



**New Irish NETs Cancer Patient Support Group is launched**

Monday, 26 November 2012 21:33

font size   | [Print](#) | [E-mail](#)



Pictured at the launch of the NET Patient Network are L-R: Margaret Flannery, Castlebar, Co. Mayo, Dr Dermot O'Toole, Gastroenterologist, Saint James' Hospital, Dublin, Margaret Plunkett, Dublin.

*Colm Mahady / Fennells*

A new support group, called Net Patient Network, for people dealing with a rare form of cancer, Neuroendocrine Tumours (NETs) was launched on Worldwide NET Cancer Awareness Day in the Stanley Quek Lecture Theatre, Trinity Biomedical Sciences Institute, Trinity College, Dublin.

Now in its third year, Worldwide NET Cancer Awareness Day aims to raise awareness about endocrine or hormone-producing tumours and the need for timely detection, diagnosis and treatment; bring hope to NET cancer patients, their caregivers and families; and drive action. More than 50% of NET

patients are incorrectly diagnosed and initially treated for the wrong disease, for three to seven years on average.

SEARCH MAYO DIRECTORY



search local listings

Local Search

OUR ADVERTISERS



AdChoices

**Building Contractor**

For all Your Building Needs House Build, Extensions/Conversions  
[www.sheridanddevelopments...](http://www.sheridanddevelopments...)

**55/YO Mum Looks 35**

Mum Reveals Shocking Trick for Erasing Wrinkles! Doctors Hate Her  
[Purit-E-Skin.com/AntiAging](http://Purit-E-Skin.com/AntiAging)

Direct Mail with

Plunkett, Dublin.

*Colm Mahady / Fennells*

bring hope to NET cancer patients, their caregivers and families; and drive action. More than 50% of NET

patients are incorrectly diagnosed and initially treated for the wrong disease, for three to seven years on average.

Often the correct diagnosis is not made until the cancer has spread (metastasized). The need for better awareness and understanding of NET cancers is underscored by the coverage of the recent death of Steve Jobs, former Apple CEO. Mr. Jobs had a pancreatic neuroendocrine tumour (pNET), a slow growing and rare cancer that is often confused with the more aggressive pancreatic cancer, which many reports said he had.

The director of the National Cancer Control Programme, Dr Susan O'Reilly opened the patient support group event and outlined the model she sees the Irish health service developing for people with NETs. And in a unique development, leading international as well as Irish experts dealing with carcinoid cancer from Dublin, Cork,

#### Treatment centres

Galway and Uppsala, Sweden, a recognised international centre of excellence for the treatment of carcinoid cancer participated in a Question & Answer session with patients.

The experts included Dan Granberg and Barbro Eriksson of University Hospital, Uppsala and Professor Dermot O' Toole, Gastroenterologist, Saint James' Dublin, Donal O' Shea, Endocrinologist, Saint Vincent's Hospital, Dublin, Criostoir O'Suilleabhain, Surgeon, Mercy Hospital, Cork, Greg Leonard, Oncologist, University College Hospital, Galway and Derek Power, Oncologist, Mercy Hospital, Cork.

Although they are usually slow-growing cancers, NETs are difficult to detect and diagnose. They can occur in different parts of the body but are most often found in the gastrointestinal tract, including the small and large intestines, stomach and appendix, and in the lungs. Worldwide NET Cancer Awareness Day organizers hope that the campaign will raise awareness of these cancers and reduce the number of undiagnosed or misdiagnosed tumours.

Commenting on the launch of the new Irish support group, RTÉ's Northern Editor Tommie Gorman, who is a principal organiser of the group and has been dealing with the rare form of cancer for almost 20 years said: "At the meeting, we teased out issues like where are the best places in Ireland to receive care, what are the improvements we need, how can we get access to treatment in places like Sweden when we need it.

"It is encouraging that the person who has overall charge of shaping cancer care services, Dr

Tri  
Wr  
He  
Pur

Di  
Ar  
De  
Po:  
a S  
Adf

Be  
Ar  
As  
pr  
on  
www

Er  
Bt  
Ea  
In  
Go  
Bu  
Get

LAT

Bal  
win  
of S  
Sch  
winr  
Cate

Mu  
Mir  
tra

Hospital, Cork, Greg Leonard, Oncologist, University College Hospital, Galway and Derek Power, Oncologist, Mercy Hospital, Cork.

Although they are usually slow-growing cancers, NETs are difficult to detect and diagnose. They can occur in different parts of the body but are most often found in the gastrointestinal tract, including the small and large intestines, stomach and appendix, and in the lungs. Worldwide NET Cancer Awareness Day organizers hope that the campaign will raise awareness of these cancers and reduce the number of undiagnosed or misdiagnosed tumours.

Commenting on the launch of the new Irish support group, RTÉ's Northern Editor Tommie Gorman, who is a principal organiser of the group and has been dealing with the rare form of cancer for almost 20 years said: "At the meeting, we teased out issues like where are the best places in Ireland to receive care, what are the improvements we need, how can we get access to treatment in places like Sweden when we need it.

"It is encouraging that the person who has overall charge of shaping cancer care services, Dr Susan O' Reilly opened our meeting and sat in on our discussions. This gave us a wonderful opportunity to help shape the services that we need to stay alive and healthy."

At the meeting, the Chairperson and Committee of the support group was selected. Commenting on his new role, Chairperson Mark McDonald, a 47 year old married father of three, said: "I am delighted to be selected as Chairman of our new patient support group, NET Patient Network. I hope we can establish our fledgling organisation as a strong and active support network for new and existing NET patients in Ireland.

"As a recently diagnosed patient, I found it very difficult to find reliable information about the disease and specifically what treatments and services are available in Ireland. www.NETPatientNetwork.ie will provide a central location of information for new and existing patients and with specific emphasis on Irish services. Having an active community of patients in every county in Ireland will be enormously helpful to patients to cope with and to manage their disease."

Read 178 times |  Like this? Tweet it to your followers!

Published in [Mayo Today](#)

Tagged under [health](#)

Social sharing 

## LATEST NEWS

**Ballina students win art prize** Pupils of St. Nicholas' Special School were First Prize winners in the Special Category...



**Mulherin tells Minister public transport...** Mayo Fine Gael TD Michelle Mulherin has said that the lack of public transport...



**Pocket guide book to The Great Western ...** The Great Western Greenway', by Iris Galloway, the very first guidebook to the immensely...



**West Mayo's young water deputies to plug...** The children of Killeen, Kilmeena and Drumgallagh National schools are aoinn the

