Syndrome patients.

### Rare Disease Day

Rare Disease Day - 28<sup>th</sup> Feb 2009 was celebrated by many countries around the world. Trustee, Helen joined many other patient representatives, Members of Parliament and the Genetics Interest Group (GIG) at an event at the Houses of Parliament on 25<sup>th</sup> February.

Helen enjoyed the day and reports on the usefulness of the event in raising awareness of rare conditions and driving forward the proposed National Action Plan for Rare Diseases in the UK. Similar events took place at the Scottish and Welsh Assemblies in the first week of March.

## 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 Doohar – 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.*

## Walk for Skin

Regular visitors to the website will be aware that details of the British Skin Foundation Walk for Skin events are now available.

We have again registered as an affiliated patient support group meaning that walkers can donate 50% of the sponsorship they raise to the British Skin Foundation and the other 50% to the Gorlin Syndrome Group.

This year 11 walks are planned and will take place at venues across England, Scotland and Wales in May and June. The enclosed leaflet provides full details of the walks and registration.

Last year we were delighted to receive sponsorship to the value of £386.50. On behalf of committee members of the Gorlin Syndrome Group and the British Skin Foundation we thank you in advance for your continuing support.

## Getting Help with NHS costs

The NHS Low Income Scheme provides help for people who don't automatically qualify for help with health costs, i.e. free sight tests, towards the cost of glasses, free prescriptions, free dental treatment and help with fares to hospital.

People are entitled to help with NHS costs if they are receiving Guaranteed Pension Credit, Income Support or Income-based Jobseeker's Allowance. The help is also available to those claiming Child Tax Credit, Child Tax Credit and Working Tax Credit and Working Tax Credit that includes a disability or severe disability element, providing income for tax credit purposes is £15,050 per year or less. Assistance is not available to those with savings over £16,000.00.

**To claim under the Low Income Scheme:** complete form HC1, which is available from your local social security office, some GP's, dentists and opticians and send it to the Health Benefits Division. If you need help completing the form you can contact the Health Benefits Division on 0845 850 1166, or to request the form HC1 call the Health Literature line on 0800 555 777.

Further info is available at

[http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public\\_health\\_benefits.hcsp#P4\\_294](http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public_health_benefits.hcsp#P4_294)

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