

## **Patrick Sandes' Summary of Wendy Gillis' Presentation to the Toronto Carcinoid-Nets Local Support Group on Sunday October 22 2006**

Patrick is a member of the Toronto Carcinoid Nets Local Support Group

### **Part 1**

First, a word about Wendy Gillis. She's a Nurse Practitioner and works closely with Drs Kocha and Reid at the London Regional Cancer Centre (LRCC). But that brief line barely encompasses what Wendy represents to anyone who has been to London for treatment. She is a truly willing, articulate, and caring source of authoritative information and guidance for patients; she always seems ready to help no matter how busy she is. Setting the unquestioned expertise of Dr Kocha, Dr. Reid and, now, Dr. Sanatini aside, Wendy is, for many, a big reason why the LRCC has become such a source of hope and comfort in dealing with neuroendocrine tumours and the resultant carcinoid syndrome.

Wendy's presentation was in two parts. The first part encompassed a review of neuroendocrine tumours (NETS), the hormones produced by different kinds of tumours, and the symptoms associated with those hormones; the second part described the various programs used by the LRCC to manage the different NETS.

Before getting into details, Wendy listed the members of LRCC carcinoid team, which includes:

- Dr. Walter Kocha, Medical Oncologist
- Dr. Robert Reid, Nuclear Medicine Specialist
- Wendy Gillis, Nurse Practitioner, working with Drs Kocha and Reid
- Rosemary Davidson, Primary Nurse with Dr. Kocha
- Dr. Michael Sanatani, Endocrinologist (who has just joined the team)
- Lisbet Williams, Primary Nurse with Dr. Sanatani

Wendy listed the types of radioisotope used at LRCC:

- Samarium-153, which emits gamma (70%) and beta (30%) radiation, is used primarily in bone metastases, especially for the management of pain
- Indium-111 octreotide is classed as an internal conversion electron reaction and is used for nuclear medicine scans as well as for therapy in a much higher dose, either with or without chemotherapy ( 20 times the diagnostic dose).
- Iodine-131 MIBG (meta-iodobenzylguanidine) emits gamma radiation. It is used for diagnostic scans and for therapy in combination with chemotherapy, or alone. (40 times the diagnostic dose.)

Both the Indium-111 and Iodine-131 are labeled in a way that causes them to either bind to receptors (In-111) or to be taken into the tumour cell (MIBG). This makes them useful in visualizing the tumours either in the liver or elsewhere in the body. Both radioisotopes alter the metabolism of the tumour cell so it can't continue to divide.

In her description of NETS, Wendy stressed the advances that have been made in detecting them. One specific advance has been the use of an index of growth rate known as Ki- 67, that can easily be detected in growing cancer cells to show how quickly they are growing. This assay, now considered the gold standard in diagnosing NETS, is done through biopsy. A low count indicates that slow cell proliferation is occurring.

Tumours with a Ki-67 of 5% or less can be treated with isotope. Those with a Ki-67 of greater than 10% behave more like a small cell cancer and are more appropriately treated with standard chemotherapy. Those with a Ki-67 between 5 and 10% are intermediate and are a bit more difficult to decide. Sometimes, depending on other factors, they may be treated with isotope plus chemo.

A tenfold increase in the incidence of carcinoid cancer has been observed over the past decade. Improved diagnostics may be a partial explanation, but is not seen as the only one.

NETS fall into many classifications. The main ones are carcinoid and pancreatic. Carcinoids are the most common and typically refer to tumours that occur in:

- the foregut (bronchial and gastric carcinoids)
- the midgut (small intestine carcinoids -- the most common cause of carcinoid syndrome when metastatic)
- the hindgut (rectal carcinoids)

Pancreatic tumours include:

- Insulinomas, associated with symptoms of hypoglycemia (intermittent confusion, sweating, weakness, and nausea)
- Glucagonomas, necrotizing migratory erythema (chronic reddish brown skin rash), cachexia (physical wasting with loss of weight due to disease), and diabetes
- VIPomas (Vasoactive Intestinal Peptide), watery diarrhea and electrolyte disturbances
- Gastrinomas, gastrin-producing tumours that result in diarrhea, peptic ulcers, gastric reflux and acid hypersecretion

Other less common NETs are pheochromocytoma (adrenal glands), paraganglioma and medullary thyroid.

Wendy then walked us through the most common hormones and peptides associated with Carcinoid syndrome and the symptoms they produce:

- Serotonin
- Histamine
- Bradykinin
- Kallikrein

These hormones and peptides cause the symptoms of flushing, diarrhea, abdominal cramps, wheezing and, eventually, the right-sided valvular heart disease known as endocardial fibrosis.

It is important to remember that there are likely many more biologically active peptides and hormones that cannot be measured at this time.

The only thing we can readily measure in London are 5-HIAA (the breakdown product of serotonin excreted in the urine), and catecholamines (also a 24 hour urine), excreted with pheochromocytomas and paragangliomas), and calcitonin (thyroid tumours)..

This more or less covers Wendy's remarks on NETS and Carcinoid Syndrome. My next email will review the programs currently used by LRCC to treat them.