

NEWSLETTER

Published by the Norfolk & Waveney Prostate Cancer Support Group
Registered Charity No. 1108384

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FREE

2nd Aug 2005



Assembly Rooms, Norwich 4th June - An Evening with Martin Bell OBE -

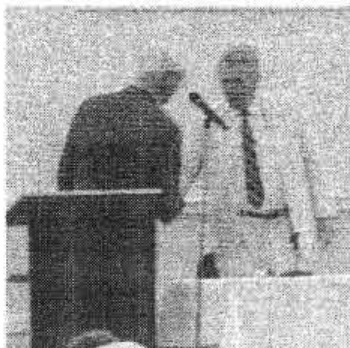
That man in the white suit, **Martin Bell OBE** came to speak at our first major fund-raising event last month. With 103 tickets sold, the profit (after deductions for staging the event) totalled £640.55p. A pleasing outcome. More ticket sales would have been better of course but equally more effort in publicising the event could not have been made.

As it was the evening and in particular Martin's talk was most entertaining.- In fact one could even go as far as inspirational. In this world, particularly made poignant to us all by recent events in London, the event, reassured one that there are people out there who irrespective of the obstacles persist in trying to make it a better place. His view of world events was realistic and yet remained hopeful. A message we share in the group in particular with

commonly held attitudes towards cancer. On behalf of us all I would like to thank David Haines our Chairman for setting up the event and not least Martin Bell, himself for the pleasure of his company and of course, his patronage. □

As promised the profit will be shared equally between UNICEF and our own group.

*Top photo: The Noverre suite, Assembly Rooms.
Below: Our Chairman thanks the speaker.*



James Paget June Meeting -

The first open meeting held outside of the NNUH took place two days later at the James Paget Hospital, Gorleston, Gt Yarmouth on the 6th June. The attendance surprised us all and sent a clear message to the committee for the need to be more inclusive of our "other" centre. A number of avenues are being explored to see what can be done. Needless to say our next 3 open meetings have already been arranged with the NNUH as venue. But please check your latest Newsletter for *Dates for your Diary*. We would welcome your views and suggestions on how best to accommodate both groups, who individually find it difficult to get to each other's centres. Watch this space for developments..... □

Norfolk & Waveney

Prostate Cancer
Support Group

Patron: Martin Bell OBE
www.prostatesupport.org.uk

Registered Charity No. 1108384

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Visit our website :

You will find information about the group, our constitution, committee activities and useful links
If you have access to the internet go to

www.prostatesupport.org.uk

A Big Thank You to; -

- James Paget urology nurse specialist, **Angie Fenn** for co-ordinating the last event and '**James Paget**' members who turned out in force at the first J.P. Hospital open meeting. - But, by no means the last - without a doubt!
- Project 2001 who have raised £1600 so far for us with another event due in October, to come. A fantastic effort and we are very grateful! Look out for details in the next issue and why not go along and make it an even bigger success. See *inside pages*.
- Everyone who attended the Martin Bell event, but then, - we certainly got our money's worth! Along with the £320 raised for our cause, £320 goes to UNICEF to provide dehydration treatment for over 300 children, and will not go to any corrupt government agencies.

Do you need help with transport to and from our meetings ?

If you are unable to get to our meetings because of transport difficulties then contact : **01603 713463** Stan will pass on your details to the nearest member so that you can share the journey. We will try to pick you up and return you home following the meeting.

How to Contact us :

write to :

Norfolk and Waveney Prostate Cancer Support Group.
Urology Dept.
Norfolk and Norwich University Hospital.
Colney Lane
Norwich
Norfolk
NR4 7FP

telephone :

Urology nurses on:
01603 289845 (NNUH)
or 01493 453510 (JPH)

e-mail :

stef.g@care4free.net

Visit our website :

www.prostatesupport.org.uk

for letters to

the editor write to :

Newsletter
Home Farm Cottage
The Drive
Hoveton
Norfolk
NR12 8JE

We welcome news items or notices of any local fundraising or other activities in connection with our charity.

It is - what you make it !

The Norfolk & Waveney Prostate Cancer Support Group is a registered Charity, No. 1108384.

Dates for your Diary

- 2nd Aug 7 p.m.** **Open meeting NNUH**
Dr Ian Hotchin will give a **GP's perspective** on Prostate Cancer, followed by Social Hour.
- 5th Sept 7 p.m.** Committee meeting NNUH
- 2nd Oct Sunday** **BIG C 20th Holkham Cycle Ride.** Another opportunity to enjoy yourself (if you have the stamina) and at the same time raise funds for cancer care and research locally. Contact BIG C direct for details.
- 3rd Oct 7 p.m.** **Open meeting NNUH**
Dr Jo Edwards, Clinical Psychologist will speak on **Urinary and Reproductive dysfunctions**, followed by Social Hour.
- 3rd Nov all day** **2nd National Prostate Cancer Conference** London.
More information in future issues.
- 7th Nov 7 p.m.** Committee meeting NNUH
- 5th Dec 7 p.m.** **Open meeting at NNUH**
Dr Marek Ostrowski, Consultant Oncologist will speak on the latest developments in **Brachytherapy**, followed by the Social Hour.

NOTE:

Boat Trip As a result of lack of interest this event will not be going ahead. Apologies to those who responded positively.

BIG C
"Walk of thoughts" For those who attended this event you will be pleased to know you helped raise in the region of £12,000. That's right - twelve thousand pounds. 288 "walked", the weather was perfect and the event was enjoyed by all.

Some Useful financial info:

More than £126.5 million disability benefits went unclaimed by people with a terminal cancer diagnosis in the UK. Expenses usually increase with illness, at the very time when income, energy and resources decrease. Yet many people affected by cancer who are in financial distress could be entitled to welfare benefits that would increase their weekly income and improve their quality of life. This problem can be easily resolved; money is there, waiting to be claimed.

Disability Living Allowance (DLA) :

DLA is a contribution towards the extra costs incurred by people with disabilities. People living with cancer may be entitled to claim the benefits if they have had difficulties looking after themselves (DLA care component) and/or with walking (DLA mobility component). People with a terminal cancer diagnosis are often automatically entitled to the higher rate of the DLA care component under the Special Rules, which is worth £58.50 a week. They

might also be entitled to the DLA mobility component, at either the lower or higher rate, if they have trouble walking - but their terminal diagnosis does not make them automatically eligible. DLA is not means-tested (income and savings are not taken into account) and can be claimed by anyone regardless of their household income or employment status. Those awarded DLA may also become eligible for extra benefit, such as income support.

Attendance Allowance - (AA) :

AA is a similar benefit to DLA but for people aged 65 and over. It is not means-tested. Unlike DLA, it does not have a mobility component, but people may be entitled to AA if they have care needs or are terminally ill.

Special Rules :

Anyone who has been given a terminal cancer diagnosis with a life expectancy of less than six months automatically qualifies for higher rate DLA for their care needs or higher rate AA. Claims made under the Special Rules for terminal illness should be processed much quicker than ordinary claims.

Macmillan Cancer Relief provide a special telephone helpline for patients and their carers who need benefits advice. To talk to them in confidence and receive advice call them on : **0800 500 800**.

Project 2001 - £1600 raised so far ! -

You will have read in previous issues about the efforts of a local group who have nominated us as their charity for the year. Our chairman attended the 2nd meeting attended by over 50 people and the ladies raised another £800 for our cause. This brings the total they have raised for us this year to £1,600.

An order is being placed for a laptop computer for use by the nurses at the NNUH. Hopefully this will be received in time to be formally presented by Pam Coldham of Project 2001 at our next open meeting.

They will be holding another function in October so look out for the details in the next issue.

Some useful Contacts and sources of information.

The Big C Appeal
Norfolk and Waveney's independent local cancer charity funding research, treatment, equipment, care and support.
10a Castle Meadow, Norwich NR1 3DE
Telephone 01603 619900
www.thebigcappeal.co.uk

The Evening News
www.en24.co.uk

The Prostate Cancer Charity

National organisation with information and helpline.
3 Angel Walk
London W6 9HX
Tel: 020 8222 7622
Fax: 0208222 7639
e-mail:
info@prostate-cancer.org.uk
website:
www.prostate-cancer.org.uk

Prostate Help Association

Support network, newsletter and a book on prostate cancer.
Philip Dunn,
PHA,
Langworth,
Lincoln LN3 5DF

CancerBACUP

Cancer nurses provide information, support and advice by telephone or letter. Newsletter, booklets, fact-sheets website and CD-ROM.
3 Bath Place, Rivington Street, London EC2A 3JR
Freephone 0808 800 1234
Fax 020 7696 9002

If you've finished with the newsletter and do not need it anymore, why don't you pass it on to someone who may not know of our activities.
Editor.....stefan ganther

Next Meetings:

Tuesday 2nd August, East Atrium NNUH at 7 - 9pm

"A GP's Perspective".

Dr Ian Hotchin is a GP, based in King's Lynn, with a special interest in prostate cancer. This interest extends to his doing regular weekly clinics at the NNUH, where he does biopsies etc.

As usual the talk will be followed by an opportunity to meet and talk to fellow members in a relaxed atmosphere. We will continue to arrange the tables according to treatments.

Monday 3rd October, East Atrium NNUH 7 - 9pm

"Urinary and Reproductive dysfunction"

Dr Jo Edwards, is a Clinical Psychologist and will be talking about typical post treatment concerns.

As usual the talk will be followed by an opportunity to meet and talk to fellow members in a relaxed atmosphere. We will continue to arrange the tables according to treatments.

Gift Aid - Update

- In the last newsletter we issued a *Gift Aid Declaration* form. It appears that more detail is required. Please find below a revised version. Please use this one or pass it on to someone who may want to make a donation to the group.



Gift Aid Declaration

Norfolk and Waveney Prostate Cancer Support Group (Registered Charity No: 1108384)

Mr/Mrs/Miss/Other.....First Name(s).....

Surname.....

Address.....

.....Postcode.....

- * I confirm that I am a UK taxpayer and would like any gift I make on or after 6th April 2005 to the Norfolk & Waveney Prostate Cancer Support Group to be eligible for the Group to reclaim the tax on my donation.
- * I understand that any gift I give will be treated as a Gift Aid Donation until I cancel this Declaration.
- * I will inform the Norfolk & Waveney Prostate Cancer Support Group should I cease to pay an amount of Income Tax or Capital Gains Tax equal to the tax the Norfolk & Waveney Prostate Cancer Support Group can reclaim on my donations.

signature.....

date of Declaration

Please send your reply to:
Martin Wolton
Norfolk and Waveney Prostate Cancer Support Group
Willowbeck House
Station Road
Pulham St Mary
Diss
Norfolk IT21 4QS

Thank you for your co-operation in this matter. It makes a

New Clinic for Men with prostate cancer

The uro-oncology Nurses at the NNUH; Sallie, Claire and Wendy, have recently begun a regular outpatient clinic to see men diagnosed with prostate cancer. The aim of the clinic is to see men in an unhurried manner who need to be monitored at the hospital by specialists, but have stable disease, so do not need to see a doctor. The aim is to provide a quality, accessible service at the same time freeing medical staff time.

The Clinic Protocols :

The aims of the nurse-led clinic are:

- To provide continuity of care for patients and their families.
- Longer appointments to facilitate better communication.
- To provide continuous, consistent, communication and information.
- To enable those patients that need additional social and psychological support to be seen in an informal and unhurried environment.
- To aid accurate patient assessment, audit and data gathering.
- To reduce the burden of follow-up appointments in consultant led clinics.

Broad Recommendations:

The Uro-Oncology Nurse Specialists will manage the clinic according to an agreed protocol, recognising the extent and limitations of their expertise.

Patient criteria

- Men who have had a Radical Prostatectomy
- Men who have received Radical Radiotherapy to the prostate
- Men receiving Hormone Deprivation Therapy with a stable PSA and stable symptoms, but are at high risk of early progression.
- Men receiving Intermittent Hormone Deprivation Ther-

apy
·The worried well men, this should be viewed as a half way measure, with the aim of eventual discharge to the care of the GP.

Referral to the clinic can be made by a:

- Consultant Urologist
- Consultant Oncologist
- Staff Grade
- Specialist Registrar
- Urology Nurse Practitioner
- Continence Advisors.

Patient Assessment:

- General well being both physical and psychological
- Understanding of condition and treatment.
- Side-effects of treatment
- Potency. If this is a cause of dissatisfaction. Has any treatment been tried? Was it effective? Would the patient like to try treatment? Advice to GP or andro as appropriate.
- Urinary symptoms. Is this a cause of dissatisfaction? Has it been investigated? Have any treatments been tried? Investigate as needed. Advice to GP or refer to urology consultant or continence advisors as appropriate.

Examination & investigations:

- PSA prior to appointment As required
- Biochemical/haematological evaluation
- Flow rate/ultra -sound
- Urinalysis
- Radiology

Referral back to Consultant :

- Significant or consecutive rises in PSA
- Abnormal biochemical or haematological results
- Skeletal pain
- Persistent urinary symptoms despite trail of medication
- Ongoing bowel problems post radiotherapy.

For further information feel free to contact Sallie/Claire on **01603 289845**.

