



NET Patient Foundation

incorporating
Living with Carcinoid

*Help and Support for patients
and their families affected by
neuroendocrine tumours*

The NET Patient Foundation incorporating Living with Carcinoid was formed at the start of 2006 and has Charity Commission status. The collaboration with Living with Carcinoid meant that the charity could spread its wings to include patients with all types of neuroendocrine tumour.

How does it feel to be diagnosed with a Neuroendocrine Tumour?

Fearful, concerned, and perhaps a bit confused.

One patient stated,

'This disease came out of the blue with no warning. Suddenly I found myself facing blood tests, urine tests, CT scans and nuclear medicine imaging. It was so frightening and I had nothing to read that seemed to relate to what I was experiencing'.

'Neuroendocrine tumour' (NET) is the umbrella term for a group of relatively rare cancers, often called the 'quiet cancers'.

Around 2,000 new cases are diagnosed every year but it is thought that a larger number of people have a NET, but remain undiagnosed.

This is because NETs are often slow growing and so symptoms can take time to develop, may be vague, or attributed to more common and less serious problems such as IBS, Crohns disease, peptic ulcer disease or gastritis.

Healthy neuroendocrine cells play a vital part in the hormonal system and are found in all parts of the body. There are particularly high concentrations in the pituitary, thyroid, lungs, pancreas, and gastrointestinal system, the most common primary sites of NETs. Cancer develops when these cells act abnormally and multiply creating a growth, in the same way as any other tumour.

The characteristics that sets NETs apart from other cancers is that usually this process is slow, although some patients do go on to suffer from aggressive disease.

One of the main characteristics is that NETs produce a large number of hormones and these hormones can affect the whole body and not just the tumour site.



By producing patient documentation, having a strong website and a community for chat, we can disseminate information to the people that really need it. Letting them know that they are not alone and that there are a number of healthcare professionals with extensive knowledge of this disease, and people to listen and help in many different ways.

The Foundation has 5 main aims:

- 1.** To provide accurate and up-to-date information for people living with, or affected by, neuroendocrine tumours. We do this through information and forums provided on the website (and links to other sources of information on the web).
- 2.** To provide support for patients and others affected by neuroendocrine tumours. We offer a support line which is manned by an experienced healthcare professional; and organise patient support groups around the UK and Ireland.
- 3.** To improve the quality of life for patients and their families. We can do this by providing support and information about services and treatments available, as well as by funding and publicising research and existing medical initiatives.
- 4.** To raise funds, which will help to support research around the UK.
- 5.** To raise awareness of neuroendocrine tumours throughout the UK and Ireland, within the medical community and the general public.

The charity relies solely on donations and fund raising initiatives, so if there is anything you can do to help then please get in touch.

We truly hope the service we offer will help you in some way

Catherine Bouvier

Director of Patient Support



A wide range of materials are available to patients



NET Patient Foundation
incorporating
Living with Carcinoid



Help and Support for those with 'The Quiet Cancer'

TEL: 0800 434 6476 / 07976578321

Enton Mill, Enton, Godalming, Surrey GU8 5AH.

Fax: 01428 685599.

Email: catherinebouvier@btinternet.com

Web site: www.netpatientfoundation.com

Registered Charity No. 1092386

Trustees: Peter Gwilliam and Roy Craft

**Patrons: Dr Martyn Caplin
Dr Sarah Brewer**