

Get A-Head Patient Group Message

In this issue we have another 'Patient Story'. Her story is an adaptation of excerpts taken from her personal journal. A journal she started to record appointments, treatments and, what has become most important, her emotions. It helps her to look back, make sense of and move on as a cancer survivor.

The **GAP Newsletter** is written for you, we therefore ask you to send us:-

- Your stories of being affected by head and neck disease (including cancer), either as a patient, family member or friend.
- Your clinical questions to publish and provide answers from the many professionals willing to contribute.
- Details about fund raising events that you have organised or know about and meetings or existing groups you are aware of so that we may share the information for others to benefit from.

We invite you to attend informal gatherings, formal meetings and social events.

We provide you with feedback on past events and welcome your comments whether you attended or not.

We want to know what we are doing right and what we can improve on.

Please register your interest to be a supporter of the GAH Patient Group. Contact the GAH office.

A Patient's Story

'I am a thyroid cancer patient (follicular) diagnosed 2011 and my article is about my decision to not tell my children. I was told by more than a few people close or otherwise I was in the wrong but it was my decision and they are my children so I knew how they were likely to react. If they had to know they would have done but there was no need with the outcome looking bright.

My oldest had started A-levels, my daughter doing her G.C.S.Es, my 3rd had just started secondary school and the youngest doing S.A.T.S. When I was told my first instinct was not to tell them but a lot of thought went into it and it meant not telling many people at all just close trusted ones who were told the children were not to know, so my journey was rather private as a result, which in away helped as I didn't have the questions etc.

My boys still don't know as I am not sure how to bring it up now, I must explain they knew everything about the lump, operation, even the radiation to get rid of cells. The radiation therapy was turned into a joke with the comparison to a character off the Simpsons 😄

My daughter was told about a year after as she became very involved with Get A-Head, with helping and raising money. She was fine when I told her even though I was worried about her reaction. I am sure at some point I will bring it up with my boys.

Please follow your journey how you wish to not how other people tell you to. This was the right decision for me and my family and I am glad that is how I took it'

Invitation to.....

GET A-HEAD PATIENT GROUP

A Cancer Charity Fighting all Head & Neck Diseases



Come join us for an informal evening, to share experiences, information and socialise.

Meetings are held on the 1st Wednesday of February, May, August and November.
Time: 17:00 to 19:00

Outpatients Dept. Area 2, Queen Elizabeth Hospital, Edgbaston, Birmingham, B15 2TH

Dates for your diary are:

Wednesdays

- 4th November 2015
- 3rd February 2016
- 4th May 2016
- 3rd August 2016
- 2nd November 2016



CHRISTMAS PARTY

For patients and their family and friends
Friday 11th December 2015 19:00-23:00

This year's party will be at the Edgbaston Priory Club. Join us for a free fun-filled festive celebration, with live entertainment from The Hurling Boys. There is no charge for this event and we hope that many of you will attend. Please book via the Get A-Head office



Past Patient Group Information and support meetings

**Patient Group
Information and Support Meeting**

**Saturday 7th November 2015
11:00 to 13:00**

At
**Yardley Baptist Church, Rowlands Road,
South Yardley, B26 1AT**

- Off the A45 Coventry Road
- Free Parking Available

**Guest Speaker
Dr Carla Moran**

Locum Consultant Endocrinologist
University of Cambridge, Metabolic Research Laboratories

**'Dr Moran's Current Thyroid Research,
The Thyroid and Its Function'**
Followed By
Question and Answer Session

Contact
Janet Prentice, British Thyroid Foundation Local Coordinator and Chair of Patient
Group Committee - Get A-Head Charitable Trust. Tel. 0121 628 7435 Email:
janetdmp@gmail.com

**The Get A-Head Patient Group, On Behalf of the Get A-Head
Charitable Trust Registered charity no. 1118326**
Room 23F, 4th Floor, Nuffield House University Hospitals
Birmingham NHS Foundation Trust Queen Elizabeth Hospital, Queen
Elizabeth Medical Centre, Birmingham, B15 2TH

Tel: +44 (0) 121 371 5047 Email: getaheadcharity@uhb.nhs.uk
Web: <http://www.getahead.org.uk>

Disclaimer
Whilst every effort is made to provide correct information it is not possible to take account of every
individual situation. It is therefore recommended that you check with a member of the medical
profession before embarking on any treatment other than that which has been prescribed for you by
your doctor.



Saturday 18th April 2015

On behalf of the GAH and British Thyroid Foundation I'd like to offer thanks to guest speaker **Mr Huw Griffiths** (Consultant ENT Head and Neck Surgeon at Heart of England NHS Foundation Trust. Honorary Consultant at University Hospital Birmingham, Clinical Director and GAH Trustee). He provided a very interesting presentation on 'Thyroid Surgery'. We learnt about the history of Thyroid surgery demonstrating the vast ongoing improvements. Mr Griffiths provided information on the different thyroid conditions that require surgery for diagnosis and treatment. With the benefits of surgery explained he also highlighted the possible short and long term side effects of surgery. His presentation generated many questions from the audience which he was happy to answer.



Saturday 5th September 2015

On behalf of the GAH and British Thyroid Foundation I'd like to offer thanks to Dr

Kristien Boelaert (Reader in Endocrinology, Consultant Endocrinologist University of Birmingham and GAH Trustee) who on Saturday 5th September 2015 was guest speaker at Yardley Baptist Church, Rowlands Road, South Yardley, B26 1AT. She presented a talk on 'Hyperthyroidism and Graves Disease'. The presentation covered a wide range of topics; thyroid function, the different types of overactive thyroid diseases, their differences, other autoimmune disorders and comorbidities most likely to already exist or develop. Dr Boelaert described the risks of treatment associated with pregnancy which included the fathering of children. After the presentation Dr Boelaert stayed to answer questions and have a chat with members of the audience.



On the 10th July 2015 the 'Under the Sea' charity ball presented a great opportunity for GAH Patient Group supporters to get together and have some fun. With our table filled with willing guests, half of the ticket cost raised £200 to go towards the cost of the Patient Christmas party on the 11th December 2015.

We were greeted at the door and on the red carpet with bucks fizz by Shirley Sea Cadets. Together with the themed decorations it set the mood for a fun filled enjoyable evening.

Earlier in the year the Shirley Sea Cadets had use of the GAH Kayak to raise much needed funds for themselves and enabled them to make a generous donation to the GAH charitable trust. The ball presented an opportunity for Mr Huw Griffiths, ENT surgeon and GAH trustee, to receive the cheque on behalf of GAH.



Question & Answers

Disclaimer: Your clinical questions are answered by health care professionals. Whilst every effort is made to provide correct information it is not possible to take account of every individual situation. It is therefore recommended that you check with a member of your health care team before embarking on any treatment other than that which has been prescribed for you by your doctor.

With no new questions provided for this newsletter I have included one from the last newsletter. No question is too silly, our professionals are very happy to answer any questions within their professional capacity and area of expertise.

Question

'I was diagnosed with an underactive thyroid when I was pregnant with my first child. Attempts to get pregnant again have failed. Having read the BTF literature I believe that my TSH, at 3.8 whilst in the normal range, is too high for trying to get pregnant. My GP has reluctantly agreed to increase my levothyroxine but has suggested that my infertility has nothing to do with my thyroid disease. Please clarify and advise?'

Answer

Current international guidelines indicate that in patients with treated hypothyroidism the target serum TSH should be less than 2.5 mIU/l pre-pregnancy and less than 2 mIU/l in the first and second trimester. A TSH of 3.8 is too high in this situation. Even slightly raised serum TSH concentrations have been shown to possibly impact fertility and pregnancy complications although the evidence is not all consistent. Consider discussing with your GP a request to refer you for pre-pregnancy counselling either jointly with an obstetrician and endocrinologist specialising in thyroid disorders or just with the endocrinologist at a thyroid clinic

Editor's Choice...

The Independent Cancer Taskforce have published its 2015-2020 strategy for improving cancer outcomes in England over the next five years.

By making the changes suggested in its report the Taskforce estimates that, by 2020, the NHS could be saving 30,000 more lives each year. Strategies like this are important. They set ambitions and dedicate resources in the right places across the NHS to improve things for patients – something that's been recognised at the highest level: the World Health Organisation believes that all countries should have a plan for cancer. And over the years, there's evidence that previous strategies have made a big impact.

Cancer Research UK are campaigning for each UK nation to have up-to-date cancer strategies. Their chief executive, Harpal Kumar, chaired the Independent Taskforce and has blogged about what he sees as the strategy's six priorities:

1. A renewed focus on prevention and public health
2. A national ambition to achieve earlier diagnosis
3. Establishing patient experience as being on par with clinical effectiveness and safety
4. Transforming support for people living with and beyond cancer
5. Investing in modern high-quality services
6. Overhauling the way the NHS commissions and provides services

Cancer Research UK are strongly backing the strategy, particularly its focus on better prevention, swifter diagnosis and modernising the NHS to provide better access to treatments. There are a lot of challenges ahead, but there are two crucial things that need to happen. First, the organisations that lead the health service need to develop clear, detailed plans for putting the Taskforce's recommendations into practice. And second, the Government needs to invest the money to make it happen.

together@cmail.news.cancerresearchuk.org Category: Science blog August 3, 2015 Emlyn Samuel

News from the Get A-Head Charitable Trust.

Get A-Head is a charity based in Nuffield House, QE Hospital, Birmingham. The charity seeks to raise money to assist the work in the field of Head and Neck cancer in as many ways as possible. Since the last newsletter Get A-Head have been able to provide funding for the following:-

- ✚ A Grant for a research doctor to undertake a research project in conjunction with the Sydney Head & Neck Cancer Institute, Australia. The research project will be investigating papillary thyroid cancer and providing evidence to guide treatment in resistant disease.
- ✚ A Grant for a Consultant in India, who works for the Christian Medical College training new doctors, to attend the BACO2015 conference in Liverpool. The conference will allow him to keep up to date on the latest practices in Head & Neck Surgery.
- ✚ A Grant for the Speech & Language Department of Sandwell & West Birmingham NHS Foundation Trust to purchase six electro-larynxes for use by patients who have had their larynx (voice-box) removed during surgery. This will greatly improve the quality of life for patients.
- ✚ A Grant for University of Birmingham to continue their work researching Medullary Thyroid Cancer and developing personalised treatment strategies.
- ✚ A Grant to pay for Speech & Language Therapists from Birmingham Heartlands Hospital to attend the European Head and Neck Cancer Course- Speech & Language Therapy Masterclass.
- ✚ A Grant for a Head & Neck Clinical Nurse Specialist at Queen Elizabeth Hospital to attend a study day entitled Sharing Good Practice in Head & Neck Cancer Nursing. This day will allow her to keep up to date with new best practices & research.

For more information on these and other Grants please call the office on 0121 371 5046.

Patient Group Committee

The committee members meet as often as possible to discuss ways in maintaining and improving the service provided for patients from a non-clinical point of view.

We are always looking for new patient members to join the committee and would love to have a variety of Head and Neck diseases represented.

We all volunteer our time maximising our skills in whatever we can for the benefit everyone concerned.

Please contact the office if would like to learn more.

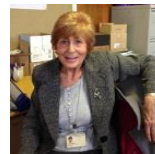
Current members:



Janet Prentice



Loretta Webb



Fran Gurney

Kellie Maddison

Maria Caprano-Wright

FEEDBACK to the Patient Group will help a great deal. You may have ideas for the Newsletter or for meetings. You may want to be put in touch with committee member volunteers, if so, please contact the Get A-Head office either by email, telephone or by post:

getaheadcharity@uhb.nhs.uk

Tel: 0121 371 5046

Get A-Head Charitable Trust,
Room 23F, 4th Floor, Nuffield House, Queen Elizabeth Hospital, Birmingham, B15 2TH