

Carcinoid Cancer Foundation Lecture

On April 26th the Carcinoid Cancer Foundation held another one of their successful annual lectures at Mt. Sinai Hospital in New York City. Over 100 attended, foregoing the warm day outside and sunny skies to learn more about Carcinoid from the experts.

The lectures served to remind us of the unique needs of carcinoid patients, and especially how they should not be “lumped together” with traditional cancers when deciding on diagnosis and treatment protocols. The overall message was upbeat and encouraging. Not only were the differences illustrated, but they were explained in a way that virtually anyone could understand.

Top experts presented information and were available to answer questions later. The lead off lecture was from Dr. Rodney Pommier of Portland, Oregon. Dr. Pommier’s lecture was very well presented and informative. He brought forth a concept of a cancer paradigm, which showed just how cancers are perceived by most, and how Carcinoid is the “upside down cancer” in this paradigm.

Continued on page 6

New Jersey is Planning Conference

Maybe you can’t make it to the Annual Patient Conference (this year in New Orleans). Or maybe that a two day conference is just “too much”.

But what if you had the opportunity to ask questions of two of the greatest practitioners in Carcinoid,

why would you not go? I am not talking about the annual patient conference being held this year in New Orleans. I am talking about in New Jersey.

Even if you went to New Orleans, Dr. Oberg is not on

Continued on page 2

Annual Patient Conference is Filling Up

The annual patient Carcinoid/NET conference will be held in New Orleans on September 24 to 26th, 2009. But hurry, seating is limited and it is already filling up fast.

The cost is \$85.00 per person and that includes the Thursday evening reception, and breakfast for Friday and Saturday. Lunch and dinner are “on your own”.

The conference is being held at the Crowne Plaza (same location as in 2004), right in the historic French

Quarter at 739 Canal St.. The hotel is offering a special conference rate of \$149 per night, but you must book before August 29th to get the special rate.

Call the hotel at 888-233-9527 and tell them you are with the “2009 NET conference”

To register, or for more information, go to <http://carcinoidawareness.mofruit.com/#> or call the Carcinoid Cancer Awareness Network at 516-781-7814. The most recent agenda is on pages 3 & 4.

Carcinoid Cancer Foundation Continues Its Work at ASCO

The Carcinoid Cancer Foundation, White Plains, NY will again continue its education efforts by again hosting a Carcinoid booth at ASCO. This year’s ASCO

conference is being held in Orlando, May 29-31 and annual attendance is around 25,000 to 35,000. Our thanks for their bearing this work and expense.

Upcoming Dates

June 14th, 2009 – New Jersey Carcinoid Cancer Network meeting at Crossroads Christian Fellowship. Union, NJ, 1:30 PM. Directions on website or contact Jim Weiveris at 609-812-9294 or Caring4Noids@aol.com
Please note that the NJ meeting is the second Sunday this month.

July 11th, 2009 - Long Island, NY Support Group meeting. Verify dates at www.carcinoidaware.org or call 516-781-7814.

September 24, 25 & 26, 2009 - 2009 National Conference, New Orleans, LA. See article on page 1, to left. or go to www.carcinoidawareness.org

October 17th, 2009- New Jersey Carcinoid Cancer Network lecture. Manahawkin, NJ. See article on page 1, to left.



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For newsletter subscriptions, 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

# New Jersey Conference

*Continued from Page 1*

the agenda, but he and Dr Warner will be speaking in Manahawkin, NJ on October 17<sup>th</sup>.

The one day conference is being held at the Manahawkin Holiday Inn on Rt. 72, just a few miles from some of the best beaches in New Jersey. Registration and check-in will start at 8:15 AM with Dr. Warner leading off the lectures at 8:45

Also speaking will be Monica Warner, who will give a presentation on the Carcinoid Cancer Foundation. There will be one other lecturer, but since final arrangements have not been completed, we cannot announce that person's name yet.

Manahawkin is just a few minutes from Long Beach Island. October is often a good time to enjoy the Jersey Shore area. The days tend to be warm, and the crowds have dwindled down. Plan to stay a day or two to enjoy the area.

The Holiday Inn is offering a special room rate for the conference and related stay of \$159 per night. The hotel offers free Internet access, exercise facilities, an indoor pool and Jacuzzi, cocktail lounge and grille. Book on-line at [www.HolidayInn.com/Manahawkin](http://www.HolidayInn.com/Manahawkin) or call 800-465-4329. To get the discounted rate, you must book before September 9<sup>th</sup>. Use the code CCN. Check-in is after 3 PM and check out is 11 AM.

There are many restaurants and eating places in the area so rather than have you pay for a limited meal, lunch will be up to the person. We are compiling a list and map of eating places and will get that

out soon.

The hotel restaurant also offers a conference special, fixed price lunch which includes soup, your choice of a selected entrée and dessert, all for \$8.95. Reservations for lunch at the hotel are not required.

The cost to attend is \$35 per person, but you must register before October 2<sup>nd</sup>. Walk-ins and late registrations, if space is available, will be \$45 per person. If you decide to cancel before October 2<sup>nd</sup>, your registration fee, less a \$5 administrative charge will be refunded shortly after the conference.

You can register with the attached form (page 9), or you can register on-line at [www.NJCarcinoidNetwork.org](http://www.NJCarcinoidNetwork.org). Click on the Conference button on the left side. Payment must be made in check regardless of how you register.

A tentative agenda and directions are on pages 7 & 8, respectively.

All of the medical professionals will be available for the question and answer session and we have specifically lengthened that segment to try to allow as many questions as possible. We are also working to have a medical professional from Novartis join us to answer any questions you may have regarding Sandostatin LAR and Octreotide therapy and administration.

Space is limited, so register early. We hope to see you there and we are looking forward to an educational and fun experience.

# A Carcinoid Trip

*By, and with thanks to, Tom Mazza*

The call came from my doctor in November 1997. He quickly explained, "I have good news and bad news. The results of the biopsy from your colonoscopy revealed that you have a carcinoid tumor in the ileum. You need to have it taken out."

I was still waiting for the good news and then was told that it is slow growing and after surgery I would probably be o.k.

Thus I started my journey into the world of Carcinoid Cancer. I followed my doctor's advice and scheduled an appointment with a surgeon at Memorial Sloan Kettering Hospital.

Within a week I was on the operating table for what I thought would be a simple resection of my intestines, removal of the tumor, recuperation, and back to my normal life. Boy was that naïve!

Nothing went according to plan. The surgeons were unable to remove the tumor and it was discovered that it had spread to the liver. The best they could do for me was an intestinal bypass which would allow me to eat.

At some point after I had been told that I had an incurable disease the inevitable question was asked, "How long do I have". In my case I was told 5 years and was referred to an oncologist at the cancer center.

During my recuperation period, I began searching on the internet and started to educate myself as to what this

carcinoid cancer was all about. In 1997 there were very few resources that reflected contemporary thinking regarding the treatment of this disease.

As I became more informed about Carcinoid Cancer I was becoming more disillusioned with the do nothing or very little approach that was being recommended.

I then became aware of a doctor in New York who specialized in Carcinoid Cancer and in April 1998 I had my first meeting with Doctor Richard Warner. What a Difference!!

This man spent hours with my wife and me going over my case. From the beginning, it was obvious that he was the person I wanted to entrust with my treatment for this orphan cancer.

I was fortunate enough to become a regular patient of Dr. Warner's and for the last eleven years I have seen him almost every month.

For me, my treatment plan has consisted of low dose chemotherapy which started out in IV form and has migrated over the years to oral drugs. Of course, one of the better developments that happened early on was the switch from self injecting Sandostatin two or three times daily to the LAR format.

So for now, other than being easily fatigued, I continue to have almost a completely normal life style and wait for the next breakthrough in the treatment of Carcinoid Cancer.

## 2009 National Carcinoid/NET Patient Conference Agenda – New Orleans, LA

**Thursday, September 24, 2009**

Astor Ballroom

|                |                   |
|----------------|-------------------|
| 4:00 - 6:00 pm | Registration      |
| 6:00 - 9:00 pm | Welcome Reception |

**Friday, September 25, 2009**

### BIOMARKERS/PATHOLOGY FOR CARCINOID & ISLET CELL

Moderator – William Go, MD  
Grand Ballroom C & D

|                  |                                                                                                                                                                   |
|------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 7:00 - 7:45 am   | Registration & Breakfast                                                                                                                                          |
| 7:45 - 8:00 am   | Welcome & Opening Comments - Eugene Woltering, MD - New Orleans, Louisiana                                                                                        |
| 8:00 - 8:45 am   | What Do You Need To Do For Accurate Tissue Diagnosis? Why Are The European & US Staging Schemes So Different? Guido Rindi, MD - University of Parma, Parma Italy  |
| 8:45 - 9:30 am   | NET Blood & Urine Markers: Does It Make A Difference What Lab You Use? What About Octreotide & Lanreotide Plasma Levels??? Thomas O'Dorisio, MD - Iowa City, Iowa |
| 9:30 - 10:15 am  | Drug Resistance Testing Robert Nagourney, MD - Long Beach, California                                                                                             |
| 10:15 - 10:30 am | Break                                                                                                                                                             |
| 10:30 - 11:00 am | Over The Counter Vitamin Supplements & Alternatative Therapies: How To Assess Safety & Efficacy Mary Hardy, MD - Los Angeles, California                          |
| 11:00 - 11:30 am | Question & Answer Session Hardy, Nagourney, O'Dorisio, Rindi & Go                                                                                                 |
| 12:00 - 1:00 pm  | Lunch & Live Cooking Demonstration By Chef Marc Gilberti                                                                                                          |

### ESTABLISHING THE BASICS: WHAT DO YOU REALLY NEED TO KNOW?

Moderator - Eugene Woltering, MD  
Grand Ballroom A

|                    |                                                                                                                                 |
|--------------------|---------------------------------------------------------------------------------------------------------------------------------|
| 7:00 - 7:45 am     | Registration & Breakfast in Grand Ballroom C & D                                                                                |
| 7:45 - 8:00 am     | Welcome & Opening Comments in Grand Ballroom C & D                                                                              |
| 8:00 - 8:45 am     | Introduction - What Is A Neuroendocrine Tumor, Islet Cell, Carcinoid? Richard Warner, MD - New York, NY                         |
| 8:45 - 9:30 am     | What Are Biomarkers & Why Are They So Important? Not All Labs Are The Same – Why? Eugene Woltering, MD - New Orleans, Louisiana |
| 9:30 - 10:15 am    | What Is The Role of Surgery In Carcinoid? J. Philip Boudreaux, MD - New Orleans, Louisiana                                      |
| 10:15 - 10:30 am   | Break                                                                                                                           |
| 10:30 - 11:00 am   | What Is Radiation, X-rays, Nuclear Medicine Scans & Radioactive Therapy? Gregory Espenan, MS - New Orleans, Louisiana           |
| 11:00 - 11:30 am   | Chemotherapy: What Is It? How Does It Work? Lowell Anthony, MD - New Orleans, Louisiana                                         |
| 11:30 - 12:00 noon | Question & Answer Session Anthony, Espenan, Boudreaux, Woltering & Warner                                                       |
| 12:00 - 1:00 pm    | Lunch & Live Cooking Demonstration by Chef Marc Gilberti in Grand Ballroom C & D                                                |

### WHAT'S NEW IN NETS

Moderator – Eugene Woltering, MD  
Grand Ballroom C & D

|                |                                                                                                                                                     |
|----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|
| 1:00 - 1:30 pm | How To Prepare For Your Expert Opinion Appointment Pam Ryan, RN, BSN - New Orleans, Louisiana                                                       |
| 1:30 - 2:00 pm | Sentinel Lymph Node Biopsies Of The Small Bowel & Pancreas: How Does This Direct Surgical Resection? Yi-Zarn Wang, DDS, MD - New Orleans, Louisiana |
| 2:00 - 2:30 pm | How To Use The Intra-Operative Gamma Detector To Find "Hot Nodes" & Hidden Tumor Deposits J. Philip Boudreaux, MD - New Orleans, Louisiana          |
| 2:30 - 3:00 pm | The Results of a Clinical Trial of Isolated Liver Perfusion - Marybeth Hughes, MD - NCI Bethesda, Maryland                                          |
| 3:00 - 3:30 pm | Break                                                                                                                                               |
| 3:30 - 4:15 pm | Genetics & Risk For Carcinoid - M. Sue O'Dorisio, MD, PhD - Iowa City, Iowa                                                                         |
| 4:15 - 5:00 pm | Question & Answer Session O'Dorisio, Hughes, Boudreaux, Wang, Ryan & Woltering                                                                      |
| 5:00 - 5:15 pm | Concluding Remarks                                                                                                                                  |

## 2009 National Carcinoid/NET Patient Conference Agenda – New Orleans, AL

**Saturday, September 26, 2009**

### Novel Treatments for NETs Moderator – Lowell Anthony, MD Grand Ballroom C & D

|                  |                                                                                                                                                    |
|------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| 7:00 - 7:45 am   | Registration & Breakfast                                                                                                                           |
| 7:45 - 8:00 am   | Opening Comments                                                                                                                                   |
| 8:00 - 8:30 am   | What's HOT In The Woltering Lab? Can You Do A Clinical Trial In A Test Tube?<br>Eugene Woltering, MD - New Orleans, Louisiana                      |
| 8:30 - 9:00 am   | Liver Directed Therapies: Bland Vs. Chemo Vs. Radioembolization<br>Andrew Kennedy, MD - Cary, North Carolina                                       |
| 9:00 - 9:45 am   | Research Drug Trials: The Role In Carcinoid, Islet Cell & Other NETS. What Is Useful & What Is Not?<br>Lowell Anthony, MD - New Orleans, Louisiana |
| 9:45 - 10:15 am  | Role Of Liver Transplantation In NETS: Autotransplant Techniques & Implications<br>Saju Joseph, MD - New Orleans, Louisiana                        |
| 10:15 - 10:30 am | Break                                                                                                                                              |
| 10:30 - 11:00 am | Nutritional Support For NETS: The Use Of Pancreatic Enzymes, Cholestyramine & Anti Diarrheal Meds<br>Leigh-Anne Burns, RD - New Orleans, Louisiana |
| 11:00 - 11:30 am | Question & Answer Session M. Warner, Burns, Joseph, Anthony, Kennedy & Woltering                                                                   |
| 12:00 - 1:00 pm  | Lunch                                                                                                                                              |

### ISLET CELL & MEN I/II Moderator – Arthur Vinik, MD Grand ballroom A

|                    |                                                                                                                                 |
|--------------------|---------------------------------------------------------------------------------------------------------------------------------|
| 7:00 - 7:45 am     | Registration & Breakfast in Grand Ballroom C & D                                                                                |
| 7:45 - 8:00 am     | Opening Comments in Grand Ballroom C & D                                                                                        |
| 8:00 - 8:30 am     | Signs & Symptoms of Islet Cell Tumors. Role of Tumors & Its' End Organ of Response<br>Jeffery Norton, MD - Stanford, California |
| 8:30 - 9:00 am     | Biomarkers For Islet Cell & MEN I/II Arthur Vinik, MD - Norfolk, Virginia                                                       |
| 9:00 - 9:45 am     | Medullary Carcinoma Of The Thyroid & MEN II Sam Wells, MD - NCI Bethesda, Maryland                                              |
| 9:45 - 10:15 am    | Pheochromcytoma Karel Pacek, MD - NIH Bethesda, Maryland                                                                        |
| 10:15 - 10:30 am   | Break                                                                                                                           |
| 10:30 - 11:00 am   | Chemotherapy For Islet Cell Tumors - Edward Wolin, MD - Los Angeles, California                                                 |
| 11:00 - 11:30 am   | Genetics & Risk For Islet Cell & MEN I Herbert Chen, MD - Madison, Wisconsin                                                    |
| 11:30 - 12:00 noon | Question & Answer Session Chen, Wolin, Pacek, Wells, Vinik & O'Doriso                                                           |
| 12:00 - 1:00 pm    | Lunch in Grand Ballroom C & D                                                                                                   |

### NUCLEAR MEDICINE SCANS, PRRT & OTHER RADIOACTIVE THERAPY

Moderator – Thomas O'Doriso, MD  
Grand Ballroom C & D

|                |                                                                                                                               |
|----------------|-------------------------------------------------------------------------------------------------------------------------------|
| 1:00 - 1:30 pm | What Are the Ways to Scan For NETS? PET, MRI, CT & Nuclear Medicine Scanning<br>David Bushnell, MD - University of Iowa, Iowa |
| 1:30 - 2:00 pm | PET scans, Gallium Scans, F-18 DOPA Scans Stanley Goldsmith, MD - New York, New York                                          |
| 2:00 - 2:30 pm | I-123, I-131 MIBG - Scans, Therapy, Results Edward Coleman, MD - Durham, North Carolina                                       |
| 2:30 - 3:00 pm | Bone Metastases- Strontium-89, Samarium-153, Bisphosphonates Richard Campeau, MD - New Orleans, Louisiana                     |
| 3:00 - 5:00 pm | Update PRRT - Question & Answer Session                                                                                       |
| 3:00 - 3:30 pm | Richard Baum, MD - Bad Berka, Germany                                                                                         |
| 3:30 - 4:00 pm | Abe Delpassand, MD - Houston, Texas                                                                                           |
| 4:00 - 4:30 pm | Professor Jan Muller - Basel, Switzerland                                                                                     |
| 4:30 - 5:00 pm | Question & Answer Session Muller, Delpassand, Baum, Campeau, Coleman, Goldsmith & Bushnell                                    |
| 5:00 - 5:30 pm | Daily Summary & Concluding Remarks Eugene Woltering, MD - New Orleans, Louisiana                                              |



# Highlights of the Mt Sinai CCF April 26th conference

The notes here are highlights and should not be taken as medical advice.

## Dr. Pommier

Healthcare providers have probably only seen a few Carcinoid/NET patients and try to apply routine treatments to Carcinoids, which have a different set of rules.

“Everything about Neuroendocrine tumors is different from other tumors”

A classic tumor paradigm (pyramid with three sections: top to bottom – Mets, Lymph Nodes, Primary Tumor) will spread only after the primary tumor has reached a large size. Primary will be larger & mets smaller. Following this formula does no good for Carcinoids.

Neuroendocrine Tumor Size Paradigm the pyramid shape is upside down, but the labels remain the same. The primary tumor can remain tiny, and often undetected.

“Carcinoid tumors are not stage able” Classic tumor staging does not take into account the upside paradigm of Carcinoids.

Carcinoid tumors tend to grow toward the outside of the bowel, not toward the inside.

You can’t compare the life expectancy of breast cancer with mets against Carcinoid with mets.

Remove the primary tumor in all cases. Established after ten year study of carcinoids. Removing the primary gave a nearly ten year extension on life expectancy, or at least an improved quality of life.

Carcinoid crisis is

caused when hormones are dumped all at once by the tumors.

Carcinoid crisis can be provoked by pain, even if patient is under anesthesia, the pain signals are still sent.

Prophylactic Octreotide is in addition of LAR.

93% of Gastrinomas are found on the head of the pancreas.

75% of all Gluconomas are on the tail of the pancreas.

There is a major difference in technique for removal/ablation of liver disease with other cancers.

Liver resection in Carcinoids will benefit from surgery if primary or other tumor is left behind. You don’t have to remove the primary in NETs. (in traditional cancers, surgeons, will end a surgery if they can’t “get it all”.)

Radio Frequency Ablation yielded a definitive improvement in Quality of Life.

“Chrono” Therapy for NETs. Typical chemo dose (traditional) only kills the cells that are dividing within 6 to 8 hours of dose.

80% of blood to the

liver is from the portal vein. 100% of blood to liver tumors is from the hepatic artery.

Delivery to liver - can put a port into the Duodenal artery (75% of population has it) which feeds into the hepatic artery. No need for femoral artery invasion and resulting risks and precautions.

## Dr. Warner

Incidence of NETs in 2008: 5 per 100,000 population newly diagnosed. Prevalence is 35 per 100,000. Many more are undiagnosed or misdiagnosed or just not reported. Incidence has doubled every decade for last 30 years.

Lanreotide widely used in Europe.

Nutmeg helps in 50% of carcinoids for diarrhea.

Carcinoids do not respond well to External Radio Beam Therapy.

## Dr. Boudreaux

Appendiceal carcinoids are usually found incidentally.

Incidence of rectal carcinoids is on the rise. High propensity to spread.

Liver transplantation – Who will do well is still not

defined. mTOR inhibitors were developed as anti-rejection treatment but were found to have other properties to inhibit tumors

Carcinoid tumors tend to not invade blood vessels, but to wrap around the outside (encase) of them. Allows you to peel tumor away from the vessel.

Must periodically reassess treatment plan.

“Inoperative” status can be changed with other therapies.

Some procedure can preclude other procedures in the future. Order of procedures is important.

## Question and Answer Session

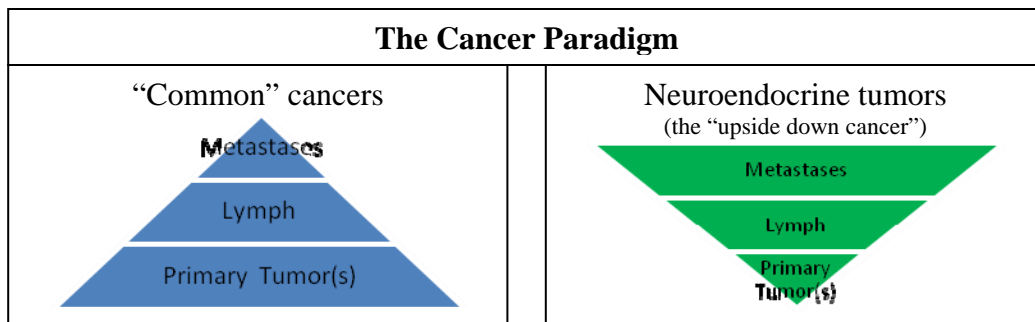
Drs. Warner, Boudreaux, Shafir, Myron Schwartz, Edward Herman

Sandostatin has a tumor inhibiting effect even in asymptomatic patients

If Octreoscan is negative, MIBG scan (not widely available) may/may not be helpful

Knowing primary can help decide treatment options, including the best chemo agents likely to work.

Carcinoid can have multiple primaries.



# CCF 12<sup>th</sup> Lecture

*Continued from Page 1*

One of the key differences is that traditional cancers have an expanding primary tumor, with mid-sized lymph involvement and small metastases. Carcinoid primary tumors may never grow beyond a very small size, while lymph involvement is mid-sized and metastases may be quite large. See the highlights notes for more information.

This upside down paradigm also explains why Carcinoid tumors can not be staged like traditional cancers. In fact, applying some traditional cancer methods can do more harm than good to Carcinoid patients.

Dr. Pommier was followed by Dr. Warner, professor at Mt Sinai and Carcinoid expert, who pointed out the expanding prevalence of Carcinoid, as well as the use of alternative drugs, such as Lanreotide in Europe. Dr. Warner also pointed out that Carcinoids do not respond well to external beam radiation therapy.

Dr. Boudreaux, a surgeon from the Kenner (New Orleans) group, rounded out the program. Dr. Boudreaux mentioned that Carcinoid tumors tend to wrap around (encase) but not invade blood vessels. This allows the surgeon to meticulously “peel away” the tumor from the vessel. It is always preferable to remove the primary tumor, but that leaving behind some tumor does not have the devastating effects for carcinoid patients that it has for traditional cancers.

One point mentioned in the Q and A session was that carcinoid tumors can have more than one primary tumor.

The patient panel started with structured questions and answers from moderator Nancy Teixeira, then became more interactive when patients in the room began to relate to the problems that others were facing and add their own experiences.

The lectures were videotaped and are expected to be available on the Carcinoid Cancer Foundation website ([www.carcinoid.org](http://www.carcinoid.org)) in the near future.

Our thanks to the Carcinoid Cancer Foundation for hosting this event.

# Sandostatin LAR Controls Tumor Growth

It has long been speculated, supported by anecdotal evidence, but Dr. Rudolf Arnold presented data at ASCO San Francisco early this year to support the suspicions. Sandostatin LAR does control certain NETs.

The study, dubbed PROMID, was outlined in a press release by Novartis on January 13th. Some of the following points were highlighted.

Data show significant 66% reduction in risk of disease progression versus placebo

Sandostatin LAR more than doubled time without tumor growth for a median of 14 months compared to six months on placebo

Results support Sandostatin LAR as first treatment after surgery in certain patients with newly diagnosed neuroendocrine tumors (NETs)

Sandostatin LAR® Depot (octreotide acetate suspension for injection) demonstrated antitumor benefit in patients with metastatic neuroendocrine tumors (NETs) of the midgut, according to interim data presented today at the 2009 Gastrointestinal Cancer Symposium of the American Society of Clinical Oncology.

Here is a portion of the information in the press release:

After six months of treatment, patients receiving Sandostatin LAR had a 66% reduction in risk of disease progression compared to patients taking placebo ( $P=0.000072$ ). This reduction is based on findings that Sandostatin LAR halted tumor growth in 69% of patients, compared with 39% of patients receiving placebo.

Patients who took Sandostatin LAR had no tumor progression for a median of 14.3 months, compared to six months for patients on placebo. This beneficial effect was seen in patients with either functioning (hormone secreting) or non-functioning (non-secreting) NETs.

The findings are from a Phase IIIb, multicenter, prospective, randomized, placebo-controlled, double-blind, study called PROMID (Placebo-controlled

prospective Randomized study on the antiproliferative efficacy of Octreotide LAR in patients with metastatic neuroendocrine MIDgut tumors).

"Sandostatin LAR has a proven track record of treating the severe diarrhea and flushing associated with neuroendocrine tumors and now this study demonstrates that Sandostatin LAR also helps control tumor growth in patients with metastatic neuroendocrine tumors of the midgut," said PROMID Lead Investigator Professor Rudolf Arnold, Philipps-University Marburg, Germany. "In addition, we saw the greatest benefit in those patients who were newly diagnosed and who had fewer liver metastases (<10% hepatic tumor load), underscoring the importance of early treatment."

This is the first placebo-controlled study to confirm previous findings that suggested treatment with Sandostatin LAR could achieve stabilization of tumor growth in up to 50% of patients with NETs of various origin

"Studies are also underway to evaluate the benefit of combination therapy of Sandostatin LAR with our investigational mTOR inhibitor, RAD001, in patients with various types of NETs."

Some important points to note about this study:

It is using Sandostatin LAR for the study, not the daily injection medication.

The study was on midgut NET patients (midgut sites include distal duodenum to mid-transverse colon) This could lead to study of patients with tumors of other sites.

2/3 of the patients had a halted tumor growth.

The study used patients with low liver tumor load, which indicates that starting LAR early has the best chance of working.

There was no difference between functioning or non-functioning tumors noted.

Surgery is still the “first line” treatment.



# New Jersey Carcinoid Cancer Network Conference



October 17, 2009

Holiday Inn 151 Rt. 72 West  
Manahawkin, NJ 08050

## Agenda

|                |                           |                                       |
|----------------|---------------------------|---------------------------------------|
| 8:15 to 8:30   | Registration              |                                       |
| 8:30 to 8:45   | Introduction              |                                       |
| 8:45 to 9:45   | Dr. Richard Warner        | “Overview of Carcinoid and Diagnosis” |
| 9:45 to 10:00  | Break                     |                                       |
| 10:00 to 10:30 | Monica                    | Last 15 minutes Q&A                   |
| 10:30 to 11:30 | To be announced           |                                       |
| 11:30 to 12:45 | Lunch                     | On or off-site                        |
| 12:45 to 1:45  | Dr. Kjell Öberg           |                                       |
| 1:45 to 2:00   | Break                     |                                       |
| 2:00 to 3:30   | Questions & Answer Period |                                       |

Times and lecturers subject to change, if needed.

Question and Answer Session is an open forum. Questions must not be patient case specific in nature.

For additional information, contact Judy at [mjmkgo@aol.com](mailto:mjmkgo@aol.com) or 201-891-2259 or Jim at [Caring4Noids@aol.com](mailto:Caring4Noids@aol.com) or 609-812-9294

*Keep this page for your records*

Directions to Holiday Inn Conference Center and Hotel  
151 Rt. 72, Manahawkin, NJ 08050  
(Approx.) N 39° 41.749 W74° 15.789

**From the North**

Take Garden State Parkway Southbound to exit 63 (from exit it is about 5 minutes)  
Bear right at end of ramp, following signs for Rt. 72 eastbound to Long Beach Island  
Merge onto Rt. 72 Eastbound  
After first traffic light, move to right lane (of three lanes)  
Holiday Inn is on right, just past Applebee's  
Park in lot in rear of building  
Follow signs to conference room

**From the South**

Take Garden State Parkway Northbound to exit 63 (from exit it is about 5 minutes)  
Bear right at end of ramp, following signs for Rt. 72 eastbound to Long Beach Island  
Merge onto Rt. 72 Eastbound  
After first traffic light, move to right lane (of three lanes)  
Holiday Inn is on right, just past Applebee's  
Park in lot in rear of building  
Follow signs to conference room

**From the West**

Take Rt. 70 to Rt. 72 Eastbound  
Follow Rt. 72 Eastbound approx. 20 miles and pass under Garden State Parkway bridge  
After first traffic light, move to right lane (of three lanes)  
Holiday Inn is on right, just past Applebee's  
Park in lot in rear of building  
Follow signs to conference room

**From the East**

Swim to Long Beach Island then follow Rt. 72 Westbound, approx 5 ½ miles... 😊

There are many local restaurants in the area. A list will be published shortly. The hotel has a very good restaurant on site and will be offering a conference special. For a fixed price of \$8.95 (tax & tip not included) you get soup, an entrée and dessert. Reservation for lunch is not required.

To book a room at the Holiday Inn, use the code CCN for the special rate of \$159 per night. The hotel offers free internet access, exercise facilities, indoor pool, Jacuzzi, cocktail lounge and grill.

Book on-line at [www.HolidayInn.com/Manahawkin](http://www.HolidayInn.com/Manahawkin) or call 1-800-Holiday (800-465-4329). You must reserve by Sept. 9<sup>th</sup> for the special rate. Check-in is after 3 PM and checkout is before 11 AM.

During breaks, the Carcinoid experts will be available to answer individual questions privately.

*Keep this page for your records*





# New Jersey Carcinoid Cancer Network Conference Registration

October 17, 2009 Manahawkin, NJ



| Please Print                | Person 1                                                   | Person 2                                                   |
|-----------------------------|------------------------------------------------------------|------------------------------------------------------------|
| First Name                  |                                                            |                                                            |
| Last Name                   |                                                            |                                                            |
| Address                     |                                                            | <input type="checkbox"/> Same as person 1                  |
| City, St. Zip               |                                                            |                                                            |
| Telephone<br>(area code)    | (     )                                                    | (     )                                                    |
| E-Mail                      |                                                            |                                                            |
| First Name<br>for name tag  |                                                            |                                                            |
| “I am a...”<br>(Circle One) | Patient,    Caregiver<br>Healthcare Professional,    Other | Patient,    Caregiver<br>Healthcare Professional,    Other |
| I have: (Circle One)        | Carcinoid,    Other NET,    n/a                            | Carcinoid,    Other NET,    n/a                            |
| Primary Site<br>is          |                                                            |                                                            |
|                             | Total Amount Enclosed<br>(\$35 per person)                 | \$                                                         |

Cost to attend is \$35 per person. Walk-ins, if space is available, will be \$45 per person at the door. We will allow cancellations until October 2nd with a refund, less a \$5 handling fee. Refunds will be processed after the completion of the conference. Registration will be closed after October 2nd. (We must notify the hotel of the number attending).

Returned checks will be charged a \$25 additional fee. (what our bank charges us)

Please make checks payable to:

**New Jersey Carcinoid Cancer Network**

Cost: \$35 per person, before October 2<sup>nd</sup>, mail payment to :

**Judy Golz,  
NJCCN,  
719 Franklin Ave,  
Franklin Lakes, NJ 07417**

If you have any problems or questions, contact Judy at [mjmkgo@aol.com](mailto:mjmkgo@aol.com) or 201-891-2259 or Jim at [Caring4Noids@aol.com](mailto:Caring4Noids@aol.com) or 609-812-9294

On-Line registration at [www.NJCarcinoidNetwork.org](http://www.NJCarcinoidNetwork.org) is available.

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(Why? So you can return the form on the back to register and not lose any information)