

Get A-Head Patient Message

The Get A-Head (GAH) Charitable Trust Patient Group is growing and this edition introduces a new key figure in Dr Sunil Handa. Read about his reasons why he has volunteered his time and what he hopes to bring to the group.

In the last edition we published details of informal gatherings and formal meetings involving a range of clinical guest speakers. If you attended any of these events please let us have your feedback? We want to know what we are doing right and what we can improve on.

The **GAP Newsletter** is written for you. We therefore need your stories of being affected by head and neck disease (including cancer), either as a patient, family member or friend. We want to publish your clinical questions and provide answers from the many professionals willing to contribute. Let us know 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.

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

Janet



Dr Sunil Handa

"My name is Sunil Handa and I am 57 years old. I am of Indian origin and was born in Nairobi, Kenya and came to the UK in 1975.

I studied Medicine at Leicester Medical School and qualified in 1982. I worked up the career ladder as a junior doctor working in 8 cities in total (Leicester, London, Birmingham, Edinburgh, Aberdeen, Stoke-on-Trent, Manchester and Wolverhampton). I was appointed to my first Consultant post at Sandwell General Hospital, West Bromwich as a Haematologist in February 1993. After 10 ½ years there, I moved to New Cross Hospital, Wolverhampton for a further 10 ½ years. I took early retirement on the grounds of ill-health at the beginning of this year after more than 31 years as a full-time doctor, of which the last 21 years were as a Haematologist.

I have a long association (since September 1998) with the Maxillo-Facial ("Max-Fax") Surgery Dept., initially at Selly Oak Hospital and latterly at the Queen Elizabeth Hospital. I have 2 relatively rare conditions affecting the oral lining (Leucoplakia and Lichen Planus) both of which pre-dispose one to cancer of the oral cavity. I had 3 previous operations (Sept. 1998, Dec. 1998 & summer 2003) which were relatively minor and only one of which showed early cancerous changes but was completely removed. Last year on a routine 6-monthly visit to the Max-Fax clinic, I was noted to have a suspicious looking lesion in the empty socket of a molar tooth. It was biopsied there and then found to be cancerous. I had major surgery with reconstruction (with a bone in the lower leg (the fibula) used to reconstruct half the lower jaw which had to be removed) resulting in a 5 day stay in the Critical Care Unit. Because the tumour was large and invading the jaw bone, I also had 6 weeks (30 treatments) of radiotherapy ending at the end of September. The treatment and care I received from the Max-Fax Department can only be classed as "World Class". They have done such a professional job of the surgery and reconstruction that no one can tell the magnitude of the surgery I have had.

There have also been several members of my family, in-laws, friends and acquaintances who have had cancer of the Head and Neck region. Although individually these cancers are rare, collectively they form a substantial burden.

I heard about the "Get A-Head" charity from one of the nurses while I was an inpatient on Ward 408 (a delightful Irish nurse, Sophie, who planned to climb Mount Kilimanjaro to raise money for Get A-Head). I resolved to work tirelessly for this charity after I had recovered from the very unpleasant and debilitating side-effects of the radiotherapy. To this end, I contacted Professor John Watkinson who welcomed me with open arms. One of my main aims is to work with the other volunteers to strengthen our Patient Support Group and make it a big success with its main focus being to provide support & information for new and existing patients and their relatives, carers and friends. I hope to meet as many of you as possible at our Christmas party. I look forward to a mutually rewarding association with Get A-Head."



Thyroid Disorders

Information and Support Meeting for Patients

Saturday 15th November 2014
2pm to 4pm

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

- Off the A45 Coventry Road
- Free Parking Available

Guest Speakers

Dr Vicki Smith

Research Fellow, School of Clinical and Experimental Medicine
College of Medical and Dental Sciences, University of Birmingham

'Thyroid Cancer Research'

Mr Matt Edmunds

Clinical Lecturer in Ophthalmology,
School of Immunity and Infection
College of Medical and Dental Sciences, University of Birmingham

'Thyroid Eye Disease Research'

Followed By

Question and Answer Session

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.

Supported by - The Get A-Head Patient Group, On Behalf of the Get A-Head Charitable Trust Registered charity no. 111882E



Contact Details: Janet Prentice, British Thyroid Foundation Local Coordinator
Tel: 0121 628 7435 Email: janedmp@googlemail.com



CHRISTMAS PARTY
for patients and their
family and friends

**FRIDAY 12TH
DECEMBER
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 Irish dancers and live music. There is no charge for this event and we hope that many of you will attend.

Please book via the Get A-Head office.

Laryngectomy Support Group

David advised that the Laryngectomy Support Group meeting went well and they plan to arrange another one soon. To find out more about future meetings please contact David.

dms27@btinternet.com

We will endeavour to keep you updated with the details of any future meetings.

Local
support for
people with
thyroid
disorders

A patient support
organisation working with
medical professionals from
the British Thyroid
Association

The British Thyroid Foundation

2nd Floor,
3 Devonshire Place,
Harrogate
HG1 4AA

Tel: 01423 709707/709448
www.btf-thyroid.org

What's going on in the background?

GAH founder Mr John Watkinson and Trustee Dr Kristien Boelaert, whilst attending the British Association of Endocrine Thyroid Surgeons, helped raise awareness of the revised British Thyroid Association Thyroid Cancer Guidelines <http://www.british-thyroid-association.org/Guidelines/>.

On the 16th October 2014 a meeting was held by The West Midlands Strategic Clinical Network – Cancer West Midlands Survivorship Expert Advisory Group at the University of Birmingham.

These are just two of many professional, charitable organisations and government committees that meet every year to discuss ways to improve the outcome of patient experiences. We will be featuring these and more in future editions of the GAP Newsletter.



The British Thyroid Foundation (BTF) meeting on Wednesday 18th June, supported by the GAP group, went well. I'd like to offer a big thank you to our guest speaker, Professor Hisham Mehanna, who talked about the diagnosis and treatment of the various types of Thyroid Cancer with particular reference to the most common form, differentiated thyroid cancer.

With regards to diagnosis he talked about the way the tumours are commonly first identified through routine investigative examination and imaging of the neck. Going onto closer examination with fine needle aspiration cytology (FNAC) (with and without ultrasound guidance), MRI, PET and CT scans. He also discussed the research and introduction of Real Time Elastography (RTE) FNAC.

In respect of treatment he discussed the new guidelines produced by the British Thyroid Association (BTA). Moving away from the one fix for all, the treatment will be guided by the individual's diagnosis.

Throughout the talk he invited and answered questions from the audience. Those who have provided feedback felt reassured by the continuing research and the new information provided.



An invitation was extended to me from pharmaceutical company Eisai to attend a media advisory board in London on the 19th August 2014.

The purpose of the meeting was to raise awareness of the 'Differentiated Thyroid Cancer' (DTC) patients who are resistant to the radioiodine ablation treatment to destroy any residual, metastatic or recurring DTC.

At the time of the meeting Eisai had filed an application to the European Medicines Agency (EMA) for the use of Lenvatinib in the treatment of patients with progressive radioiodine-refractory differentiated thyroid cancer (RR-DTC) following successful completion of a phase III study.

Eisai were looking for a RR-DTC patient representative however it was difficult to find anyone who could attend given the short notice provided. As a DTC patient representative I went along and expressed how disruptive just one session of the necessary radioiodine ablation treatment was on the life of my family and myself. Having been able to talk to a RR-DTC patient prior to the meeting I was able to explain to the media advisory board what a devastating effect the multiple treatments and the progression of the disease has had on the general health, social and work life of the RR-DTC patient.

It is evident that more needs to be available to help this patient group.

Janet

QUESTIONS & 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.

Q. I have medullary thyroid cancer, please explain why my blood tests are sent off site when other thyroid cancer patients have their blood tests done in the hospital lab?

A. Medullary thyroid Cancer is one of the rarest types of thyroid malignancy and as such there are a number of differences between it and the commonest type (Differentiated Thyroid Cancer). With regards to the latter this is hormonally sensitive and as such is usually treated with a higher rather than a lower dose of Thyroxine. It is monitored using the marker Serum Thyroglobulin.

In sharp contrast Medullary Thyroid Carcinoma secretes a hormone called Calcitonin which is used as part of assessment and follow-up investigations as a measure of tumour status. This is only measured in a few centres, such as Cardiff and Imperial Hammersmith. Other blood tests that are measured in MTC can be done locally and these include thyroid function, serum calcium as well as serum parathormone. Occasionally MTC is familial and in which case the RET Proto-oncogene is positive. This is measured by a blood test done off-site in centres such as Cambridge. If the gene is positive some of the familial types of MTC are part of syndromes such as MEN1 and MEN2a and these can be associated with tumours in the abdomen called Pheochromocytoma's. If they are present your plasma metanephrines will be raised and these are measured in the blood.

Q. Why are mine packed in ice and theirs are not?

A. A number of blood tests require placing immediately in ice and calcitonin is one of these.

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. Over the last 6 months Get A-Head have been able to:-

- ✚ Provide funding to Birmingham Children's Hospital to help them purchase a Surgical Navigation Unit, which is an advanced computer-assisted and image-guided navigational system that allows surgeons to precisely position surgical instruments during head and neck surgery. This will allow the hospital to develop its pioneering endoscopic surgery and provide children with the best possible care.
- ✚ Purchase a NIOX MINO analyser for the Multidisciplinary Allergy Clinic at Queen Elizabeth Hospital, Birmingham. The equipment analyses exhaled nitric oxide and will assist in diagnosing allergies and allow for instant decisions of the management of the conditions.
- ✚ Continue funding for the Complementary Therapy Service at the Queen Elizabeth Hospital, Birmingham. The Service was set up with the aim of offering deep relaxation therapies to patients who attend the Head & Neck Unit. The therapies are not seen as an alternative to medical care, they are offered to complement the care. It is well recognised that many people choose to use complementary therapies in the home and community, however very few therapists have detailed knowledge of head & neck disease and the medical treatments required. With this in mind we felt it was appropriate to provide access to therapies which are given under the supervision of a Clinical Nurse Specialist who has expert knowledge of head & neck disease and is also a qualified complementary therapist.

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 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

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