



EDITOR'S NEWS

••• 'What - so soon?' I hear you exclaim as another copy of *UKI NETS News* rolls off the press (this time physically as well as virtually). In this dynamic second edition we have a word from our new chairman Prof Ashley Grossman and as he is far too modest himself, we have a short biography overleaf for those unaware of his eminence. Also in this issue: 'The NET Patient Foundation - A New NETs Charity' and another 'Did you catch this one?' Enjoy! **ALAN ANTHONY**

Chairman's Letter

••• I am delighted to introduce this edition of *UKI NETS News*, the first in my role as Chairman of UKI NETS.

Founded 5 years ago, principally due to the drive and motivation of Martyn Caplin, the group of physicians, surgeons, endocrine nurses and many others interested in NETs has now formally developed into a society with a constitution and rules administered by BioScientifica, who have extensive experience in running academic and clinical societies. We are keen to enlarge our existing membership as rapidly as possible in order to substantiate ourselves as the first port of call for all, from government to patients, who have an interest in this fascinating group of tumours. Having established a structure including an Executive Committee, which will be subject to democratic election by our membership, it is only by expanding our membership to include all branches of medicine that we can indeed represent the sub-specialty of NETs in the UK and Ireland, and I urge you to get your colleagues with a similar interest to join us. The membership fees are not high, with special rates for those in training and others on lower salaries, and automatically include membership to the European Neuroendocrine Tumour Society (ENETS) and access to its journal *Neuroendocrinology*. Indeed, the reduced payment for members for attendance at our annual meeting means that membership virtually pays for itself. These low fees are at least in part due to our excellent relations with the pharmaceutical industry, specifically Novartis and Ipsen, in a partnership purely based on an educational initiative. In my tenure as Chairman I very much look forward to a greatly



Ashley Grossman

enhanced membership, continuing close supportive ties with our pharmaceutical colleagues and a greater impact of UKINETS on clinical academic life.

While we originally focused on gastrointestinal and pancreatic islet cell tumours, we have agreed to embrace a wider range of NETs, particularly to include such tumours which may not be emphasised in the more traditional clinical societies: these include bronchial carcinoids, phaeochromocytomas and paragangliomas, and medullary thyroid carcinoma. This is not to say that we wish to abrogate these areas for ourselves, but to emphasise the multidisciplinary importance in the care of patients with such tumours, an approach that we feel uniquely able to offer. In the fullness of time we may consider joint meetings with some of the more traditional clinical organisations. In addition, we may consider at some time whether other 'orphan' tumours, such as adrenocortical carcinomas,

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would also benefit from being included within our orbit. It is however up to you, our membership, to decide the overall focus of our activities.

Part of our mission is to encourage nationwide clinical research protocols. To date the randomised chemotherapy trial, NET01, and the UKI NET conceived, Ipsen-sponsored placebo-controlled trial of lanreotide autogel in the treatment of asymptomatic NETs - now with Martyn Caplin acting as PI, a world-wide study - are successfully recruiting. I hope that UKI NETS can be the powerhouse for developing many more national initiatives and, as an example, we have set up an ad hoc working group of nuclear medicine physicians to assess the use of radiolabelled octreotide in the therapy of NETs, and to liaise with industry in making such treatment widely and uniformly available.

Our next major meeting is at the Royal Society of Medicine in London, on 1 December 2008. I warmly invite you to come along and enjoy the science and clinical cases at the meeting, and encourage all junior clinical staff and nurses to attend. Prof Mike Richards will give a keynote address in the afternoon: as the cancer czar he is in a very important position to emphasise the structured care of these 'Cinderella cancers', now that national strategies for the more common cancers are being implemented. Many of us believe that NETs are among the most difficult and controversial tumours to treat, but only as a group can we hope to offer our patients the best possible treatments now available, and devise the best strategies for the future. I hope and indeed believe that we are now pushing at an 'open door' in getting central funding agencies to agree with us.

ASHLEY GROSSMAN

WANTED - your news for future newsletters

Your news, views, meeting reports, and reviews of papers are all welcome. Please send your contributions to the Editor (Alan.Anthoney@leedsth.nhs.uk).

A profile of our Chairman...

Having qualified with a BA in Psychology and Social Anthropology, and a BSc in Neuroanatomy from the University of London, Prof Grossman graduated from UCH Medical School in 1975 with the University of London Gold Medal. He has been with the Department of Endocrinology in this institution since 1978. He has been on the Council of the Society for Endocrinology and is currently President of the European Neuroendocrine Association, as well as Chairman of UKI NETS. He previously served on the Ministry of Defence Advisory Committee on Research into Gulf War Syndrome. In 2001 he was elected Fellow of the Academy of Medical Sciences. He has co-authored nearly 600 original and review papers in endocrinology and had senior editorial responsibilities for the textbooks *Clinical Endocrinology* (1992, 1997), *De Groot's Endocrinology* (5th edition), the journal *Clinical Endocrinology*, and is on the Editorial Board of a number of journals.

A new NETs charity

WWW.NETPATIENTFOUNDATION.COM

The NET Patient Foundation, incorporating Living with Carcinoid, was formed in early 2006 and has now secured charitable status. By collaborating with Living with Carcinoid the charity is able to encompass patients with all types of neuroendocrine tumour.

The charity aims to: (i) support patients and their families through a manned support line; (ii) raise awareness of neuroendocrine tumours through campaigns, roadshows, fundraising events etc; (iii) improve the quality of life for patients and families through the moderated forum, help line and information; (iv) support research initiatives at the NET centres around the UK; (v) provide accurate and up-to-date information in the form of booklets, a quarterly newsletter, the website and patient support group meetings.

The charity is run by a small but dedicated staff with clinical or personal experience of neuroendocrine cancers aided by a medical and nursing advisory panel. The charity website can be found at www.netpatientfoundation.com

Did you catch this one?

There are many different modalities used in imaging NETs and some lend themselves to direct therapeutic intervention. A recent review in *RadioGraphics* - Neuroendocrine Tumors: Role of Interventional Radiology in Therapy (Stewart MJ *et al* 2008 28 1131-1145) - gives an up to date analysis of these methods and their roles in treatment. In addition there has been a recent update on the epidemiology of NETs from the American SEER database showing trends in incidence and survival. This can be found in the *Journal of Clinical Oncology* (Yao JC *et al.* 2008 26 3063-3072).



UKI
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