

## HOPE Annual Report 2003 - 2004

### **Chairman's Report**

Once again I find it difficult to believe that another year has gone by. I am still sat in my office at 6pm, ending my day job and staring at HOPE work. But what a year! I do feel that this has been the busiest and most productive year to date for HOPE and I would like to personally thank the committee for the hard work and substantial achievement that have been made this year.

After much hard work we have seen the publication of a number of specific tumour guidance from NICE, with more to come, but the most significant for all Occupational Therapists working in Oncology and Palliative Care was the publication of the Supportive and Palliative Care Guidance, which will be a benchmark for future service development in the provision of rehabilitation in oncology and palliative care.

Within HOPE we have worked hard to produce and distribute freely the Guidance for Professionals, Managers and Decision Makers, Occupational Therapy Intervention in Cancer, a joint publication with COT. We currently have 2,500 copies of this in circulation across the country, more copies are available and can be purchased from COT or down loaded from the website. We have tried to get this to key people in the Cancer networks, palliative areas and social services. It's out there so you should use it to your advantage locally to promote your work, role and service development.

Throughout this year we have invited representatives from the countries to attend the national committee meetings with the aim of aiding better communication and more joined up thinking about our activity. This has been most successful and we are proposing at the Annual General Meeting (AGM) that we formally create these positions as committee posts, with the approval of the membership.

We have delivered a number of successful study days across the country and the annual conference was attended by over 100 members, the most to date. Scarborough appears to work as a venue for a number of reasons, hence we have booked the dates again for next year is 15 & 16 June 2005.

We have made many developments with the website and strive to continue to keep this updated as an information source and support to our members. Agenda for Change will impact on us all and we will use the website to post all current information and developments about this issue.

At this years AGM I formally stand down as the serving Chairman of HOPE for the last 11 years. Its time for new ideas and new leadership, (and as I now live, breathe and dream NHS Foundation Trusts and haven't treated a patient in over five years I feel its time to move on!!). I would like to thank all the committee

members who have contributed so much to the life and development of HOPE throughout my time as Chairman, it truly has been a pleasure to work with such skilled and dedicated professionals. I would also like to thank you as members for the kind wishes and lovely brief case that I was presented with at the HOPE conference, and was quite lost for words at the time..... Thank you indeed.

There are a number of positions within the committee that representatives will be elected at the AGM, of which I wish my successor as Chairman my very best wishes in further developing Occupational Therapy in Oncology, Palliative Care and HIV and Aids and the work of HOPE.

Jo Bray  
Chairman

### **College of Occupational Therapists Liaison Representative Report**

As the COT Liaison I attend meetings at College as HOPE's representative. These meetings take the form of two committees, the Business Forum which meets twice a year and the Clinical Forum which meets up to four times a year. The Business Forum is an opportunity to discuss the administrative and practical issues of running a Specialist Section and the Clinical Forum considers a wide spectrum of current issues relating to OT practice. The twelve Specialist Sections are represented at the meetings at which Louise Cusack, Specialist Sections Officer, is always present.

The meetings provide a method of communication to and from College and issues are fed back to the HOPE committee and then disseminated to the wider membership via the newsletter and web site. It also allows for the views of the HOPE committee and members to be fed back to College.

Recent topics of discussion have included (at the Business Forum) financial guidelines for SS, membership fees, web site content and updates and the updating of SS constitutions and (at the Clinical Forum) the DOH paper on AHPs with Special Interests, R&D strategies and the issues of being involved in the development and consultation process for NICE Guidelines.

A review of the administrative and business functions of the Specialist Sections is currently underway. All the Sections operate different systems when handling their data bases, conference organisation and production of newsletters etc and the review is aimed at establishing common issues and will explore strategies for more cohesive and effective working.

Helen Barrett  
College of Occupational Therapists Liaison Representative

## Research and Development Report

Over this past year, I've continued to work to develop the profile of OT research in oncology and palliative care. This has included the following:

- Teaching / presenting nationally on cancer, palliative care, rehabilitation, outcome measures and research.
- Representing HOPE at multi-professional palliative care research events.
- Answering queries related to research and evaluation.
- Working with a group of members and COT to develop a Research and Development strategy for HOPE.

I've had the opportunity to present papers / teach at a number of events, including study days in Edinburgh, Stoke-on-Trent, Dundee, Reading and Oxford (to both OTs and physios). Doing this has provided a great opportunity to meet colleagues from around the country and hear about work being done in other centres. One of the main items on the agenda has, of course, been the implications of the new NICE guidance. This has presented OTs with excellent opportunities to get involved in service development in their local cancer networks, but, of course, also presents the challenge of balancing strategy and policy with a clinical case-load.

I'm always happy to offer advice and support to students and colleagues looking at doing research or evaluations related to cancer and palliative care. This is one of the most enjoyable aspects of my committee role: it gives me the opportunity to share ideas, and hear about some really interesting projects that people are involved with. One of the most frequently asked questions is around the need for / process of obtaining research ethics permission. The new research governance framework has meant that this procedure is very rigorous, and can be daunting for a new researcher.

My own research is continuing. I'm just over half way through a three-year period of funded research, aiming to identify the rehabilitation needs of patients with malignant spinal cord compression.

Developing the HOPE research strategy has provided the opportunity to do some work with COT. A small group of HOPE members and myself have met with Liz White, COT's head of R&D to tailor the COT R&D strategy to HOPE's circumstances. I'd like to thank those who have been involved for their inspiration and ideas: Janice Jones, Camilla Hawkins, and Karen Ward. The strategy is being approved by COT R&D Board, and we are anticipating that it will be ready to launch at the forthcoming Research Study Day on the 23<sup>rd</sup> September at COT.

Research and Development Officer  
Gail Eva

## **Newsletter Editor's Report**

There continue to be three editions of the Newsletter each year. Due to the quantity of work in compiling each edition, there are no plans to increase this number. However, there are plans to co-opt a member to provide some assistance. It is envisaged that this will be in the form of reviewing *Hospice UK online*, a weekly publication, and the *AHP Bulletin*, monthly, from the Department of Health. This will free the editor to pursue other sources and for compiling.

The Summer 2003 edition was the first with the new boxed layout. Feedback from the membership has indicated that this is clearer than the previous column layout. Therefore, the decision is to continue with the boxed layout.

A first for the Summer 2004 edition will be the publication of a photograph. At the time of writing it is not known how this will stand up to the printing process. The result will determine whether photos can be used in the future.

In the last two years there have been an increasing number of reports from regional groups. It has been really interesting to know what is going on and a good source of encouragement and ideas for other groups, and for those who are thinking of starting a group.

The copy deadlines for issues in the coming year are currently:

11 October 2004

14 March 2005

4 July 2005

17 October 2005

Please be aware that these may be subject to change (primarily due to whether they will clash with the Editor's annual leave which is governed by the Editor's husband's unpredictable work schedule!) If a submission is received close after a copy deadline, every effort will be made to include it in the current edition. If this is not possible then it will be included in the subsequent edition.

Feedback on issues in the last year has been very positive. Constructive feedback and suggestions are always welcome.

Anna Kittel  
Newsletter Editor

## **Web site Development Report**

The HOPE web site continues to be one of the most used sites of the special interest group in the COT. It is continually updated and relevant information is posted on the web site as soon as possible.

There are more electronic resources available to download, including

- Hope Resource book
- AHP Palliative Care Project
- Occupational Therapy Interventions in Cancer (launched in June 2004)

Useful links to other web pages has been expanded and includes relevant NICE Guidance documents on Cancer outcomes, so that members can easily access these. As other documents become available links will be put onto the web site. Agenda for Change is an issue which affects all HOPE members and there is information and links that members may find useful, on the membership pages.

The Scottish Occupational Therapy Network in Oncology and Palliative Care (SOTNOP) has its own page in the Membership section and there is opportunity for the other countries to have their own section, for information relevant to local members.

The discussion forum, which was started last year continues to be used, although this is not used as frequently as before, with 22 different topics posted, 13 this year. This is an opportunity for all HOPE members to have a say, ask for information or take part in a current debate.

HOPE and relevant study days are listed, usually with downloadable application forms.

The HOPE Web site is resource with access to a wealth of easily accessible information available to HOPE members providing valuable evidence for clinicians, managers and commissioners.

In the next few months the web pages will be redesigned to fit in with the main COT web site and comply with accessibility guidelines. This should make it easier for those technophobes among you to navigate your way around the HOPE Web Site.

Sheila Barnett  
Web Support Officer

### **Secretary's Report**

In October 2003 the HOPE membership data base was handed over to a company called Marlborough to look after. After ten years of keeping the data base up to date and dealing with many, many members enquiries, I was rather dubious about how all this was going to work! After a few early teething problems with members forgetting to return their application forms to Marlborough direct, the change over has gone remarkably well and the

company has continued to update the data base perfectly and provide Jill with labels for mailshots and whatever else she asks for! We still have over 400 members and people are continuing to join. A big thank you to Marlborough and Jill for helping with this transition and for preserving my husband's and my sanity!

**Occupational therapists who have forgotten if they are members of HOPE need to contact Jill Cooper at :**

**HOPE, PO Box 44382, London, SW20 8WB  
Or [jill.cooper@rmh.nthames.nhs.uk](mailto:jill.cooper@rmh.nthames.nhs.uk)**

**the HOPE application form is on the HOPE web site for you to download and send to the address above.**

Also last Autumn, Jill and I got together to compile the 'Resource Book'. This is a sort of compendium of information - which will need continually updating - so please use the form at the back of the Spring 2004 Newsletter to let us know of any changes that you know need to be made. We will produce a new edited version for members again this year, so we do welcome you input, and contributions of information to share with members.

Although I am no longer the HOPE membership secretary, I still function in a secretarial role to HOPE without the nightmare of membership database management. I welcome any enquiries or calls but please be aware that I can no longer access my aol email and all emails should be addressed to [hazellake@stfrancishospice.co.uk](mailto:hazellake@stfrancishospice.co.uk). Thank you.

Hazel Lake  
Secretary

### **HIV/AIDS Representatives Report**

I continue to be available to advise OT students and professionals regarding clinical and education issues relating to this area. I am the contact point for the therapy press.

I have recently been exploring external teaching opportunities at various Universities in and outside London, but am finding that all the colleges I have contacted so far have either not replied, or do not feel they require this input currently.

I presented a session as part of the SIG of OT's in HIV/AIDS on a recent Study Day (June '04) on HIV/AIDS.

Camilla Hawkins  
HIV/AIDS Committee Representative

## **Study Day Support Report**

Study Days 2004 -The introduction to Oncology study day that we ran in Bristol proved to be overwhelmingly popular with over 50 people attending. It is always difficult to arrange study days at a distance and Debbie Fletcher was a great help. We were especially lucky to have James Brennan as a speaker-he gave a very clear and thought provoking account of his theories on promoting psychological well being. Much of this appears to be already included in our practice as client centred Occupational Therapists.

Research Study day, London. Gail has kindly put this together in what looks to be a very thought provoking day. Hopefully this will result in more quality research!!! I hope to learn loads.

Conference 2004-I assisted in organising some speakers and also carried out one workshop on fatigue

Conference 2005 and practical issues of coping with cancer Jan 2005-speakers now provisionally booked.

Thoughts on the overall planning strategies for the study days and conference has been outlined in a paper that I hope can be discussed at the next committee meeting. If agreed this will then be published in the newsletter.

NICE-feeding into the NICE guidance has taken the majority of time. NICE presents an amazing opportunity to input into future developments of cancer and how much rehabilitation is recognised as a part of that. This could also turn into a threat if the challenge is not taken up, so with this in mind I jumped in feet first to be the AHP rep for skin tumours. I was amazed at how open they were to my presentation on the AHP role. Since July a radiographer has taken on the AHP role as I changed my job and was not able to continue.

Following discussions with Jo Bray and Julia Roberts I was asked to try to link with the AHP reps and provide some OT input for the AHP representation at the time of formulation of the document and prior to the draft being circulated. This is a huge challenge and requires much consideration and quite a bit of work so that hopefully this committee position could be shared.

Having started a new post in neuro-oncology I have asked for 6 months to get the job running thus the study days being organised so much in advance.

## **STATEMENT OF RECEIPTS AND PAYMENTS**

**27.7.04**

**Receipts**

Balance b/f		
HSBC	13888.35	
cash	nil	
Interest on a/c 0.86		
Membership fees	5300.00	
Study day fees	12214.25	
Capitation	240.00	
RMH sponsorship	5000.00	
Help the Hospices	50.00	
N.Ireland balance	156.20	

**Payments**

Travel	5487.87
Postage,copying,etc Conference bags, etc	13.40
Database	488.00
Catering and venues	16090.55
Advertising	75.00
Speakers' fees	2720.00
Typesetting/printing of Newsletters Certificates	7769.10
IHIC, HIS	
Help the Hospices Research grants/supporting members to conferences	300.00
Floats to countries	300.00
Reimbursement for study day	20.00
Balance: Midland Interest	3565.74

TOTAL 36829.66

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