



# HEADS TOGETHER

Patient Support Group Newsletter

Spring 2012



Dave Rogers

## Mouth Cancer survivor delivers powerful message

A grandfather whose jaw had to be reconstructed using a bone from his shin following mouth cancer is urging people to learn the warning signs of the disease.

Dave Rogers, 62, first realised that something was wrong when noticed that some of his front teeth required root canals. After being referred to Charles Clifford Dental Hospital he was told the cause was an aggressive form of cancer called Mucoepidermoid Carcinoma.

He said: "The diagnosis came as a complete shock as I only went into the dentist for an annual check-up. I wasn't expecting anything like that - at the time I felt fit and healthy. Because in the past I enjoyed spending spare time doing high-altitude mountaineering, skiing and golfing but suddenly I had to come to terms with having cancer and of course the operation."

Dave, from Doncaster, was referred to Royal Hallamshire Hospital's Oral and Maxillofacial team and underwent two operations totalling 36 hours which involved cutting away his jaw and replacing it with bones and skin from his shin. This was after the first operation to remove the tumour at the Thornbury Hospital in Sheffield.

continued...

If you require any further information about The Group please feel free to contact a member of the team that supports the group, or just come along to the next meeting and you will be given a warm welcome.

**CONTACT US** - Call Louise Marley or Tracy White on 0114 226 8776 or Jane Thornton on 0114 271 2676.

## Hello and welcome to our 7<sup>th</sup> newsletter!

**Heads Together** is a support group for Head and Neck Cancer patients and their carers held at Burton Street Project, Hillsborough in Sheffield. It's open to all people who have had treatment for Head and Neck Cancer. The aim of The Group is to offer expert professional and friendly support from the healthcare team, alongside valuable peer support from other members of The Group within a relaxed and friendly atmosphere.

Peer support is invaluable and is becoming the focus of The Group. The meetings are very informal allowing time for a chat and a laugh with new friends. Sharing personal knowledge and guidance from other people in a supportive environment. Outside of the meetings there is a chance to socialise more with group members on organised trips and social events for group members to attend.

The Group is constantly growing in numbers, strength and confidence. New members are becoming more involved in the running of their group. Members also meet outside of the bi-monthly meetings to socialise and help with the running of the group. Anyone attending The Group would also be very welcome at these meetings to provide and gain this peer support that many find invaluable. New members are always given a warm welcome and made to feel part of the family. Many new friendships have developed which is a real bonus, alongside healthcare professional support and input as needed by this lovely group.

## Mouth Cancer survivor delivers powerful message (continued)

He said the thought of the operations were very daunting and said the support of his family, friends, work colleagues and the hospital team were key.

He said: "Everyone, especially my family and the hospital team at the Hallamshire were fantastic. At the hospital they made you feel that you were part of their inclusive team and you were fighting this together."

Following his operation Dave had to learn to walk properly again due to the bones in his leg being weaker and also had to cope with other effects of the operation.

He said: "It's been hard as I've had to relearn to do some of the things I took for granted before the operation. I've had to learn to walk properly again as the operation removed some bone from one of my legs. I even copied my two-year-old grandson trying to walk for the first time. I've also had to learn to speak and breathe properly again. I've also had to get used to some really bizarre changes. For example at one of my follow-up hygienist's appointments I asked the team why I kept getting

hairs growing in my mouth. With amusement they reminded me that they'd reconstructed my jaw using bone and skin from my leg! I have hairy legs!!! so now the ladies have leg waxes I now have to have my mouth waxed regularly!"

Despite the challenges, Dave has had a remarkable recovery, running a 3km race for Weston Park Hospital Charity in June. He now enjoys walking 5km a day and spending time with his grandson Alfie.

Dave, who works as a senior manager for phone company O<sup>2</sup> who have supported him magnificently, said he wanted to share his story during Mouth Cancer Awareness week to encourage other people to spot the warning signs of mouth cancer.

He said: "I can't emphasise enough the importance of getting checked out. If you're over 45, have a regular x-ray of your jaw when you have a annual dental check, even if you don't think there's anything wrong. If you have a sore or ulcer in your mouth, a red patch or an unexplained pain for longer than 3 weeks, go and see your

GP. Don't just hope it will go away."

Mouth Cancer is more common than cervical and testicular cancer combined. It is more likely to develop in people over the age of 50, but is on the increase in younger adults, especially men. Even though Dave did not drink or smoke the main causes are tobacco and alcohol.

Dr Afshin Yousefpour, Consultant Oral and Maxillofacial/Head and Neck Surgeon at Sheffield Teaching Hospitals NHS Foundation Trust, was part of the team that operated on Dave.

He said: "It is very important that if people notice something even minor was wrong that you get it checked out straight away.

Finding the problem early allows surgeons like me to get the best possible results by treating the cancer quickly before it gets beyond a cure."

For more information about Mouth Cancer please visit the Mouth Cancer Foundation at [www.rdoc.org.uk](http://www.rdoc.org.uk)

## Fund Raising for the group

Fund raising goes on in all different ways throughout the year to keep the funds available for the groups upkeep and events. The group members do a lot towards this by organising stalls, helping and donating with prizes for raffles and competitions.

Last Christmas raffles were held the Hallamshire and Charles Clifford to raise money all gifts were donated by members of the group or staff and friends. Two ladies work very hard in ENT to sell raffle tickets Lisa and Maria and they raised over £800. The nurses at Charles Clifford also raised money for the group in a separate raffle.

Maria and Mandy who both are staff at the Hallamshire put on their running shoes and raised some more money. So thanks to everyone who contributed in any way to keep this lovely group running.

## Christmas 2011 shopping trip to Chester



Off we went on our adventures to Chester this time. Rather a cold day, but bright and the rain held off. We had a couple of games of bingo on the coach on the way down, rather

precarious at times going round the corners we nearly lost our bingo balls on numerous occasions. Sister Sandy Birley was an excellent bingo caller! Chester is a very 'pretty' city historic

walls, monuments and the town crier was in full voice. Lots of lovely shops so the ladies did some spending and some of the gents too. Also plenty of markets stalls selling Christmas gifts and a lovely smell of roasted chestnuts. There were plenty of bars and restaurants to choose from for lunch and snacks.

We undertook a quiz with the questions all being related to Chester, some of our group members were very ingenious and visited the tourist information to gain there answers well done to everyone for taking part.

We hope everyone had an enjoyable day, and look forward to our next adventure.

## First Meeting of 2012

At the meeting held on January the 4<sup>th</sup> at Burton Street Eric Bailey did a DVD show of old Photographs, with music, which lasted for 35 minutes. It appears that it was a success as I was approached by a number of the group afterwards. One of those people was Terry Brookes, who after seeing me boarding an aircraft, with Aden Airways on the Aircraft steps, in one of the photographs; he asked me when I was stationed out there. I replied between 1960 and 1962,

and many other places in between, as Aden was my Headquarters. During the conversation, it became apparent that he served in most of the places that I had, although he didn't serve in the conflict between Iraq and Kuwait in July 1961, to October 1961. Yes that's right 1961, but he was on standby for it. Not many people know of this conflict. You can find it on your computer. We also sailed on the same ship, SS Nevasa to the Middle East, albeit

Terry sailed in August 1960, and I sailed in November 1960. I was later able to give him photographs of the SS Nevasa Troop ship, and one of the Type of Aircraft we flew in and one of Port Said. The Aircraft being Beverley's. I have known Terry for well over a year now, and neither of us knew about each other serving in the Middle East. What a small World. Are there any more ex military people from that time who served in the Middle East within the group?

## Changes to orders from Countrywide

Hopefully you will have been contacted by Countrywide already to let you know that they now need to get a prescription from your GP before they can deliver your supplies. They may be able to do this automatically if you have completed the paperwork for them to be your 'nominated' supplier for electronic prescriptions. The main change is that you now need to contact them at least one week before you need your supplies in order for them to get the prescription and post the goods out to you. In exceptional

circumstances same day ordering is possible.

If you have any questions regarding this either contact Countrywide on 0800 783 1659 or speak to Tracy/ Louise or Jane, the numbers are on back of this newsletter.

## Head and Neck Cancer Awareness Day

Our annual mouth cancer awareness day was held at Crystal peaks shopping Centre by the Macmillan group, with Helpers from the Hallamshire Hospital, namely Louise Marley and Tracy White, and helpers from the Head and Neck Cancer Support Group. Many thanks to you all. It was a very successful day. Following on from this Dave Rogers who is very keen to raise awareness

was interviewed for the media, and his story was published in the press and then again on the radio. Thank you to Dave for his time and sharing his story.



**2012 MEETING DATES**

1.00 - 2.30pm

- 25<sup>th</sup> May
- 20<sup>th</sup> July
- 21<sup>st</sup> September
- 23<sup>rd</sup> November

Venue: Burton Street Project, 57 Burton Street,  
Hillsborough, Sheffield, S6 2HH. 1-2pm.  
[www.burtonstreet.co.uk](http://www.burtonstreet.co.uk)

Speakers for this year 2012 following on from ideas from the group members.

- January Eric our Chairman and editor presentation
- March Christine Pitt- Lets Face It
- May Ralph Goodison and AGM
- July Dave Birds from 'Physical Activity referral scheme'
- Sept Look good feel Good Cancer Support Centre
- Nov WW rationing / social get together quiz/bingo

**Other Events during the year**

Stall to raise awareness of the group and funds- 19<sup>th</sup> May 10am Rose Public House Walkey- Everyone welcome to help or just come and pay a supportive visit.

June 22<sup>nd</sup> trip to Bridlington should be a fun day

July 1<sup>st</sup>- Many staff taking part in the Weston Park Run in the Park – All welcome we will all need plenty of encouragement.

Christmas Show? Cinderella at the Lyceum

**Sub Meetings**

All members are very welcome to join the sub-group meetings dates.

First Meeting in the New Year was 7<sup>th</sup> Jan then every two weeks at the Bankers Draft Weatherspoons in Sheffield City Centre. Meeting starts at 12 pm. Many things are discussed, from doing leaflets to put in Hospitals to make new patients aware that there is a Head and Neck group, should they wish to join. Raising funds is ongoing but the sub-group have had bring and buy sales, jumble sales etc. to help raise funds. Alongside this they benefit from each others support in a friendly and informal setting. The attendees would like to see more people at these meetings; this will help in making decisions on different items as any decisions made may not suit everyone.

**Heads Together Web Page**

There is work on going for the group to have its own web page where we can publicise the group our newsletters and events. Also any member's stories so that any patient accessing the site can read about the lovely things you all get up to.

**Calendars**

It seems that the entire calendars have sold out. Well done to everyone who bought or sold them. We need a different theme for next years calendars. I thought about family pets. We need the photographs quickly as they have to be ready for the November meeting.

**Write in**

Eric Bailey is a group member and we think of him as our editor. He works behind the scenes with this newsletter providing stories and ideas on content. He is always happy to receive any stories or tips to include in the next issue.

Any correspondence will have to have your consent in order for it be published. If interested please send either by post or internet to Mr Eric Bailey, 102 Kingsway, Mapplewell, Barnsley S75 6EU, email [eric.bailey1sky.com](mailto:eric.bailey1sky.com).

**OTHER USEFUL INFORMATION****RHH phone numbers**

- ENT ward I1 0114 271 2504
- ENT out patient appointments 0114 271 2411
- Charles Clifford appointments 0114 271 7829

**BDGH**

- Mr Wickham's secretary 01226 432843
- Mr Nussbaumer's secretary 01226 432195
- Cavendish Centre (complementary medicine), [www.cavcare.org.uk](http://www.cavcare.org.uk) 0114 278 4600
- Cancer support centre, 0114 226 5391, [www.cancersupportcentre.co.uk](http://www.cancersupportcentre.co.uk)

**NATIONAL GROUPS**

- National Association of Laryngectomy Clubs [www.laryngectomy.org.uk](http://www.laryngectomy.org.uk) 020 7730 8585
- Let's Face it (support network), [www.lets-face-it.org.uk](http://www.lets-face-it.org.uk)
- Changing faces [www.changingfaces.org.uk](http://www.changingfaces.org.uk) 0845 4500 275
- Macmillan cancer care/bacup [www.macmillan.org.uk](http://www.macmillan.org.uk) 0808 808 0000

**The Healthcare professionals (Royal Hallamshire Hospital)**

- Louise Marley, Clinical Nurse Specialist (for oral and maxillofacial) 0114 226 8776
- Tracy White, Clinical Nurse Specialist (for ENT) 0114 2711587
- Jane Thornton, Ceri Robertson and Karen Jackson, Speech and Language Therapists, 0114 2712533

**The Healthcare professionals (Barnsley)**

- Lisa Smith Clinical Nurse Specialist (outpatients) 01226 434492