

## HOPE ANNUAL REPORT 2002-2003

### Chairman's Report

Once again I reflect on the year and find myself, and the committee preparing for the annual conference. It does seem to have been a busy year. I think I would summarise this into three elements of work. The most important saw changes in the committee as a result of the elections at the conference and the planned expansion to share the workload and latterly the plans for closer working with the country groups. The contribution to the NICE document, Supportive and Palliative Care, and the progress in producing the lung and breast guidelines for occupational therapy.

### **The Committee**

The AGM last year saw the introduction of new posts in the committee, and on behalf of yourselves as members I would like to thank Sheila, Kathy and Anna for their support and commitment to HOPE this year, and congratulate them for the outstanding progress and contributions they have made o their respective roles.

Sheila has worked to strengthen the website, the result of which means HOPE is the most frequently visited specialist section site for COT. We plan throughout the year to build upon this. The proposed closer working with the countries will enable more information to be shared across the web, so keep visiting the site, its going to keep on developing.

Kathy has been the backbone to arranging the study days and is already working on the plans for next year.

Anna has developed the newsletter and has taken on this role now singled handed as Andrea MacDonald resigned in the autumn last year. We thank Andrea for her contribution and wish her all the best with the new addition of a baby boy to her family. Anna not only having to develop the newsletter single hand idly but has also had to find a new company to edit this for us, so you may notice one or two changes along the way. As always Anna is keen to cover issues from members and we would encourage you to share information through the newsletter.

Hilly Quigley, as COT liaison resigned during the year, and we hope to elect to this position at the AGM. We would like to thank Hilly for her contribution and wish her well in her new working role.

### **Changes to the role of membership secretary**

The most important news for the coming year as a member is that as a committee we have made a decision to out source the membership database management. Renewals of membership will be managed by a company called **Marlborough printing, PO BOX XXXXXXXX**

I don't know what words I can find to describe the gratitude that as members we owe Hazel and her husband Andrew. The commitment and dedication to the membership database management is beyond belief. If I told you that Hazel took on the role of membership secretary with approximately 35 members, in the days when we never thought we would ever become a recognised specialist section of COT, in reaching the magic 100 members to be officially affiliated. Well, the membership of HOPE for the last two years has been over 350. And this means for Hazel and Andrew about a day per month sorting this out, keeping it up to date. This has really extended beyond volunteering to support a small group and has lead us to use your membership fees to

pay for professional support. Hazel's role will now enable her to develop the yearbook into a resource book and support members with networking. From the membership we sincerely thank Hazel and Andrew for both their roles in supporting HOPE over the many years.

### **Future developments of the Committee**

In July we held a special committee meeting, the aim of which was to explore how the national committee could work closer with the country groups. The outcome of this meeting was very positive. We agreed that the world of oncology and palliative care was indeed developing at such a pace that we were all trying to influence policy, create standards and guidance to OT practice and underpin this with education and networking. By sharing local developments could only be a good thing to support each other in strengthening and developing OT at a local level. We have therefore established four meetings throughout the year with representatives from Wales, Scotland, Northern Ireland and the Irish Republic. We will evaluate the outcome of these meetings. We aim to share more information of country developments through the website and the newsletter.

### **Call for new Chairman**

I find this difficult, however with much reflection I have decided to serve out my present term of office and will stand down at the AGM September 04, when I will have served 11 years as Chair of HOPE. I wish to announce this now, to enable and support some succession planning to the role. For nearly three years now I have not held a job as a practicing OT and haven't ventured near a patient. I feel that my contribution is not as clinically focused as it should be. I would welcome discussions from any member who wishes to find out more about this role.

### **NICE Supportive and Palliative Care Guidance**

Many of you are aware of the work we commenced at last years conference for the Supportive and Palliative Care Guidance. From late July to mid August the guidance is still available on the NICE website for the consultation ([www.nice.org.uk/pdf/supppalldraftmanual.pdf](http://www.nice.org.uk/pdf/supppalldraftmanual.pdf) pages 79 –106 cover the section on rehabilitation). The final document will be published in February 04. This I hope will underpin the development of equity for rehabilitation services in oncology and palliative care across cancer networks. It will also mean that as OTs we will have to co-ordinate and communicate across service boundaries to improve patient care.

The Supportive and Palliative Care Guidance will be underpinned by the first DoH AHP Cancer Strategy for England and Wales, which will set out what will be needed to deliver the defined standards in the guidance. Work is currently underway and a final version is anticipated prior to Christmas. I am most encouraged by these documents, as for the first time the role of OT is set in cancer standards and will be developed to fill the requirements of policy.

We have responded throughout the year to the consultation for the developments of other site specific NICE guidance, these have ranged from haemato oncology, head and neck, child and adolescent, colorectal, lung, sarcoma, skin tumours including melanoma and tumours of the brain and central nervous system. Last year saw the publication of the breast and urological guidance.

### **The Breast and Lung Clinical Guidelines for OT**

The focus of this years study days was to produce these guidelines. The first day in November set about defining the framework of the presentation and content of the documents, the snowy day in Leeds in February set about working on the content for the lung document and the day in June in Manchester went about defining the content for the breast document. We meet with COT and the author the week after the conference for editing the progress to begin. We would hope that we will produce something before Christmas but this is going to be hard to define with a date, as we seek joint authorship with COT to give the national professional endorsement on these documents. This will be a lengthy process but I hope you agree is well worth waiting for the recognition it will bring.

### **Future study days through the year**

We are currently working on a study day, which will act as an introduction to oncology and palliative care and this will be in Bristol in January 04.

The next study day will be in the summer and will launch the joint COT and HOPE Research and Development Strategy.

Building on improving the links with the countries the local study days will be published on the website and the newsletters to enable members to access these days with advanced warning and prevent duplication.

And once again we need to make a decision about next years conference, the location, content and time of year. While I think we are almost set on Scarborough as a venue as its cheap, clean and reasonable food, we do welcome your feedback. The timing of the conference has been criticised as poor, as those with children find this difficult to attend due to the start of the new term. However the timing has to coincide with venues that are pre term to students for availability and thus enable us to take advantage of the cheaper end of the conference venue market in using student accommodation. The content of next years conference we would welcome your ideas.

### **News from Coventry re the distance learning modules for oncology and palliative care**

For those of you who attended last years conference Karen Ward, Senior lecturer at Coventry University spoke about potential developments of a post graduate course at diploma level. This course will now be available from October 03. Please contact Karen directly for further information or see the flyer enclosed in the conference packs and on the website.

### **HOPE Support to study days**

It has being a long standing agreement that two HOPE members can apply to the committee for support for the funding for their travel to study days and the conference. Applications should be directed to Jill Cooper and should state why the support is sought and how the information gained will be cascaded to other members. Applicants will be informed one month prior to the study day of the committees decision.

### **Enjoy the conference**

I hope you enjoy the conference programme for this year, I do feel it's the best on yet ! but may be that's because I am bias.

### **AGM**

The AGM will be held at the close of the first day.

Minutes of last years AGM are available on the website, were published in the newsletter proceeding last years conference and copies are available at the front of the conference venue.

Jo Bray, 25 August 03  
Chairman

### **Membership Secretary's Report**

Membership of HOPE has continued to flourish over the past year – we must be doing something right!

Over 200 members immediately renewed their membership following our successful conference in Scarborough last year, mostly occupational therapists who have been members of HOPE for many years now. Following a reminder sent out to all those on the data-base at Christmas, another 100 odd people remembered to renew their membership. Over the past 6 months many occupational therapists new to this speciality have either emailed or telephoned to enquire about joining HOPE or printed the HOPE application form directly from the COT website themselves - yes, more and more people are moving into the 21<sup>st</sup> century!

To date (13<sup>th</sup> August 2003) the HOPE membership comprises

269 Full Time members	66 Part Time members
16 Student members	7 Overseas members
4 Non Practising members	1 Associate member
9 Honorary members	

.....a total of 371 members all together.

Out of interest you may like to know that our overseas members include one OT working in Sweden, one from Denmark and five working in Eire.

The Japanese and Australian members we had are now over here in England and are presently engaged in securing jobs in this speciality - in fact I believe Karen Taylor from New South Wales is hoping to attend the conference this year.

The honorary members include Help the Hospices, St Christopher's Hospice Information Officer, the Mildmay Education Department, the Chair of the ACPOPC (Assc. Chartered Physiotherapy in Palliative Care) Louise Cusack (COT), June McCarthy (COT) and the COT Library, and two OT's working in Bombay, India and Uganda. These members are only sent newsletters and we hope you agree that these people are interested parties worthy of receiving our news for free.

Hazel Lake, 13<sup>th</sup> August 2003  
Membership Secretary

### **Newsletter Editor's Report**

I was elected on to the HOPE committee as sub-editor for the Newsletter at the 2002 AGM. As Andrea MacDonald (Editor) was initially unavailable and subsequently resigned from the committee, I have taken over the role of Editor since September 2002. Since then, newsletters have been collated and sent to the typesetters in December 2002, March 2003 and June 2003. In May 2003, we were informed that the company who typed up the Newsletter were no longer able to do this. Having investigated various

other options, we now have another source who is able to do this for the same low cost at the previous company. The only difference that the membership will observe is a different, layout.

There is an inevitable time delay between my sending the Newsletter to the typesetters, and it being returned, copied at the Marsden printing room and sent out to members. This time may be reduced with the new plan to outsource mailshots/postage to a private company. A change for 2003 will be that the newsletter will need to be at the typesetters by end of October. This will ensure that the three newsletters will be more evenly distributed throughout the year.

I have aimed to make the newsletter a mixture of personal experiences of HOPE members and of looking at the wider, national picture. The personal experiences are supported by letters and reports from HOPE members, whilst the wider, national picture is supported by reporting on publications through a wide variety of sources which are all referenced accordingly. However, reporting on national issues is certainly an area for development to ensure equal representation for each country.

There are increasing cross-references to web-sites within the newsletter, as this reduces the amount of printing and reduces risks of breaching copy right. However, I am aware that not all members will have access to the web. Despite asking for feedback regarding this, I have not yet received any. I feel it is necessary to continue to give web-site information for members who do have web access, but it remains a concern that members who do not have access are missing out.

My aim for future newsletters is to have a focus on what is happening within the HOPE membership of the Cancer Networks. Once there is an established method of communicating with members within each Network, I plan to write to each Network lead once per year, requesting a summary of what is occurring locally. I would request that the Network lead co-ordinates the response from the HOPE members within that Network, in order to establish a picture across each Network. Therefore each Newsletter should contain several reports from different Networks. I feel that communication between ourselves, is highly valuable, and I hope that this is a way of enhancing it..

All feedback, positive and negative, will be gratefully received as this will enable future Newsletters to be tailored to the needs of the membership.

Anna Kittel, August 03  
Editor

### **Study Day Support Report**

I hope that 2003 will be remembered for the production of the lung and breast consensus documents for which I assisted with the organisation of the Days in Leeds and Manchester (the latter with Kate Gem).

At Cooridge I also organised three HOPE study days aimed at Community OT's with little or no previous experience in Oncology. This proved overwhelmingly successful. The information and content of the days is available for anybody who wants it!

I've also been involved in responding to various documents from NICE and I am currently applying to be on the development group for skin tumours. I think that this

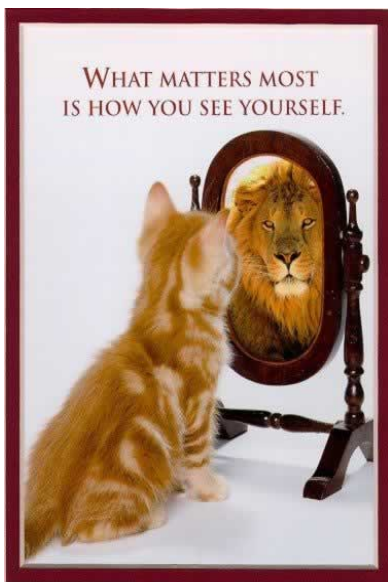
represents an exciting opportunity to influence policy from the top! This is open to anybody who is interested – you do not have to be on the committee!

On behalf of HOPE I also attended the business forum meeting for specialist sections. I am amazed at how much work is expected of the specialist sections, and never realised how much goes on behind the scenes too. Following this I also went to another meeting on the roles of the specialist sections, where future roles and support for the groups was evaluated.

I now have much more of an insight into how COT runs, where it spends it money etc!

I do have display board, which can be hired out for a returnable deposit of £25. HOPE pays for postage out and you pay for the return. So far this year we have had two enquiries so its an under developed resource which I hope you will make more use of next year!

Finally I would like to leave you with this thought



Kathy Thompson, August 03  
Study Day Support Officer

### **Research and Development Officer**

As Research and Development Officer for HOPE, I have the following roles and responsibilities:

1. Keeping up to date with new research, particularly related to occupational therapy in HIV/AIDS, oncology and palliative care, but also more widely in these fields. This includes networking and creating links with other researchers, both occupational therapists and other professionals. I have attended, on HOPE's behalf the annual meeting of the UK Palliative Care Research Society.

2. Providing advice and acting as a resource for students and colleagues with regard to research issues.
3. Co-ordinating the development of HOPE's Research and Development Strategy in collaboration with COT. This piece of work has recently got underway, and the aim is to have it completed in late spring 2004.
4. Continuing to develop my own research activities. My present research is on "The Rehabilitation Needs of Patients with Malignant Spinal Cord Compression". This is now nine months into its three year funded period. The lengthy process of ethical approval has been negotiated and I have begun to recruit participants.
5. Presenting papers / teaching at conferences and on study days nationally, on topics related to occupational therapy and palliative care, in particular, rehabilitation, research, measuring outcomes, and multiprofessional team-working. Activities in the last year have included:
  - *Outcome measures for OT in palliative care.* Allied Health Professionals Conference, St Barnabas Hospice, Lincoln. June 2003.
  - *Rehabilitation in palliative care.* (Seminar for palliative care nurses) Pretoria Hospice, South Africa. April 2003.
  - *The contribution of occupational therapy to quality of life for palliative care patients.* (Lecture to 3<sup>rd</sup> year OT students) Coventry University. March 2003.
  - *Multi-professional palliative care.* Worcestershire's Third Annual Palliative Care Conference, St Richard's Hospice, Worcester. February 2003.
  - *Communication at the end of life: issues for health care professionals.* (Lecture to MSc students) Coventry University. February 2003.
  - *Palliative care patients' perceptions of occupational therapy intervention.* Study Day for Allied Health Professionals, Arthur Rank Hospice, Cambridge. October 2002.
  - *How do occupational therapists cope with death and dying?* Occupational Therapy Study Day, LOROS Hospice, Leicester. September 2002.
  - *Rehabilitation with the dying: why bother?* The Royal Society of Medicine Palliative Care Conference, Scarborough. September 2002.
  - *Outcome measures update.* HOPE Conference, Scarborough. September 2002.

Gail Eva, August 03  
 Research and Development Officer

### **Web Development Officer**

This has been my first year on the HOPE committee and:

Part of my activity on the committee has been updating the HOPE web site. There is now, on the web site a feedback form, which can be completed if anyone has difficulty with or comments about the site. This has been used only three times, once with a request for an application form and twice by students requesting information. These requests are dealt with rapidly, or forwarded to the appropriate committee member.

I have set up the discussion forum, the first special interest group to do this, (rapidly followed by NANOT). This gives members the opportunity to discuss topics openly on the web.

Hope web site consistently remains amongst one of the most visited special interest group web site. It was the second most popular special interest group web site visited by the public and members, but topped the list with the most downloaded documents, for the special interest groups, by both members and Public in July 2003.

Hope Web site available at the COT web page on  
[www.baot.co.uk/members/specialist/hope/intro.asp](http://www.baot.co.uk/members/specialist/hope/intro.asp)

The committee members have responded to the NICE Improving Outcome Guidance Documents, including Lung, Breast and Supportive and Palliative Care Document. I supported this and taken the lead on respond to the Haemo-Oncology Document, collating responses from others for submission. It is hugely important that Occupational Therapy is included in these documents if we are to be recognised as having a valuable contribution to patient care. Inclusion in these documents will also impact on funding for posts as Commissioners of services would not be able to ignore the recommendations of NICE.

Other work the committee have involved members in has been the Consensus documents for Lung and Breast Cancer, which will support the evidence of the value of OT, and I look forward to the launch of these two documents.

I believe that the effort put into the above will be well worth while, and will be seen when the benefit of Occupational Therapy are properly recognised resulting in appropriately funded services for people who have cancer.

Sheila Parnaby 27 August 03  
Web Development Officer

#### **HIV AIDS Officer's Report**

Continued to support OT students and qualified practitioners in sourcing information for research projects and presentations

Continued links with OT college at Colchester re: teaching on HIV and AIDS

Responded to requests for visits from O.T's and students re visiting workplace - as part of problem based module on HIV and AIDS

E mail contact with Occupational Therapists practising outside the UK, e.g: assessments for HIV related brain impairment

Recently, myself and two other O.T's in HIV and oncology have been asked by COT to comment on NICE Guidelines for TB

Trends:

Recognition of increased need for OT input with those with an HRBI diagnosis e.g: student completing a poster presentation to her peers on this.

Camilla Hawkins, August 03  
HIV AIDS Officer

