



Toronto Conference

From Maureen Coleman. Co-Chair Task Force for the Conference ...

Please Register Now for the Toronto October 16-19 Carcinoid NET Patient Doctor Conference and Symposium.

We have a new improved easy to use Registration Process in place for \$75.00 CDN or USD for the conference. Please check the Registration Page for our ONLINE and our PRINT OUT registrations.

The Crowne Plaza Toronto Don Valley 1-800 number is also on that page at the bottom of the page. Our special rate is \$112.95 per night, for 9 nights, from the 13-21 October inclusive, in case you would like to take some time to explore Toronto and the surrounding region.

Toronto is a theatre and sports hub. Fall will be in bloom with beautiful reds, yellow, and oranges.

For our US registrants, if you fly to Buffalo, you can get a really cheap bus for about \$7.00 for a two and a half hour trip from Buffalo Airport to downtown Toronto. Please Google Megabus.

Toronto Pearson is a major International Airport.

You can also fly from Newark, New York to Toronto Island on Lake Ontario with possibly the

Continued on page 3

CCAN Upcoming Events

The Carcinoid Cancer Awareness Network, Inc. has scheduled the following events:

Saturday September 13, 2008 11 am - 12 pm Webinar with J. Philip Boudreaux, M.D., FACS: "The Role of Surgery in the Management of Patients with Abdominal NETS" With a Question and Answer session

Friday Oct 3, 2008 MN Support Group Fundraiser Banquet, \$45 per person

Saturday Oct 4, 2008 8:30 am- 5 pm CCAN and Minnesota Carcinoid Cancer Support Medical Conference "The Diagnosis and Treatment of Carcinoid Cancer & Neuroendocrine Tumors" \$20 Per Person.

Speakers include Dr Eugene Woltering Dr Thomas O'Dorisio , Dr Timothy Sielaff, Nancy Gardner , PhD, ARNP - BC and Sidney Levinsohn, R.PH.

Both events held at the Hilton Mall of American ,3800 American Blvd, Bloomington, MN 55425 Overnight accommodations at the for \$99 if reservation made by 9/3/08

Registration will open soon for the following events :

Friday November 21,2008 and Saturday November 22,2008 CCAN 5th Annual Fundraising Gala and Medical conference. To be held at the Glen Cove Mansion , 200 Dororis Lane Glen Cove, NY 11542 Details to be announced soon.

Nov or Dec 2008 DTA A Webinar with Dr. Richard R. P. Warner, MD Medical Director of the Carcinoid Cancer Foundation. Professor of Medicine, at The Mount Sinai Hospital and School of Medicine with his focus of

Continued on page 4

Upcoming Dates

September 7th, 2008 – New Jersey Chapter meeting at Crossroads Christian Fellowship. Union, NJ, 1:30 PM. Contact Jim Weiveris at 609-812-9294 or Caring4Noids@aol.com

September 7th, 2008 - Long Island, NY Chapter meeting. Verify dates at www.carcinoidaware.org or call 516-781-7814.

September 20th, 2008 - SEA Lecture, Glendale, CA. See article to left for information.

October 16th to 18th, 2008 - Toronto Patient-Doctor Conference. See article to left.

Nov. 21 & 22, 2008 - CCAN Fundraising Gala & Medical Lecture. Check www.carcinoidaware.org or call 516-781-7814 for mor information

September 24, 25 & 26 2009 - 2009 National Conference, New Orleans, LA. Details will be published as they become available.

SEA Group Lectures

From Nickolette Way...

SEA is very pleased to be hosting a 1 day seminar for patients, caregivers and families on September 20, 2008 in Glendale, California. We have posted an updated flyer on our website.

I am hoping you can let the patients of your groups know about this event and let the members know how they can register. You may note that

some of the speakers have changed since our initial notice. We apologize for any confusion but this is frequently the result of working with busy physicians and their very full schedules. I believe the speakers we currently have scheduled are incredibly knowledgeable, very experienced and will do a terrific job in presenting the

Continued on Page 4



~~~~~  
For newsletter questions & submissions please contact: Jim Weiveris  
Phone/Fax: 609-812-9294  
[Caring4Noids@aol.com](mailto:Caring4Noids@aol.com)  
Mailing address is:  
9 Maplewood Dr.  
Little Egg Harbor, NJ 08087

## Bringing Lu<sup>177</sup> to the US

The Carcinoid Cancer Foundation has asked everyone to help out by writing the U.S. Food and Drug Administration (FDA) for approval to bring the Lu-177 treatment into the US. Currently Lu-177 is only available in Europe, despite several studies that show the effectiveness of the method.

From the Erasmus Medical Center website (in Rotterdam, where many of these procedures are done), "From January 2000 until August 2006 1772 treatments with lutetium-octreotate were given to a sum of 504 patients. Most patients had neuroendocrine tumours. A preliminary analysis in 310 patients with so-called gastroenteropancreatic tumours was performed after obtaining all results after finishing the treatment. This showed a decrease in the size of the tumours in 46% of patients, stable disease in 35% and progression of the tumour despite treatment in 20%. A significant improvement of quality of life in those patients with tumour regression was also noted. The average duration of the effect of therapy was 40 months, calculated from the start of therapy. In addition, there are strong indications that patients treated with Lutetium-octreotate, on average, survive several years longer (3-6 years) than patients who did not get this treatment."

The Carcinoid Cancer Foundation (CCF) has contributed initial funding to Dr. Ebrahim S. Delpassand, Principal Investigator of the project to test treatment with LU-177 for the first time in the United States. CCF's goal of this project is to achieve

the same successful results with this treatment in the US that have already been obtained in Europe.

Carcinoid and NET patients, their families, and friends can help by writing to the FDA and asking for expedient approval of this project. Please send your e-mails to: Mrs Milinda Vialpando at [Milinda.vialpando@fda.hhs.gov](mailto:Milinda.vialpando@fda.hhs.gov)

The following is an excerpt from a letter to the Carcinoid Cancer Foundation from Dr. Delpassand:

*"We have now completed our response to the FDA and need help of the carcinoid community. We are thoroughly dedicated to bringing the LU-177 treatment to the United States. Our institution has spent thousands of Dollars and my research team and I have spent hundreds of man hours on this project. This treatment has been available in Europe for more than 5 years and hundreds of patients have received treatment. There are more than ten peer-reviewed publications regarding this treatment in reputable medical journals documenting its safety and efficacy. When writing to the FDA, this is a very valuable piece of information. On our end, we will continue focusing our efforts for all our patients;*

*As always, thank you very much for your help.*

*Best Regard,  
Ebrahim S. Delpassand, M.D.  
Principle Investigator, IND  
78,256"*

Take a few moments and e-mail the FDA now and show you support of adding this treatment to our arsenal. The life you save may someday be your own...

## Our Sister Groups

**Arizona Carcinoid Team** – Meets in Phoenix, For information contact, James at [act\\_mail@yahoo.com](mailto:act_mail@yahoo.com)

**NorCal CarciNet (NCCN)** meets at the Wellness Community in Walnut Creek, CA. For information: [cancerfighter@sbcglobal.net](mailto:cancerfighter@sbcglobal.net)

**Northern CA - NCF** meets in Fairfield. For information contact, Kathy at [karbanis@yahoo.com](mailto:karbanis@yahoo.com)

**Carcinoid One on One** meets in Orange, CA. For information contact, Terri at [Terris12@att.net](mailto:Terris12@att.net)

**SEA (Support Education & Awareness for Carcinoid Patients)** Not affiliated with CalCF. Meets in SanGabriel/San Fernando Valley area. For information contact, Nickolette at [sea4carcinoid@msn.com](mailto:sea4carcinoid@msn.com)

**South Bay Carcinoid Fighters (LA)** Meets in Redondo Beach, CA. Pat [carcinoidfighter@yahoo.com](mailto:carcinoidfighter@yahoo.com)

**Connecticut Carcinoid Initiative** - Meets at the Veterans Home & Hospital in Rocky Hill. Contact, Pat [PStrongLaw@aol.com](mailto:PStrongLaw@aol.com)

**Capital Area Carcinoid Survivors** (Washington, DC) – For information visit the group's web site, <http://hometown.aol.com/cacs/ya/>

**Florida** (informal group) Pam [prpowell@cfl.rr.com](mailto:prpowell@cfl.rr.com)

**Chicagoland Carcinoid Fighters** Meets in Gurnee, IL contact pending

**Boston Area** –At the Dana-Farber Cancer Institute - contact Sarah Murphy, LICSW at 617-632-6463 or the New England Carcinoid Connection (NECC)at [www.carcinoid-newengland.org](http://www.carcinoid-newengland.org)

**Michigan** - Meeting place may rotate. Contact Dave at [Dav2005@earthlink.net](mailto:Dav2005@earthlink.net)

**Minnesota Carcinoid Peer Support Group**, contact Jan Jackson [jaxon7@msn.com](mailto:jaxon7@msn.com), also covering western WI and surrounding areas

**Arkansas**– Meets near Hot Springs. Contact Kathy, [terris12@cablelynx.com](mailto:terris12@cablelynx.com)

**Central Pennsylvania** - (Harrisburg/Hershey), For information contact, Teresa [CarcinoidSupport@juno.com](mailto:CarcinoidSupport@juno.com).

**Pennsylvania / Philadelphia** Delaware Valley Carcinoid Connection, contact Suzi [info@phillycarcinoid.org](mailto:info@phillycarcinoid.org)

**Dallas, Texas** Contact Carol-Anne for information [CarolAnne52@gmail.com](mailto:CarolAnne52@gmail.com)

**Houston, TX** Contact Jan Peine, [carcinoid@comcast.net](mailto:carcinoid@comcast.net)

**Austin, TX** - For information contact, Ann Meyer [ameyer@swrcc.com](mailto:ameyer@swrcc.com)

**Carcinoid NeuroEndocrine Tumour Society Canada** - For information contact Maureen C. [maureenc@sympatico.ca](mailto:maureenc@sympatico.ca) or <http://www.cnetscanada.org/>

**Oregon Chapter of Pacific Northwest Group** - contact Kari at [Kbrendtro@yahoo.com](mailto:Kbrendtro@yahoo.com)

**Washington (state) Chapter of Pacific Northwest Group** - For information contact, Corie at [cadean@NATPIPE.COM](mailto:cadean@NATPIPE.COM)

For the latest list of support groups visit the Foundation's web site ([www.carcinoid.org](http://www.carcinoid.org)), our web site ([www.carcinoid.us](http://www.carcinoid.us)) or Susan Anderson's web site <http://www.carcinoidinfo.info/>

To list your group or update a listing, please send us a note

# Toronto Conference

*Continued from Page 1*

shortest Ferry Ride in the world to downtown Toronto on Porter Air as part of the ticket.

Detroit is a four hour drive. New York, Boston, Washington, Cincinnati, can be driven in less than 12 hours. Virginia or St Louis, which are further south, take a little longer.

Passports are required for air travel. Two pieces of ID including birth certificate and drivers' licence are required for land border crossings. Travel Health Insurance is important.

Please take a look at our comprehensive program at [www.cnetsconference.ca](http://www.cnetsconference.ca).

We have many interesting sessions on diagnosis, treatment, therapies, and research. One session is on important NET research using a mouse model.

The presenter is Prof Girish M Shah from Laval University in Quebec City, Quebec, Canada, whose student, now Dr Mathieu Beland, won a poster award in Portland in 2006 from the Carcinoid Cancer Foundation. Dr Shah is now on the Board of Directors of CNETS Canada.

World renowned faculty is coming from Canada, the US, Sweden, the UK, France, Germany, and India.

This program has been created for patients, caregivers, and medical professionals of all kinds.

Many of the biggest NET names worldwide will be there, including, from the US, Drs Richard RP Warner, Dr

Eugene A Woltering, Dr Edward M Wolin, Dr James Pingpank, Dr Thomas O'Dorisio, and Dr M. Sue O'Dorisio, who will be speaking on topics of great interest to the NET patient and caregiver, at a level patients and caregivers can understand....while not compromising the need for the integrity of the CME credits.

From France, Dr Philippe Ruzsniowski, who has researched Lanreotide, and is President elect of ENETS, will be speaking.

Nuclear physicians, Prof Dr Richard Baum, (Bad Berka, Germany), Dr Muriel Buxton-Thomas, (King's College, London, UK), Dr Manoranjan Chowhan, (Pune, India), Dr Robert H Reid, (London, Ontario, Canada), Dr Irina Rachinsky, (London, Ontario, Canada), and Dr Sandy McEwan (Edmonton, Alberta, Canada) will be speaking.

Dr Peter Metrakos (theraspheres) is coming from Montreal, Quebec, Canada. Dr David Liu, interventional radiologist, will be coming from Vancouver BC, Canada.

Dr Kjell Oberg, and Dr Dan Granberg, from Uppsala, Sweden, both renowned for ground breaking work will be there.

Dr Doug Quan of London, Ontario, Canada will talk about his work with transplant patients.

There will be a number of surgeons presenting on different aspects of NET surgical procedures, including Dr Quan, Dr Daryl Gray, London Ontario, Pancreatic

NET surgery and Dr Janice Pasioka of Calgary Alberta on Aggressive Palliative Surgical Intervention.

Medical oncologists from Canada, including Dr Walter Kocha, Dr Simron Singh, and Dr Lillian Siu, and the US, mentioned above, will discuss many aspects of NETS.

Quality of Life issues are on also the programme led by Dr Michael Sanatani, medical oncologist, of London Ontario, Canada.

NET cardiologist Dr Bryan Dias of London, Ontario will talk about Carcinoid NET heart issues.

Dr Stan VanUum of St Joseph's Hospital London, Ontario, will talk about MEN1.

Monica Warner will be there in conjunction with Philippa Davies of the London UK Royal Free Hospital to talk about their new work on nutrition for NET patients.

Lunchtime Round Tables will be conducted by our own Dana Sussman, and Kathy Arbanasin as well as Cathy Bouvier from NETPatient Foundation in the UK and also the Access Sandostatin Program, which is a Canadian home program through parent company Novartis.

Cathy will also be available for patients throughout the conference as a support group advisor.

The Arizona Group will be bringing copies of their new Patient Handbook and will have a table at the conference.

Patient Support groups are welcome to join us and have a

table.

The London Health Sciences Centre in London Ontario Canada will actually have over a dozen members of their fabulous team presenting.

We expect to be offering 15 Continuing Medical Education Credits through the Nuclear Medicine Department of the University of Western Ontario, in London, Ontario.

To comply with CME requirements, 25 per cent of the conference programme needs to be interactive. These sessions will be interspersed through the program.

Bill Claxton is going to be there to video record all sessions. Bill ably recorded the National US conferences for the last few years in NOLA, Philadelphia, Portland, and Virginia.

We are thrilled to have Bill on board here at the Toronto Conference.

Dr Robert H Reid of the London Health Sciences Centre and I are Co-Chairs of the CNETS Canada Task Force for the Conference which also includes Kathy Arbanasin, Jim Kormos, Susan Oliver, Patrick Sandes, and Silvia Steinhilber.

There is simply too much on offer for patients and medical professionals, to adequately describe here. Please check out [www.cnetsconference.ca](http://www.cnetsconference.ca) and register for our conference.

Please inform your wider NET community about this conference. cancers and lung carcinoids.

## Novartis Announces SOM230 Trial

Novartis Oncology has begun distributing literature asking for participants for the Phase III trial of SOM 230, also known as pasireotide.

SOM 230 has an affinity to bind with more receptors than Octreotide. The drug shows possible indications for use in patients with NETs, Cushing's and Acromegaly.

SOM230 works by suppression of cell proliferation and inhibition of growth and adrenocorticotrophic hormone. It also has a very long plasma half life.

In vitro data shows that while Octreotide has a primary affinity for tumor cell receptor SST2, SOM230 has a 20 to 30 times greater binding affinity to SST1 over Octreotide, 5 times greater binding affinity to SST3 and 40 to 100 times greater binding affinity to SST5. The purpose of this study is to evaluate the effectiveness and safety of pasireotide vs. Octreotide. LAR

Candidates to participate in the trial must be 18 years old or older, have inadequately controlled (using maximum approved doses of Somatostatin analogues) symptoms of carcinoid disease, and have biopsy proven metastatic carcinoid tumors of the digestive tract.

Patients may not have gallstones, poorly controlled diabetes, have had major surgery and/or radiotherapy within a month of starting the study, or have not recovered from any side effects of chemotherapy.

Other inclusion and exclusion

criteria may also apply.

The study will be held at multiple centers and is a randomized, blind trial. Patients will receive either Octreotide LAR or pasireotide by random assignment. Pasireotide is administered once a month by intramuscular injection.

Effectiveness will be based upon symptom control (reduction in bowel movements and flushing episodes).

If interested in participating, or for more information, contact Novartis at 1-800-340-6843 or visit [www.novartisclinicaltrials.com](http://www.novartisclinicaltrials.com).

For more information on clinical trials in general, visit the National Institute of Health (NIH) website at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). This trial is Protocol No. CSOM230C2303.

Attempts to verify information at the Novartis website found this trial to not be listed with a search feature. The NIH clinical trials website listed locations in California, Oregon, Louisiana, Florida, Texas, Arizona, Indiana, Maryland, Massachusetts, North Carolina and Washington as participating in this study.

The NIH website shows this study to be "not yet recruiting" as of this writing. These may be lag times in updating website information.

As with any clinical trial, it is suggested that you discuss this option with your professional medical care team before enrolling in any trial.

## You Paid How Much?

Want to know what others are paying for medical procedures? Then check out the new, free website, [www.outofpocket.com](http://www.outofpocket.com). Launched in June 2007, this is a grass-roots website, aimed at exposing the true costs of routine health care.

They allow consumers to post the actual costs paid for services. They have a search feature that allows you to search by procedure name, and you can limit that search with a zip code. You can also browse by category.

Anyone can post to the website, but before posting they do require you register. They only ask your screen name, gender, year of birth and to choose a password. All information is kept confidential.

With insurance companies frequently reducing their payments, citing fees above "reasonable and customary", the information posted may be an asset to getting them to change that number.

For "fun", a search on Octreoscan only returned one entry (\$3100) even without a zip code limit. A search on Colonoscopy returned 281 entries.

Matches to your search include the "list price" (what the provider wanted to charge), the actual cost (what insurance agreed to pay) and the out of pocket cost (what the patient paid). The entry also has date of service, provider, and insurance information listed.

The information supplied is only as accurate as those who entered it, but it can be

better than nothing in fighting providers and insurance companies to reduce their rates or raise their limits.

The list of entries is rather limited, but as more people find the site and add their experiences, it should become more comprehensive.

## SEA

*Continued from page 1*

information to our patients. We are so pleased that each of these doctors has been willing to make time in their schedule for us. An Information Flyer can be found on our SEA website 'Special Event' page at: <http://www.sea4carcinoid.com/pages/events.html>

Patients can mail in the flyer via us postal (obtain registration form at this web address)

[http://www.sea4carcinoid.com/pages/downloads/2008\\_Registration\\_Form.pdf](http://www.sea4carcinoid.com/pages/downloads/2008_Registration_Form.pdf)

OR those interested can use our new, easy to use online registration form accessed via our SEA website.

## CCAN

*Continued from page 1*

activity entirely devoted to clinical practice, teaching and development of a Center for Carcinoid and related Neuroendocrine Tumors. at The Mount Sinai Hospital and School of Medicine

For more information, visit their web site at [www.carcinoidaware.org](http://www.carcinoidaware.org) or call 516-781-7814.