NCCP appoints new Neuroendocrine Tumour National Lead Clinician

National Cancer Control Programme establishes network to manage rare form of cancer

The National Cancer Control Programme has today, Thursday June 6th, announced the appointment of Professor Dermot O'Toole as the National Clinical Lead of the Irish Neuroendocrine Tumour (I-NET) group.

A Consultant Gastroenterologist at St James's Hospital and Trinity College Dublin, with a specialist interest in digestive tumours and especially neuroendocrine tumours (NETs), Prof O'Toole has worked closely with the NCCP to further develop a multidisciplinary group devoted to NETs in St Vincent's University Hospital (where he will also have a part time commitment). Working with consultant colleagues across the country, he will lead a project to develop a National Programme for Neuroendocrine Tumours, building a network involving the designated cancer centres in Dublin, Cork and Galway.

A graduate of TCD, Prof O'Toole has worked (obtaining dual accreditation in gastroenterology and GI oncology) as a Professor in the University of Paris attached to Beaujon University Hospital – the leading French unit devoted to pancreatic tumours and an internationally-recognised group in the Neuroendocrine tumour field (lead by Professor Philippe Ruszniewski). Following almost nine years in France he returned to Dublin to take up his position in St James's and TCD.

Announcing the appointment of Prof O'Toole, the Director of the National Cancer Control Programme, Dr Susan O'Reilly said she was delighted that a clinician with the expertise and experience of Prof O'Toole had agreed to assume the role. "This development is ultimately about our patients. This is an uncommon cancer and requires a particular focus and approach. We want to ensure that patients are diagnosed as swiftly as possible and have access to multi disciplinary teams to provide a comprehensive diagnosis and to allow for the most appropriate treatment plan to be put in place".

"We are taking a network approach which means that patients across the country will have access to the same standardised service and will be seen and treated directly by the clinicians with the most experience and depth of knowledge in this particular specialised area."

Neuroendocrine tumours (NETs) are cancers formed by cells emanating from endocrine components of many organs and tissues and may release hormones or peptides in response to signals from the nervous system. They occur at various sites in the body but are most commonly diagnosed in the digestive system, particularly the stomach, pancreas and small small bowel. Many NETs are benign – they do not invade the surrounding tissue or spread to other parts of the body. However, around 200 invasive NETs are diagnosed annually in Ireland with the most recent statistics showing that 206 cases were diagnosed in 2010.

As neuroendocrine tumours are an uncommon form of cancer, some patients in recent years had been referred abroad for treatment. The appointment of Prof O'Toole, along with the establishment of the network will offer a fully comprehensive and clinically advanced treatment and management regime for patients. Although a minority of patients may still require specialised therapy abroad, the majority will access treatment and care in Ireland. This new approach will provide for a dedicated service for all patients, regardless of location. It also means that Ireland now offers a service on a par with similar services internationally.

Explaining the challenge facing those working with patients with NETs, Prof O'Toole explained that NETs "is a complex group of tumours where diagnostic methods and therapies vary widely and require a dedicated multidisciplinary approach. International evidence suggests that optimal survival and reduced mortality are achieved when by focusing and concentrating a programme to a limited number of institutions with a high volume of patients thus providing the necessary diagnostic and therapeutic skills".

Prof O'Toole currently serves as an Executive Committee member of the European Neuroendocrine Tumour Society (ENETS) – a large society that has been extremely active in developing international guidelines and standards for the management of patients with neruoendocrine tumours.

The importance of concentrating expertise is outlined in the Pan-European ENETS-Centre of Excellence programme, chaired by Professor O'Toole. This has led to the certification of 25 centres throughout Europe with independently ISO-recognised standards. Each centre is capable of providing an excellent quality of care to patients on a standardised basis.

"While neuroendocrine tumours represent a rather rare disease, many patients live a long time so the overall prevalence is quite high. We estimate that there are at least 2000 cases in Ireland (the total number of people living with and managing their condition on an ongoing basis) at any one time and this clearly underscores the need for a dedicated network in Ireland which is the approach we are now taking."

NETs are classified according to where the cancer started (where the primary tumour is) in the body inclusive of small bowel NETs; large bowel NETs; appendiceal NETs; pancreatic NETs; gastric NETs. Lung NETs are also relatively common but are dealt with by the Thoracic Physicians and Surgeons. Rarely, NETs are found in other areas, including the liver, gallbladder, bile ducts, kidneys, ovaries or testicles. NETs often grow slowly, and it may be several years before symptoms appear and the tumour is diagnosed.

However, some NETs may be fast-growing and more likely to spread to surrounding tissues, liver and to other parts of the body. While the incidence of the disease in Ireland is on a par with other countries (around four per 100,000) - since 1994 there has been a steady increase in numbers being diagnosed. A total of 58 cases were diagnosed in 1994, while in 2010, 206 cases were reported representing an annual increase of eight per cent.

Many patients are diagnosed incidentally – the tumour is likely to be have been detected while the patient was undergoing investigations or treatment for an unrelated illness. One third of adrenal NETs and 22% of invasive NETs of the appendix were detected in this way between 2006 and 2010. A large proportion of NETs of the digestive system, particularly the small intestine are carcinoid tumours. Some tumours may secrete substances resulting in specific recognisable symptoms (e.g., carcinoid syndrome - combining diarrhoea and flushing).

Surgical removal of the tumour is the main treatment for patients when possible; in patients with digestive NETs, up to 60% will present with an advanced pattern (often with liver metastases) and surgery is therefore not always possible. Other treatments are available such as standard chemotherapy and newer chemotherapeutic drugs that have recently been tested in large clincial trials. "The number of available therapeutic options are fortunately increasing and this is having a really positive impact on patient management", according to Prof O' Toole.

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