

EDITOR'S NEWS

With the UKI NETS 7th Annual Conference upon us I hope this edition of the newsletter will get you in the mood for interdisciplinary intercourse. We live in interesting times with an increasing concern from the pharmaceutical industry in all things neuroendocrine. Randomised trials of novel therapies are occurring but looming health service financial restraints pose questions over implementation of new treatments.

An active and dedicated neuroendocrine cancer community should be best placed to deal

with such challenges. A healthy membership of UKI NETS gives it the authority to speak on NET-related issues at the highest level. Local interdisciplinary dialogue acts as peer support and allows exchange of best practice (see the NONETS review below). These also allow development into less well researched NET areas (bronchial NETs in this issue). I hope you enjoy this issue. Please note the exciting information about the 2010 UKI NETS 8th Annual Conference overleaf.

ALAN ANTHONY

North of England Neuroendocrine Tumours Group

A little local get together

Neuroendocrine cancers: you think that you've got the hang of them and hey presto, the very next patient breaks all text book conventions and you're left wondering if what you're doing is reasonable. Just as likely you think your management plan for, say, mid-gut carcinoids is sound but how do you know? Do you ask the audience or go 50:50? How about getting together informally with a group of your colleagues on an occasional basis to discuss cases, practice and perhaps even do a bit of auditing or develop some research. Under just these circumstances the North of England Neuroendocrine Tumours (NONETS) group was started in 2008.

The 5 main centres treating neuroendocrine cancers in the North of England (a mythical place of flat caps, clogs and smoky mills - or Liverpool, Manchester, Leeds, Sheffield and Newcastle to the uninitiated) decided not to form a splinter group of UKI NETS but to have a bi-annual get together for the purpose of sharing practical information.

The first meeting was held in Leeds in October 2008 where each of the centres gave a short presentation of their set up, the kinds of patients seen and what facilities they had to offer. For a relatively new set up in Leeds it was reassuring to see just how much some of our more established neighbours had had similar teething problems in bringing together a truly multidisciplinary team for the management of NETs. Various cases were discussed and in the end the group felt that it had been such a worthwhile exercise that they wanted to do it twice a year.

The latest meeting was in Newcastle (after a very successful March meeting in Liverpool) on October 2nd 2009. The weather was inclement



Angel of the North, Gateshead

and various clinical emergencies had resulted in last minute alterations to the agenda but, Professor Manus brushed them aside to preside over an enjoyable and clinically orientated meeting. There was a talk on interventional radiology (Dr J Rose, Newcastle) where differences in the use of chemoembolisation and bland embolisation between the centres came to light. Its benefit in symptom control certainly made me consider bringing it up the treatment algorithm. Mr G Sen presented some local treatment and outcome data from the Newcastle NET group. The emerging role of sunitinib was discussed by Dr J. Valle (Manchester) including presentation of some cases who had taken part in the pivotal study. After lunch there was a practical explanation of the WHO and TNM pathological staging/grading systems from Dr C Verbeke (Leeds) - to be repeated at the UKI NETS annual meeting: don't miss it!

Finally, a series of case presentations from each of the centres highlighted issues such as the difficulties in treating ectopic ACTH production from pancreatic NETs and renal carcinoids.

At the end of the meeting we all still felt that it was a useful, informal, non-judgemental setting in which to improve our experience, and hopefully management, of patients with the whole range of NET conditions. With the generous support of Ipsen and Novartis we plan to have the next meeting in Manchester next March.

THE NONETS GROUP

DID YOU MISS?

Neuroendocrine Tumours of the Lung

❖ Neuroendocrine tumours of the lung perhaps at times sit uneasily amongst the endocrine and gastrointestinal domination of the NET world. However, they represent an important and under-studied subset of neuroendocrine disease requiring interaction with a different range of medical specialties. A consequence of this was a recent referral for a second opinion to the regional 'specialist clinic' of a condition that I had never heard of before. Diffuse intrapulmonary neuroendocrine cell hyperplasia (DIPNECH) is a recently defined (1992!) entity ranging from non-invasive proliferations of scattered neuroendocrine cells within the bronchial or bronchiolar epithelium, through tumourlets invading through the basement membrane to tumours >5mm in size. DIPNECH is thought to be a primary proliferation and is sometimes associated with constrictive obliterative bronchiolitis. The largest series of cases to date is presented in a review from the Royal Brompton and Royal Liverpool Hospitals (Diffuse idiopathic pulmonary neuroendocrine cell hyperplasia: an under-recognised spectrum of disease. Davies S.J. *et al* 2007 *Thorax* 62 248-252).

This series amounts to only 19 patients and descriptions of presentation, radiology, pathology and clinical presentation are given. Although thought to be benign, a word of caution is given due to associations with other conditions such as atypical carcinoid. Presumably in such a recently characterized entity the true natural history remains uncertain and one for further analysis.

Along a similar vein, a paper published in the *Journal of Thoracic Oncology* (Ferolla P *et al*. 2009 4 383-387) from the Umbrian regional neuroendocrine multidisciplinary group discusses the significance of tumourlets, multicentric disease and lymph node metastases in a series of 123 resected bronchial carcinoids. The high incidence of such features in both typical and atypical carcinoids leads to the suggestion that major surgical resections with systemic nodal dissection and identification of multifocal lesions is required. A number of relapses at > 10 years is also noted, indicating the need for long term and careful follow up.

Finally, at the more advanced end of the spectrum, colleagues at the Royal Free Hospital have reported their series of 45 patients with bronchial NETs treated through the Neuroendocrine Tumour Unit (Srirajaskanthan R *et al* 2009 *Lung Cancer* 65 68-73.). Many of these patients presented with advanced disease and the review describes the patient demographics and imaging studies as well as the range of treatment modalities used and likelihood of benefit.

ALAN ANTHONY

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.Anthony@leedsth.nhs.uk)

UKI NETS 8th Annual Conference

❖ The UKI NETS 8th Annual Conference will be held at the Europa Hotel, Belfast on Monday 6th September 2010, as part of a joint meeting with the 18th International Symposium on Regulatory Peptides and the 1st National NET Patient Foundation Conference, from 5th-8th September. The three days of sessions will feature some very high profile speakers and the clinical focus on the 7th and 8th September promises to be of great interest to UKI NETS members.

The UKI NETS 8th Annual Conference 2010 will be held in Belfast



Berlin is the setting for the 7th Annual ENETS Conference



PHOTO: THOMAS WOLF

7th Annual ENETS Conference

❖ The 7th Annual ENETS Conference will be held in Berlin, Germany, from 11th-13th March 2010. Full details will be updated on the ENETS website (<http://www.neuroendocrine.net/conferences10.html>).

UKI NETS

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UKI NETS Membership

❖ UKI NETS welcomes new members who have demonstrated an active interest in the management of NETS. To become a member of UKI NETS, please complete the application form (<http://www.ukinets.org/membership/application.html>). Your application will be reviewed by the UKI NETS Committee. Please view the terms and conditions of membership.