



## EDITOR'S NEWS

Welcome to the first edition of *UKI NETS News* - the newsletter of the UK & Ireland Neuroendocrine Tumour Society. Our aim is to inform, educate and perhaps even entertain with news, views and comment on the activities of the society and the wider field of neuroendocrine oncology. First and foremost, this newsletter should represent UKI NETS members and submissions for inclusion in future editions are

actively encouraged. Despite the diverse membership of the society (from clinical staff across a wide range of specialties to those involved in more fundamental research) there is much that is of common interest and we want to pass it on.

I hope you find it of interest and that it becomes a recommended read rather than a straight to recycle.

ALAN ANTHONY

## Chairman's Letter

As I finally finish my term as chairman of UKI NETS it is interesting to reflect on my personal journey leading to where we are today. In the early- and mid-1990's I had a number of patients at the Royal Free Hospital with metastatic carcinoid tumours and it was difficult to manage them. Some were on s.c Octreotide, others on Lanreotide LA, some went for transarterial embolisation while others had interferon or chemotherapy and we transplanted a couple of patients. It was clear that there was no evidence base or even guidelines available for management. Not only that, but within our own hospital different doctors from different specialities had different ideas for patient management. So in 1997 I set up the multidisciplinary clinic at the Royal Free Hospital. The ethos was very much that of team work and surprisingly there was little in the way of politics! Everyone saw a need and there was genuine enthusiasm, especially from my nuclear medicine colleague John Buscombe.

Having co-authored a review in the *Lancet* that further discussed the then novel concept of multidisciplinary teams I was invited in 1999 by Kjell Oberg and Michel Mignon, two highly esteemed figures in the field, to join what was then the European Neuroendocrine Tumour Group. I was very taken with their ambition and the friendship within the ENET group (also including Bertram Wiedenmann, Philippe Ruszniewski, Guido Rindi, Barbro Eriksson, Eric Krenning *et al*). The ENET group subsequently became a successful society. It became obvious that the UK needed to have some direction if we



Martyn Caplin

were going to improve the care of NET patients. Thus on 22 January 2000 a 2 day meeting for all interested parties was held at the Carlton Tower Hotel, London.

At that meeting we planned to form a specialist steering committee for neuroendocrine tumours named UK NETWORK, of which I was elected chairman. We contacted all the teaching hospitals and various specialist colleges to include on the committee those who wished to participate with a NET specialist interest. There were fears over politics and personalities but I have to say the defining feature has been the convivial atmosphere and the determination to make the committee a success and improve patient care in the UK. In November 2000 we held our first National Conference at the Royal College of Surgeons. We set out a programme for collaborative clinical studies and education, and began the process of developing guidelines. We were and still are grateful for the grants from Novartis and Ipsen which enabled the committee to function and they generously supported our annual conferences. The UK NETWORK committee met every 4 months and by 2004 we had published the UK guidelines for the management of NETs thanks to the leading work from John Ramage. I will take this opportunity to remember the late Keith Buchanan who was such a personal supporter and for years a leader in the field. He

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was recognised by UK NETwork for his enormous contribution to the field of NETs with the first life-time achievement award in 2004.

Briefly, the steering committee evolved and we developed collaborative studies on chromogranin assays, clinical trials related to somatostatin analogues and chemotherapy, as well as the annual conferences which continued to be a great success. More importantly one could see that patients were benefiting. Many centres were now developing their own NET clinics and these were becoming part of the recognised cancer network pathway. Patients were getting more appropriate work-up and there was a move to individualisation of care based on the biology of the neuroendocrine tumour. We had close links with the patient support group as well as encouraging the development of specialist NET nurses. In 2007/08 we took forward the process of becoming a formalised society and broadened our geographic horizons to become the UK & Ireland Neuroendocrine Tumour Society. Our remit also broadened. Having originally concentrated on gastroenteropancreatic NETs we are now also focusing on the other NETs including bronchial, thymic, thyroid, paragangliomas and pheochromocytomas. So it is time to move aside and let someone even more rounded (not just physically!) take the Society forward and I can think of no-one better than Ashley Grossman to do this.

I have felt privileged to lead the development of the Society over the last 8 years and the committee members have become not only colleagues but good friends. I am indebted to many for their support and I am convinced UKI NETS will continue to flourish and expand and would like to thank everyone who has contributed to make all this possible.

MARTYN CAPLIN

# UKI NETS 6th National Conference

MONDAY 1<sup>ST</sup> DECEMBER 2008

• The UKI NETS 6th Annual Conference will be held on Monday 1st December 2008 at the Royal Society of Medicine, London. Although not finalised, the programme hopes to include sessions on: molecular pathways in NET as targets for novel drugs, carcinoid heart disease, interventional radiology in NET and NET and the cancer reform strategy.

UKI NETS members will receive priority notification and will be eligible for the discounted registration rate. If you are a member, please ensure that we have your latest email address so we can notify you when registration opens.



## ENETS

• As a member of UKI NETS, you are entitled to free membership of the European Neuroendocrine Tumor Society (ENETS). Registration is very simple and will only take a few minutes of your time. To start the registration process, please visit the Membership page of the ENETS website.

Fill in your personal details making sure that you tick the box "I am already a member of UKI NETS" at the end of the form. This will enable you to register without submitting payment. If you require any assistance with this process then please contact the secretariat.

## Clinical trials & guidelines

• UKI NETS provides guidelines on clinical management of NETs available for download. In addition there is information on the multi-centre clinical trials open nationally including:

- Lanreotide Autogel vs placebo in non-functioning gastroenteropancreatic NETs and NET01
- Chemotherapy in metastatic pancreatic NETs and NETs of unknown origin (NCRI adopted).

Participation in, or referral of patients for, these studies is encouraged.

## Did you catch this one?

• Even with rare cancers there is such a diverse range of papers published that it is impossible to keep up. Have you read something you feel might be of general interest but in a single speciality journal?

We would be glad to pass it on. For example, there is nothing that excites a medical oncologist more than talk of molecular pathways and new drugs to target them. The review in *World Journal of Gastroenterology* (Hopfner, M. et al. 2008 14(16) 2461-73) gives a concise review of novel molecular targets in NET and drugs tested against them. There is a review of current clinical trials with these agents and ample references. Go read!

# UKI NETS

**UK and Ireland  
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