



The Juli Spendley Foundation

In September 2009, Juli Spendley was diagnosed with Neuro-Endocrine Tumors (NETs), a rare and poorly understood form of cancer which affects a minority of the cancer suffering population.

Much like many other forms of cancer, Neuro-Endocrine Cancer can affect the Liver, Pancreas, Digestive Tract, Bone and the Lungs. However unlike some more common cancers, NETs are quite rare (it is believed that there are up to 3000 new cases diagnosed every year – around 1% of the UK cancer diagnosis rate*) and usually slow growing tumours often spreading to multiple organs, and as such are rarely diagnosed at a sufficiently early stage to facilitate effective treatment by conventional methods.

**In 2007, Cancer Research UK published figures indicating that there were in excess of 293,000 diagnoses for the more common forms of cancer.*

This is compounded by a general ignorance of the condition within the medical profession, resulting in symptoms being dismissed as minor infections and mistreated accordingly, furthermore NETs are not as responsive, to standard chemotherapy treatments, as the more common forms of Cancer.

In June 2010, having been frustrated by the general lack of understanding of this life threatening condition, Juli and her family set up the **JULI SPENDLEY FOUNDATION**, to assist sufferers, who like herself, have been denied funding for specific targeted treatments that could prolong their lives; as well as helping to bring a better understanding of this disease to the medical profession allowing faster diagnosis and earlier treatment.

Synopsis for Targeted Radionuclide Therapy

Targeted Radionuclide Therapy (TRT) kills cancer cells by delivering a lethal dose of radiation. The radiation is usually attached to a 'carrier' that selectively seeks out tumour cells.

As with external beam radiotherapy, TRT offers the advantage of delivering high radiation doses to a specific target but in common with chemotherapy it can deliver treatment systemically, attacking multiple sites throughout the body.

It is a relatively benign treatment that does not incur the side-effects, such as hair loss and prolonged nausea, often seen in more conventional radiotherapy treatments. Regular blood tests are required after therapy to monitor blood count and kidney function.

How radiation works for cancer management

When a radioactive atom decays, one or more of a number of particles are emitted. Beta particles act like small billiard balls, travelling only short distances in the body until hitting nearby cells and killing or damaging them. It is these particles that are mainly responsible for delivering radionuclide treatment.

Since the radioactivity is constantly decaying, the success of a treatment is dependent on the amount of radioactivity that is taken up in a tumour and how long it remains localised.

With many radioisotopes used in TRT, gamma rays are also emitted. These rays are simply high energy light that is invisible to the naked eye but imageable by the specially designed cameras which are used in nuclear medicine. It is therefore possible to simultaneously administer treatment and to see the radiation that deliv-

Professor Martyn Caplin, is the consultant in gastroenterology and hepatobiliary medicine at the Royal Free Hospital in Hampstead, he is the founder and immediate past-chairman of the UK & Ireland Neuroendocrine Tumour Society as well as scientific secretary of the European Neuroendocrine Tumor Society. He is chairman of the National Cancer Research Institute Neuroendocrine Tumour Clinical Studies Group. He additionally leads a research programme into the science of NETs promoting new understanding of the biology of these tumours and also leading to new therapeutic developments as well as being significantly involved in clinical trials for these tumours. He has published extensively in the field and lectures both nationally and internationally.

The foundation aims to raise funds in a number of ways including sponsored activities and events as well as private and corporate donations.

A diary of upcoming events along with the results and details of previous events is available from our website at:

<http://www.thejulispendingfoundation.net>

For information on ways in which you can help the foundation please contact us at:

info@thejulispendingfoundation.net



Juli's Story

I was diagnosed with Neuro-Endocrine Cancer in September 2009 after a year of non-specific signs and symptoms, making diagnosis difficult. I was offered a trial chemotherapy which was delivered in four cycles. Unfortunately, due to the time delay prior to diagnosis, this had no effect and the tumors had already spread from the lung, to the liver and to different bones around the body.

I later had some radiotherapy to ease the pains in my hip, whilst this was helpful, the bone metastases have since increased, and hence the associated pain has increased.

The Royal Free Hospital in London are pioneering a targeted treatment, aimed specifically at blocking the receptors of Neuro-Endocrine Tumors. This is called Radionuclide Therapy, and I am eligible for this treatment.

However, the Dorset PCT have turned down funding so my friends and family are helping to raise the £24,000 needed to have this treatment following my next course of chemotherapy.

I am currently awaiting a decision from the Dorset PCT as to whether they will fund this chemotherapy.

The purpose of the Juli Spendley Foundation is also to help others like myself who have been denied funding for treatment that could prolong their life.

Professor Martyn Caplin is the head of the Neuro-Endocrine Unit at the Royal Free Hospital and he is passionate, like myself, at raising awareness about Neuro-Endocrine Cancers in the medical profession, so that earlier diagnosis is more likely, and the patient then has more time and treatment options available to them.