



The Ben Walton Trust

Dear Friends and Supporters

PROGRESS REPORT: NOVEMBER 2006

You may be a first time reader or one of our many long-term supporters; whichever, thank you for your interest and we hope that you will find this, our seventh report, informative.

It is now eleven years in December since Ben died from oral cancer and ten years since the Trust was set up in his memory. So it provides an opportunity to reflect on what has been achieved in that time and report on some of the positive things that have happened since our last report.

The timing also coincides with national **Mouth Cancer Awareness Week (MCAW)**, which takes place from Sunday 12th November to Saturday 18th November 2006. So look out for events near you.

Many things have improved in those ten years; public and professional awareness is higher. Oral Cancer has been the subject of many articles in newspapers, magazines and on radio and television. To some extent it has come out of the shadows and found a place on national agendas; this can only do good. It would be wonderful to report that numbers of new cases have decreased and survival rates have improved. However, I cannot do that, and have to be realistic and take a longer-term view. There is some evidence that survival rates are improving marginally, as while incidence (new cases) is now around 4,400 per year, deaths from the disease are still reported as around 1,700 per year. **This still means that someone in the UK dies every five hours from mouth cancer.** But there does appear to be some progress here, perhaps because of increased awareness and consequent earlier referral, however statistically too early to be sure yet. It is also true that reconstructive techniques become ever more sophisticated and improved palliative and specialist care are more than ever patient focussed.

The real problem is that the incidence continues to increase in all areas and in young and old and male and female. If we look at the figures in 1990, there were 2,800 new cases reported to cancer registries in the UK. This has now increased to around 4,400 per year in 2002 (latest available figures).

In a recent paper by David Conway published in Oral Oncology and supported by SOCAG / The Trust, he looks at incidence in the UK between 1990 and 1999. From this recent trends and regional variations clearly emerge. As we know, incidence generally increases as you go north, so that in Scotland it is almost double that of some registries in the south. Of the 32,850 cases looked at, 65% were male, 35% female. The annual increase rose over the period from 2,800 to 3,885, representing an overall increase of 18% in males and 30% in females. In Scotland amongst the under-45 year olds, there was a respective increase of 22% in males and 50% in females. This was up to 1999, which are the latest figures available from the cancer registries. There is every reason to believe, given the latest overall incidence figures, that these increases are continuing at an even greater rate.

We know from the King's College, London, study, also supported by The Trust, that around 25% of the under-45 year old group cannot be explained by the traditional causes of alcohol and tobacco.

We have speculated before what the causes may be and it seems apparent that changing lifestyles with binge drinking and increasing smoking by young women will take its toll and account for some of the increase but it is far from the full story. Genetics, occupation, infection and viruses such as the human papilloma virus may all play a part. The fact of the matter is that the causes are not yet fully understood and further large-scale research is needed to explore these factors. In the meantime, we do know that reducing alcohol and tobacco, red meat, fried food and fat and increasing fruit and vegetables (particularly tomatoes), olive oil and fish oils intake will help.

UPDATE

Some positive news. SIGN (Scottish Intercollegiate Guideline Network)

I am very pleased to report that a shiny new copy of the completed guidelines on head and neck cancers arrived by post this week. It will shortly be sent to all GPs, surgeons, dentists, nurses and allied health professionals in Scotland, around seven thousand of them! It gives evidence-based information on the diagnosis and management of head and neck cancer patients. In short, it will become a national standard. It has taken over 3 years to develop by a team of about 35 people and went out for both specialist review and public consultation.

It has been seven years since The Trust, encouraged and supported by the late Professor Jim Petrie, first made an application to SIGN to develop guidelines. Thanks are due also to Freda Cunningham who worked with me as a patients' representative on the guideline development panel. Thanks to the members of SOCAG too, who pored over and corrected the final application (I think we had six revisions!)

The Guidelines are available on the Internet at www.SIGN.ac.uk. Click on Guidelines and then on Head and Neck Cancers. For lay people, the introduction and section on information for patients is probably the most relevant. It now states as a 'good practice' point that patients should be seen within two weeks of urgent referral.

LETTERHEAD & WEBSITE

Previous readers will have noticed a change to our letterhead and the fact that we now have a website at www.benwaltontrust.org.

Many thanks to Ken Gray for his generosity in setting up the site and updating it free of charge. His website is at www.holding-pattern.co.uk (free advert there, Ken!).

THE NEXT PROJECT

Patience is a great virtue and much needed, as our patients' needs project has been around for some time and filling several files. It does seem incredible how long relatively simple research projects can take to get off the ground. However "A Pilot Study of Oral Cancer Patients' Experiences During Their Journey Through Pre-Diagnostic NHS Care" is almost there. We now have a team, comprised of principal investigators, Dr Rosemary Day of Glasgow University, co-ordinator Liz Grant, Public Health Pharmacist at GGHB, a steering group with members of Edinburgh University, King's College London and Glasgow Dental School ready to go. The papers are almost complete that will go to the medical ethics committee for consent to carry out the study. My thanks to all for continuing support and sheer hard work.

The intention is to pilot the project on fifteen under-45 year old patients in Greater Glasgow and the Lothians to look at emerging symptoms and what action was taken prior to diagnosis, to see what can be learned. One of the novel aspects of the project is that patients will be interviewed at Maggie's Cancer Care Centres near their homes or at home is appropriate. This is our next funding challenge and we would hope that a large national project will flow from this.

THE BEN WALTON AWARD

At the suggestion of Mr Edward Larkin, Maxillo-Facial Surgeon at St John's, Livingston, we have instigated an annual award with the aim to encourage junior members of staff to embark on small research projects for publication in scientific peer-reviewed papers.

This year the award was presented at the Scottish Association of Maxillo-Facial Surgeons in Dundee. The winner was CHRISTINE GOODALL. The subject was "Alcohol related trauma".

It is intended to also make this a national award and to dedicate it each year to a different young person who has had oral cancer although at the time of writing there are some ethical problems with this.

It is also intended to have a bi- or tri-annual lecture on the same basis.

FUNDRAISING

Over the last ten years we have raised and distributed quite large sums of money and I have never been aware in advance quite where funds will come from or when. Yes, we have initiated and participated in fund-raising events but remarkably the bulk of our funding has arrived without this. In many cases from people who contribute annually by covenant or via CAF cheques, but also individuals just emerge who run marathons, give talks or make collections. To all of you very many thanks; we could not have carried out our work without your quiet thoughtfulness and enthusiastic support.

To mention some since our last report:

- Scotland's Gardens Scheme
- Dundee Dental Student Society
- Joseph Murray and Rebecca Chin of Edinburgh College of Art (London Marathon)
- Royal Bank of Scotland (give £250 annually for the voluntary work of our Treasurer)
- West Linton SWRI
- Dr Fiona Crawford, Edinburgh Dental Institute (The Great North Run)
- James Dwyer, parachute jump
- Hotel Russell, Russell Square, London
- Karyn Becconsall-Ryan, Edinburgh Marathon
- Dundee Dental School, Students Yearclub
- Carlops Village Hall, coffee morning
- St Mungo's, West Linton
- Portner Pittack, Dental Care
- Findlay Irvine
- Old Nick Tavern (David Dean has now moved on and I do not like singling out individuals but he and his team have been tremendous supporters raising quite staggering sums and increasing awareness locally).

VERY MANY THANKS

DISBURSEMENTS

Since the last report these are some of the organisations and individuals we have given support to:

- Patient funds at:
- Dundee Dental School
- St John's, Livingston
- Support to an individual with advanced disease to take his young son on holiday
- Lincoln County Hospital, Maxillo-Facial Department, equipment for use with patients
- Support to Scottish Oral Cancer Action Group (SOCAG)

It may seem that we have distributed less funds recently, but we have been conscious of the need to conserve funds for our next project. We have always maximised the funding we have received and minimised costs, for instance the SIGN work came at no cost as the small expenditure involved was reimbursed by SIGN. All our Trustees give their time and advice free but we are conscious that any significant price of research does have real costs associated with it.

I very much hope that you will feel this is the right course of action. We are always pleased to provide information on any of our projects and to reply personally to donations. We can also supply information on tax efficient giving as this increasingly becomes an important source of additional funding at no extra cost to the donor.

With Best Wishes, Thanks and Early Seasonal Greetings,

Yours sincerely

M K WALTON
(for and on behalf of the Trustees)