



---

---

**Patient-Doctor Seminar**

**June 9-10, 2007**

***Round-table Discussion***

***Sunday, June 10***

---

---

## Overview

The group met at 9:00 a.m. for a buffet breakfast and the meeting started at 9:30. About 50 patients and doctors, including Drs. Granberg, Kocha, Reid, Rivera, and Wong, were in attendance. This substantial group was testimony to the commitment of all involved to helping CNETS evolve as a strong, focused advocate for patients with carcinoid-neuroendocrine disease and the doctors, nurses, and researchers treating them or looking for new solutions.

## Process

The meeting was scheduled to run until 11:00 a.m., so we faced the challenge of producing a concrete result, drawing on the knowledge, experience, and insights of 50 people, in 90 minutes or so. We therefore decided to facilitate a brainstorming session with the group working in teams of three-to-six people.

## Outcomes

### *Goals*

The first order of business was to establish explicit goals for the months and years ahead. These would not be carved in stone, but they would certainly give us a track to run on for the time being. Each team was asked to generate a list of what it saw as the three priority goals. Once they had accomplished this, they presented what they saw as their Number 1 goal so that, by the time we'd heard from every team, all the goals they had discussed had been tabled and recorded on the flipchart. Here were the priority goals:

- Partnerships – developing strong partnerships with key players in the health field, i.e. ministries of health, other advocacy groups)
- Easier, funded access to drugs not approved in Canada
- A new, more efficient approval pathway for new drugs
- An active patient support network across Canada
- Stable funding (at provincial level) for treatment programs for carcinoid patients
- Increased and sustained publicity for carcinoid-neuroendocrine disease
- International cooperation and better access to out-of-country medical resources that offer treatments not available in Canada
- Increased awareness of carcinoid symptomology among General Practitioners
- Improved communication and education for carcinoid patients

### *Action Plans*

The headings below are not a precise reflection of the goals listed above. This is because there was considerable overlap in the goals and the action plans reflect this.

## Funding

1. The CNETS Board is to develop a clear understanding of how to maximize its opportunities while minimizing the risks associated with funding initiatives and report back to the membership in 90 days.
2. A parallel initiative will increase *communication* and *education* among CNETS members and others on the subject of funding, with these objectives:
  - a. A better understanding of the approval process

- b. Improved cooperation and strategic partnerships with pharmaceutical companies
  - c. Finding ways to reduce the burden on doctors in the fight for improved funding
  - d. Establishing a strong, clear *voice* for carcinoid-neuroendocrine disease in Canada
  - e. Improving the education of lay people around carcinoid-neuroendocrine disease
3. *Strategic partnerships* should be developed between CNETS and key pharmaceutical companies such as Novartis.
4. A support group database, capturing all individuals and groups identified across Canada, is to be built, with the work starting immediately.
5. Improve our knowledge of how to access and influence specific audiences, e.g., politicians, government agencies, pharmaceutical companies, hospitals etc.; make sure that key CNETS people know exactly what it takes to get our messages through.

## Support Groups

1. Establish a database of patients and caregivers across Canada.
2. Aim for 50 CNETS groups across Canada in 2007.
3. Make sure all libraries across Canada have up-to-date inform on carcinoid-neuroendocrine disease and CNETS.
4. Establish better web-based support resources.

## GP Communication & Education

1. Devise a better, quicker way for doctors to identify carcinoid symptoms and quickly refer their patients on to specialists.
2. Develop a new Continuing Medical Education approach, i.e.:
  - a. Approach and work with CME creators
  - b. Create a web-based talk by a carcinoid specialist and find a way to motivate GPs to take it in
  - c. Tap into family practice journals
  - d. Make CME events interactive to double credit for participating doctors
3. Establish a website for doctors with information about carcinoid-neuroendocrine disease.
4. Find better ways to help all the health professionals associated with a particular carcinoid patient to connect and share information (so that GPs learn more about the disease).
5. Create a simple, clear information tool so that patients can quickly get a better understanding of their disease and of where to go for more information.
6. Establish a library of carcinoid-neuroendocrine disease information that GPs and others can easily access.
7. Establish better links and partnerships with other support groups and societies to exchange information and ideas.
8. Find ways to access local medical media.

## Publicity

1. Establish an E-bay registration to increase visibility.

2. Make our website easy-to-find and accessible so that visitors get important information quickly.
3. Get our website considered an "approved resource" with the CCS – high standard to get approval; need to have reciprocal links to carcinoid.ca - they are already an "approved resource."
4. Create a pamphlet for physicians.
5. Provide a flow of stories for local and national media.
6. Find a famous 'noid" poster-person.
7. Write and distribute a monthly newsletter.
8. Build a list of all physicians in Canada.
9. Find one or more corporate sponsors who will adopt CNETS.
10. Create marketing products to make carcinoid-neuroendocrine disease more visible over time.

### **Government Intervention**

1. Encourage the Ontario government to adopt the *Centers of Excellence* model, to make the largest possible pool of patients available.
2. Encourage government to establish a minimum standard for carcinoid patient care, i.e., ensuring that everyone gets an initial evaluation by a knowledgeable doctor.

### **International Cooperation**

1. Educate doctors on treatment alternatives not available in Canada.
2. Increase doctor-to-doctor communication within Canada and abroad.