

Get A-Head Patient Group Message

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.

In this issue we include:-

- a summary of the patient information meeting held on the 12th March 2016 highlighting quality of life aspects of research.
- We fondly remember Get A-Head supporter, volunteer and fundraiser Janet Wiggins
- 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 as detailed on the final page.

Janet's husband Ken wrote, *'When things settle down weeks or months later, there are still tasks ahead, as life in some cases will never be quite the same as it was before – learning to cope with the illness the loved one has had, the after effects of the illness, and of course dealing with the future.'*

One of the best ways to try to overcome all those fears before, during and after illness, such as head and neck cancers, is to share those fears and apprehensions with hospital trained staff, or indeed people like Janet the patient, or myself the husband, who have experienced those fears, and know first-hand the experiences patients and family members are going through.'

Both Janet and Ken offered to be a contact for people who wished to share those fears, or ask about anything related to coping with a serious illness such as head and neck cancers.

To show their appreciation of what surgeon Mr Watkinson and his team did for them *'....before, during, and many times after treatment and recovery...'* Janet and Ken *'....decided to undertake a charity walk weekend every year for the Get A-Head charity. That was 11 years ago – and we've done walks for charity every year since, with work and ex work colleagues participating, raising over £11,000 to date for a great cause.'*

Ken and his friends have decided to continue with the *'Wiggins Walk'* and are organising the *'Janet Memorial Walk'* to take place in Guernsey in June 2016. A truly remarkable woman, Janet will be sadly missed but remembered with love and pride by all those that knew her. As requested by Ken we have included the letter sent to Ken from Mr Watkinson (edited to remove personal details)



Janet Wiggins

Janet passed away peacefully on the 2nd November 2015.



In the 1st edition of the Patient Group Newsletter 2013 Janet and her husband Ken wrote about their experience of Janet's illness and the impact it had on them and their family.

Here we are going to remind you of their courage and selflessness in the face of a devastating life changing diagnosis.

Janet wrote 'Nearly sixteen years ago, after a series of throat problems, I was diagnosed with having a tumour on the base of my tongue. I had never smoked, or drank heavily, at any time of my life. So to discover I had this illness was quite a shock. Plus it was a worrying time for all my family and friends. I had two young sons and a husband.'

After surgery to remove the tumour Janet put her quick recovery down to *'...the great care and attention that I received, and a good positive mental attitude.'*

'The discovery of the illness I had was a shock in itself, and the recovery of the operation that followed was long and hard. However, there was a host of other things I had to deal with, which I never accounted for family impact, eating and diet, stress and worry, dependency on family and friends, side effects of radiotherapy etc.'

However her positive attitude remained with her throughout, *'... having put up with all that was thrown at me I recovered and was able to lead an active life, go back to work, be a Mother to my children, and a wife to my husband. With the support of my friends and family, they got me through the dark times – of which there were many.'*



Dear Ken,

I just wanted to put pen to paper and say how sorry I was to learn of Janet's recent and sad passing. I do hope that she did not suffer too much towards the end?

She was a fantastic lady and a tremendous patient who suffered her disease with great dignity, she was a pleasure to treat and you and the family can be proud of her. Please pass on my condolences to the rest of the family.

Please keep in touch.

With very best wishes,

Yours sincerely,
John Watkinson MSc. MS. FRCS. DLO
Consultant ENT Surgeon
Vice Chairman



The Importance of Research and Education

**Patient Group
Information and Support Meeting
Head & Neck Disease (Including the Thyroid)
Saturday 12th March 2016**

Professor Hisham Mehanna, Chair of Head and Neck Surgery, School of Cancer Sciences. Director, Institute of Head and Neck Studies and Education, University of Birmingham and **Dr Kate Reid**, Head of Speech and Language Therapy at the Queen Elizabeth Hospital Birmingham were invited to show, through research, the experiences patients have when diagnosed and treated for head and neck disease.

Professor Hisham Mehanna took to the floor first. To help demonstrate the clinical approach he presented research work 'PET-Neck'.

The aim of the project, 'To compare the efficacy of a PET-CT guided watch and wait policy with the current practice of planned neck dissection on overall survival, disease-specific survival, recurrence, **quality of life** and cost-effectiveness in the management of advanced (N2 or N3) nodal metastasis in patients treated with chemo/radiotherapy (CRT) for their head and neck squamous carcinoma (HNSCC) primary.' (<http://www2.warwick.ac.uk/fac/med/research/hscience/ctu/trials/cancer/pet-neck>)

For the purpose of the meeting Hisham concentrated on the standard operating procedures to collect the data for quality life and provided the results of the data collected.

Kate Reid described that the quality of care can be measured by looking at three aspects, safety and effectiveness of treatments and the experiences of patients.

Her work focussed on the latter by scrutinising how patients experience their symptoms and care. The purpose of achieving this is to enable patients to be experts in aspects of their care that they are able to be and to help centre the care around them, so that they can live as well and as long as possible with the impact of their disease, treatments and care.

The work has highlighted that whilst quality of life measures include the topics of how patients are physically, emotionally and socially and explore their sense of mortality, they overlook two other themes, which might be termed the reality of life and the quality of the care. The work has identified five different ways of experiencing symptoms and care. This was achieved by asking patients treated for head and neck cancer to have opinions about statements created from patients and structured around the different themes identified from the quality of life measures, the literature and other patients. The results suggest whilst the experiences might be different for patients they are not unique and there are patterns. These different styles have been named:

1. Meaning and Attachment of Illness;
2. Overwhelmed by the Cancer;
3. Change and Recovery;
4. Survive or Not;
5. Keep Control- For the Greater Good of Others.

It is the belief of the research team that if these patterns can be identified the patients and the teams working with them will benefit from the information. It would mean that the interactions compliment rather than disrupt the styles of experiencing symptoms and care that patients might have. The value of this work is that it is not just about describing the experiences but it is a way of guiding both patients and the teams with how patients are more likely to respond. Instead of experiences for patients being seen as the same or as unique a specific style can be discussed and worked with. As yet we do not know whether the style of experiences for patient's changes over time and the work completed so far has been with a small group of patients. Kate described how the concept is complex because care is not easy to identify or measure; there is no unit of care-experience. However, just because it isn't easy to identify, describe, or measure it should not mean the patients, carers and teams do not acknowledge it exists and improve upon the experiences for patients by working with the styles identified.

The future

Kate believes that what is important is that patients can make decisions as problems unfold with the support of care from the health-care team that has acknowledged their style of experience. No one has ever worked from this aspect of care before but this seems essential so that possibilities discussed become ways of managing situations together as they develop through patients' lives. This aspect of the quality of care will remain complex and hard to simplify but it is hoped this work will progress to enable patients to influence, on their terms, their experiences of the symptoms from the disease and treatments and care. What is important is that patients can discuss, in as much, or as little detail as they want the impact of symptoms and care on their ability to carry on with their lives. She would be very happy to discuss any aspects of this with members of the group.

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.

There were no new questions provided for this newsletter.

No question is too silly, our professionals are very happy to answer any questions within their professional capacity and area of expertise.

Your questions could lead to research!

Invitation to....



Patient Group
Information and Support Meeting
Head & Neck Disease (Including the Thyroid)

We aim to provide 2 to 3 meetings per annum.

Usually held on a Saturday
14:00 to 16:00

At

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

- **Off the A45 Coventry Road**
- **Free Parking Available**

With Guest Speakers offering clinical expertise and patient experience.

Don't miss out, keep checking the charities web and social media sites for updates. There may be changes to venue, day of the week or time of the meeting.

Contact

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

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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.

GET A-HEAD PATIENT GROUP

A Cancer Charity Fighting all Head & Neck Diseases



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

Meetings are held on the 2nd Monday of February, May, August and November.
Time: 10:00 to 12:00

Outpatients Main Waiting Area, Costa Coffee by Check-in Kiosks, Queen Elizabeth Hospital, Edgbaston, Birmingham, B15 2TH

Dates for your diary are
Monday:-

8th August 2016
14th November 2016
13th February 2017
8th May 2017

Christmas Future



CHRISTMAS PARTY

For patients and their family and friends
Friday 9th December 2016 19:00-23:00

This year's party will be held at the Tally Ho, Edgbaston.
Join us for a free fun-filled festive celebration, with live entertainment from the **Tom Walker Trio**. There is no charge for this event and we hope that many of you will attend. If you wish to make a voluntary donation on the night it will be gratefully received. Please book via the Get ahead office

And Christmas Past

The Get A-Head patient Group Christmas Party brought patients, families and friends together to have fun.



The night got off to a very energetic start with a show from Sylvia Brenan's Irish Dancers. The Irish theme continued with music from the 'Hurling Boys'.

We had generous donations for the raffle, including 2 of the Get A-Head teddy bears. Named Victor and Molly, the bears went to good homes.

After the fund raising games the 'Hurling Boys' provided us with more musical entertainment and encouraged the audience onto the dance floor to do an Irish line dance. Everyone enjoyed the performance.

We had a fantastic turn out at the Patient Group Christmas party 2015. Because of the high demand we are trying a new venue at the Tally Ho Edgbaston, which offers more space. I hope you'll join us for a very merry Christmas party 2016.

News from the Get A-Head Charitable Trust.

Get A-Head seeks to raise money to assist the work in the field of Head and Neck disease, including cancer in as many ways as possible.

The generous support from our patients and their families is always greatly appreciated by us all at the charity. Over the last few months several patients and their families have held fundraising events to support our work, including:-

Jenny & John Leadbetter held an event to celebrate their Silver Wedding Anniversary and raised **£870**.

Jill & Paul Morgan held a fundraising event at Rubery British Legion and raised **£234.66**.

Martin Thomas organised a Golf Day and raised **£2930**.

Carlton Matthews held a fundraising event at Ridgemere Private Members Club and raised **£152**.

Kathleen Tolladay and family were involved in organising a Quiz at The Spotted Dog in Digbeth and raised **£577**

Andrew Jennings organised a Golf Day at Harborne Golf Club and raised **£792**

Because of the support and fundraising by these and many others supporters we have been able to provide funding for the following grants since the last newsletter:-

- ✚ A Grant for a **PhD Student at University of Birmingham** to provide funding for the cost of consumables, for a new research project looking into why 30% of thyroid cancers recur.
- ✚ A Grant for the **Speech & Language Department of Barts Health NHS Trust in London** to purchase five 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 to the **Get A-Head Patient Group** to help fund the cost of their Annual Christmas Party that is free for patients to attend
- ✚ We provided funding to **Queen Elizabeth Hospital, Birmingham** to purchase an Endoscope to be used specifically in the ENT Outpatients Department. This will allow the hospital to develop its pioneering endoscopic ENT treatment surgery and will enable more accurate visualisation of important surgical areas.
- ✚ Funding provided to the Queen Elizabeth Hospital Birmingham Charity to sponsor a Christmas Tree and Christmas Hampers for staff and patients to enjoy whilst being treated in hospital at Christmas.
- ✚ **A Grant has been provided to The Institute of Cancer Research** at The Royal Marsden Hospital to enable them to purchase specialist equipment for use in the Adenoid Cystic Carcinoma research they are undertaking.

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 of everyone concerned. Please contact the office if you would like to learn more.

Current members:



Janet Prentice



Loretta Webb



Fran Gurney

Kellie Maddison



http://twitter.com/#!/Get_AHead_Trust



<http://www.facebook.com/pages/The-Get-A-Head-Charitable-Trust/194543653897453>

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,
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