

# New Jersey Carcinoid Cancer Network Newsletter

March 2010

[www.NJCarcinoidNetwork.org](http://www.NJCarcinoidNetwork.org)

## CCF Announces Conference

Since 1968, the Carcinoid Cancer Foundation of White Plains, NY has been educating people about the latest advancements in the diagnosis & treatment of Neuroendocrine Tumors. As part of that effort, they have announced the next lecture in their ongoing series.

The Carcinoid Cancer Foundation will host patients and caregivers on April 11<sup>th</sup> at 1:00 PM to 4:30 PM. The lecture will be held at the Goldwurm Auditorium, across from Mt. Sinai Hospital, NYC.

The events of the day will be kicked off with a brief talk about the future of the Carcinoid Cancer Foundation by Keith Warner, the recently appointed Chief Executive Officer. He will be followed by an introduction given by Dr. Richard Warner.

The keynote lecture will be delivered by Dr. Michael J. Demeure, entitled "Determining Molecular Signature: A Guide for Targeted Therapy of Neuroendocrine Tumors"

Now, before you try to understand that title, read the accompanying article to the right. It is not as difficult as it may sound.

From Grace at the Foundation: In a nutshell a person has a biopsy of his/her tumor, it is studied and then a treatment plan is



Michael J. Demeure, MD,  
MBA

devised specifically for that person based upon the makeup of that person's tumor.

Not a one-treatment fits all concept but an individualized, specific treatment based on what is happening in each person's body. Dr. Demeure assured Sheilah that he speaks to students (not medical students) and can definitely bring this more difficult subject down to a level that the average person understands.

If you have never been to a CCF lecture, then you know one of the highlights is the Question and Answer Panel. Usually, this panel consists of not just the lecturers, but of medical professionals from various disciplines. It is your chance to ask (non-case-specific) questions and has always been a popular part of the day.

Check out the agenda and other information on pages 5 through 8.

Refreshments will be served.

We hope to see you there.

## What on Earth are they talking about?

OK, when I saw the title of Dr. Demeure's lecture that was my first thought... Apparently, I was not alone, since just about everyone took the position that this would be way over their head.

I spoke to the Carcinoid Cancer Foundation, and was assured that Dr. Demeure would be able to bring the lecture down to level that all can understand.

The next question might be something like "why do I need to know that"? the answer is simple...Most doctors will have no idea how to properly manage your cancer, and that leaves you to stay informed on what new stuff is out there, now and for the future.

After my conversations with the Foundation, they sent out this additional information:

### **Determining Molecular Signature: A Guide for Targeted Therapy of Neuroendocrine Tumors**

Imagine a treatment created just for you as a carcinoid or other neuroendocrine tumor patient based upon a personalized genomic analysis. This is the cutting-edge research which is the focus of the work of

*Continued on page 2*

## Upcoming Dates

**April 11<sup>th</sup>, 2010** – Carcinoid Cancer Foundation lecture at Mt. Sinai Hospital, New York City. See article to left.

**May 4<sup>th</sup>, 2010** – 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](mailto:Caring4Noids@aol.com)

**May 4<sup>th</sup>, 2010** - NY Support Group meeting, Long Island, Verify dates at [www.carcinoidaware.org](http://www.carcinoidaware.org) or call 516-781-7814.



~~~~~  
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

## Adding to the Arsenal

One of the major frustrations of dealing with a serious illness is dealing with health care insurance. Then try dealing with insurance while dealing with a “rare” cancer. Sanity can often be questioned.

The Carcinoid Cancer Foundation has added another weapon to aid with that problem. Laurie Todd, known as “The Insurance Warrior” is featured on the Carcinoid Cancer Foundation’s website at [www.carcinoid.org](http://www.carcinoid.org).

Laurie has been helping folks, based upon her personal success while fighting her own rare disease. She offers tips and insights in how to properly deal with an insurance company, reminding us that they are there to make money, not give it away.

She is an author, teacher, and insurance strategist. Laurie has also lectured at CCAN events.

One advantage to her being available is to allow her to become involved early in the process, as soon as that first denial comes in the mail. The CCF website lists a strategy plan, as well as sample documents & letters.

One of her first cases has been to try and find anyone who knows of a case where Medicare has paid for the external pump for Sandostatin. If you know of any such instance, could you kindly contact Laurie at [laurie@theinsurancewarrior.com](mailto:laurie@theinsurancewarrior.com). This request is to specifically help a fellow Carcinoid patient win her case.

## What Are They Talking About?

*Continued from Page 1*

**Michael J. Demeure, MD, MBA,** and his team at **TGen, the Translational Genomics Research Institute**, based at the Virginia G. Piper Cancer Center, Scottsdale Healthcare, in Arizona. Dr. Demeure will talk about this research when he is the guest speaker for the **Carcinoid Cancer Foundation’s** symposium for patients, family, friends, and healthcare professionals on **Sunday, April 11, 2010 at Mt. Sinai Hospital** in New York City. The title of Dr. Demeure’s lecture is **“Determining Molecular Signature: A Guide for Targeted Therapy of Neuroendocrine Tumors.”**

Dr. Demeure and his colleagues, medical oncologists and surgeons, are using the knowledge and technologies developed from the Human Genome Project to develop new ways to diagnose and treat disease including cancer. The Human Genome Project, completed in 2003, was a 13-year project coordinated by the U.S. Department of Energy and the National Institutes of Health. Among the project goals were to identify all of the approximately 20,000 – 25,000 genes in human DNA and to determine the sequences of the 3 billion chemical base pairs that make up human DNA. Though the project is finished, analysis of the data continues and will for years.

The goal of the program at TGen is to develop new treatments for patients with rare cancers including tumors of the neuroendocrine system, such as carcinoid and pancreatic neuroendocrine tumors. According to Dr. Demeure, “Our team’s

approach is to use a personalized genomic analysis of a patient’s tumor and then select drugs targeting particular mutations found in a patient’s tumor. For this, a patient must undergo a biopsy and then in the lab, we analyze the genes in the tumor to try to identify what abnormalities are present. We believe tumors have an Achilles’ heel and if we can identify it then we can be more successful in treating it.”

How does the genomic analysis work? “All genetic material is encoded in the chromosomes which serve as a blueprint for all the genes and functions of cells in the body,” explains Dr. Demeure. Abnormal genes result in cancer. “Soon, we will be able to sequence the genetic code of a patient’s tumor rapidly and at a cost that makes in practical for clinical use,” says Dr. Demeure. At the present time Dr. Demeure and his team use a small cartridge or chip that “looks for copy number of over 1 million areas or features in the chromosomes of the tumor cell. If we see deletion for example in a gene that controls growth, one can surmise that growth will proceed more rapidly than it should. Uncontrolled growth as a result of loss of tumor suppressor gene function through deletion or mutation is a common feature of cancer cells.”

Among the challenges for researchers seeking to develop new treatments for rare cancers is the fact that it is not possible to do traditional large clinical studies involving thousands of

patients to compare new drugs to older drugs as well as limited access to funding. There is also a lack of sufficient tumor samples for study or cell lines that serve as models in the lab. And patients can have difficulties in finding doctors with experience with these cancers and may have to travel to get promising new investigational treatments.

Dr. Demeure is a fellowship-trained endocrine surgeon who has been in academic surgical practice since 1991. He has maintained an active clinical and basic research program during this time focusing on the mechanisms of tumor metastases.

Dr. Demeure graduated from medical school at Hahnemann University in Pennsylvania, and completed his surgical residency at the University of Arizona. His fellowship in endocrine surgery was in Perth, Australia and then at the University of California, San Francisco. Dr. Demeure has been a Senior Investigator with TGen since 2005. He also serves as Director of the Rare Tumors Center at Scottsdale Healthcare and as Director of the Pancreatic Cancer Biospecimens Repository for a recently awarded pancreatic cancer program project grant from the NIH.

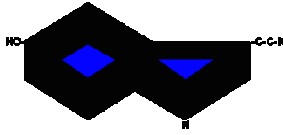
For further information about the Carcinoid Cancer Foundation’s April 11 symposium or to register go to <http://carcinoid.org/events/index.shtml> or call the Foundation at 888-722-3132, Tuesday through Thursday, 10 am to 4 pm, Eastern Standard Time. There is a \$25.00 tax-deductible fee per person, payable by check or credit card, at the time of

# Notes from Dr. Oberg's NJ Conference Lecture

Please note that these edited and cryptic records are those taken by one person and that not all points of any lecture are covered. Due to the possibility in error or interpretation, it is highly advised to seek a professional medical opinion before relying on treatments from these notes. These notes are provided only to give you some insight in to which ideas you may want to seek further follow-up information & discuss with your doctor.

*Thanks to Mike L. for providing the technology that made these notes possible.*

- Not as rare as believed, becoming more common
- Registries in US and Sweden are showing increased incidence and diagnosis, including all sub-types
- Digestive system is by far the most common site for classical carcinoids
- NETs are more common than gastric, pancreatic, esophageal and HBC cancers
- Pancreatic NETs & GI carcinoids all have slower growth, well differentiated, release hormones, are highly vascular and express ST receptors
- Carcinoids are not all the same and can not be lumped together-different DNA
- Classification system has been changed to follow rate of proliferation and differentiation traits
- Patients in different classes need different treatment plans
- ENETS has a TNM classification system  
T=Primary tumor,  
N=Regional Lymph nodes,  
M=Distant Metastases
- ENETS also introduced a grading system, based upon rate of proliferation
- General markers include Chromogranin A, (U.S. has 4 different assays with no correlation), Pancreatic polypeptide, and HCG-subunits
- Specific markers include Gastrin, 5-HIAA, etc
- CgA can be cleaved into smaller fragments such as Pancreastatin to measure
- CgA follows tumor volume
- Use of Somatostatin analogues block the release of CgA without reducing tumor size
- Working on finding new markers to follow disease
- A 3 mm tumor has about 1 million cancer cells
- PET (with FDG) scan is not reliable for NETs, MRI detects about 2/3, CT about 80%, Octreoscan about 90% and PET with specific isotopes have higher results.
- Specific Isotopes for NETs include <sup>11</sup>C-5HTP, <sup>11</sup>C-Dopamine, <sup>18</sup>F-Dopamine, <sup>68</sup>GA-Dota Octreotide, and others
- Octreoscan will be replaced within about 5 years by better tests
- PET & CT combined scans are common
- <sup>68</sup>GA-DOTA shows much promise as an imaging agent-No Cyclotron required, more sensitive than Octreoscan, possible to label for treatment, can quantify receptors density, one image only needed (not a multi-day test)
- Majority of patients are seen with metastatic disease (60%)
- Therputic options include surgery, Medical therapy (Chemo, Sando, a-Interferon, mTOR & VEGF inhibitors), Irradiation (bone & brain
- metas and targeted therapies)
- PRRT (Peptide Radio Receptor Therapy) had a 22% partial response (PR) for Carcinoid patients, a 42% PR for Gastrinomas and a 60% PR for Insulinomas. and is showing promise
- PRRT is usually 3-4 courses over about 4 months. Working on fine tuning intervals
- Chemoembolization results vary, depending upon study used, and duration until disease progression fairly short
- Temozolomide (Temodar) was developed for brain mets and showed an affect in NETs, may be better in pancreatic cases than midgut
- SOM 230 (Pasireotide) binds to receptors 1, 2, 3 & 5. Bids to 5 with higher affinity than natural occurring Samatostatin
- Use of Samatostatin analogues results in biochemical response and symptomatic response in 2/3 of patients but reduces tumor growth in about 5% with about half having stabilization
- LAR showed extended time to tumor progression over placebo, clearly showing anti-tumor effect in patients with low tumor load
- NCCN has changed guideleines to include use for non-functioning tumors
- Current study compares Pasireotide to Octreotide
- Use of Interferon must be titrated for individual
- patient, 65% showed stabilization
- Use of Interferon can upregulate Samatostatin receptors (make them more sensitive)
- Interferon gave good disease control but tumor continued to grow, with Pasireotide added, tumor size reduced and markers dropped
- MTOR blocks growth signal pathway
- MTOR, combined with LAR, had 70% stable disease
- Use of Affinitor alone resulted in progression free survival of 9.3 months, adding Octreotide got 12.9 months
- Rationale for use on angiogenesis inhibitors: GEP NETs have dense vascular structure, VEGF is overexpressed in GEP NETs, Elevated VEGF correlates with tumor progression, overexpression is associated with decreased progression-free survival in GEP NETs
- Therapeutic algorithm depends on WHO classification but still requires individualized treatment plans
- Metastatic Carcinoid Survival was 17 months from 1973 to 1987, then 37 months from 1988 to 1999 in US. In Sweden, survival for midgut Carcinoids is 115 months
- Treatment of NETs takes a multidisciplinary team, all working together



**THE CARCINOID CANCER FOUNDATION**  
presents

***Determining Molecular Signature:  
A Guide for Targeted Therapy of Neuroendocrine Tumors***

A symposium for patients, family, friends, and healthcare professionals

**Sunday, April 11, 2010**

**1:00 – 4:30 pm**

Goldwurm Auditorium, 1st Floor, Icahn Institute  
Mount Sinai Hospital, New York, NY

Introductory Remarks by

***Richard R.P. Warner, MD***

Professor of Medicine, Mount Sinai School of Medicine, NYC  
Medical Director, Carcinoid Cancer Foundation

**Guest Speaker**

***Michael J. Demeure, MD, MBA***

Director, Endocrine Tumor Center, Scottsdale Healthcare  
Senior Investigator, TGen (Translational Genomics Institute)  
Clinical Research Service, Arizona

**Q&A: Physician/Patient Panel**

**Refreshments**

**Together We Make a Difference**

RSVP before April 1

**THE GOLDWURM AUDITORIUM is located in the Mount Sinai Hospital Icahn Institute at 1425 Madison Avenue, SE corner of 98<sup>th</sup> Street, (Upper East Side of Manhattan).**

***Parking is available on 99<sup>th</sup> Street between Madison and Park Avenue***



*The Carcinoid Cancer Foundation*  
*presents*  
Carcinoid/NET Symposium

***Determining Molecular Signature:  
A Guide for Targeted Therapy of Neuroendocrine Tumors***

April 11, 2010 ♦ Mount Sinai Hospital ♦ New York, NY

- 1:00 – 1:05 pm **Welcome and Meeting Objectives**  
**Robert Wahmann**  
President, Carcinoid Cancer Awareness Network, Inc. (CCAN)
- 1:05 – 1:15 pm **Message from The Carcinoid Cancer Foundation**  
**Keith R.P. Warner**  
CEO, Carcinoid Cancer Foundation
- 1:15 – 1:30 pm **Introductory Remarks**  
**Richard R.P. Warner, MD**  
Professor of Medicine  
Director of the Carcinoid Neuroendocrine Tumor Center  
Mt. Sinai School of Medicine, New York City  
Medical Director, Carcinoid Cancer Foundation
- 1:30 – 2:15 pm **“Determining Molecular Signature”**  
**Michael J. Demeure, MD, MBA**  
Director, Endocrine Tumor Center,  
Scottsdale Healthcare  
Senior Investigator, TGen (Translational Genomics Institute)  
Clinical Research Service, Arizona
- 2:15 – 3:00 pm **Refreshments/Networking**  
(Turn in Question Cards for Q & A Session)
- 3:00 – 4:30 pm **Question and Answer Period: Carcinoid/NET Experts and Patients Panel**

**Thank You for Joining Us Today**

## Directions to Goldwurm Auditorium

**By Subway** : Take # 6 to 96th Street and Lexington Avenue. Walk west on 96th Street to Madison Avenue. Turn right and walk to 98th Street. Entrance to Mount Sinai Hospital Icahn Institute is on the right side of Madison Avenue, at 1425 Madison Avenue, SE corner of 98<sup>th</sup> Street.

**By Public Bus** :Take M1, M2, M3 or M4 Bus (Fifth Avenue Buses) traveling South to 98th Street Stop. Mount Sinai Hospital Fifth Avenue Entrance) is located on 98th and Fifth Avenue.

Take M1, M2, M3.or M4 Bus (Madison Avenue Buses) traveling North to 98th Street Stop. Mount Sinai Hospital The Icahn Institute entrance is located at 1425 Madison Avenue, SE corner of 98<sup>th</sup> Street.

### **By PATH Train**

Take PATH Train (from NJ) to 33rd Street. Transfer to N or R subway, 34th Street station. Take Uptown N or R to Lexington Avenue. Transfer to #6 subway, 59th Street station. Follow #6 subway directions above.

### **By Car**

#### **From Manhattan's East Side**

Take FDR Drive to 96th Street and turn onto East 96th Street. Follow until Madison Avenue. Make right turn to 100th Street. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located at 1425 Madison Avenue, SE corner of 98<sup>th</sup> Street.

#### **From Manhattan's West Side**

Take West Side Highway to 96th Street Exit. Travel across West 96th Street, through Central Park. Follow East 96th Street to Madison Avenue. Turn left. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located on 1425 Madison Avenue, SE corner of 98<sup>th</sup> Street..

#### **From Brooklyn and parts of Queens (Brooklyn Bridge)**

Take Brooklyn-Queens Expressway to Brooklyn Bridge Exit. Follow signs to FDR Drive North. Exit FDR Drive at East 96th Street. Follow traffic onto E. 96th Street to Madison Avenue. Turn right on Madison Avenue. Mount Sinai Hospital is at 100th Street and Madison Avenue. (The Icahn Institute entrance) is located on 1425 Madison Avenue, SE corner of 98th Street.

#### **From Brooklyn and Staten Island (Brooklyn Battery Tunnel)**

Take Verrazano Bridge (Staten Island only) to Brooklyn Queens Expressway. Follow signs on BQE to Brooklyn Battery Tunnel. Turn right out of Tunnel. Take West Street to West Side Highway. Exit at W. 96th Street and follow through Central Park to Madison Avenue. Turn left on Madison Avenue. Mount Sinai Hospital is at 100th Street and Madison Avenue, the Icahn Institute entrance is located on 1425 Madison Avenue, SE corner of 98th Street.

#### **From Queens, Long Island and parts of Brooklyn (Triborough Bridge, 59th Street Bridge)**

Take Grand Central Parkway (West) to Triborough Bridge to the FDR Drive. Exit at 96th Street. Follow until Madison Avenue. Turn right on Madison Avenue. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located at 1425 Madison Avenue, SE corner of 98th Street.

#### **From Westchester and New England**

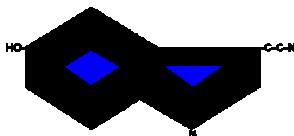
Take New England Thruway (95 South) to Triborough Bridge to FDR Drive. Exit at 96th Street and turn right onto E. 96th Street. Follow until Madison Avenue. Turn right on Madison Avenue. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located at 1425 Madison Avenue, SE corner of 98th Street.

#### **From Upstate New York**

Take New York State Thruway (87 South) to Major Deegan Highway (same road). Exit at Willis Avenue Bridge and bear right. Follow signs to FDR Drive. Exit at 96th Street. Turn right at 96th to Madison Avenue. Turn right on Madison Avenue. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located at 1425 Madison Avenue, SE corner of 98th Street.

#### **From New Jersey**

George Washington Bridge to West Side Highway. Exit at 96th Street and travel across 96th Street through Central Park to Madison Avenue. Turn left on Madison Avenue. Mount Sinai Hospital is on 100th Street and Madison Avenue. The Icahn Institute entrance is located at Madison Avenue, SE corner of 98th Street.



## The Carcinoid Cancer Foundation

### REGISTRATION FORM

#### *Determining Molecular Signature: A Guide for Targeted Therapy of Neuroendocrine Tumors*

Symposium at Mount Sinai Hospital, New York, NY  
**April 11, 2010, 1:00 - 4:30 pm**

#### **3 WAYS TO REGISTER: RSVP before April 1**

We are serving light refreshments and need to know how many will attend.

1. **By phone:** 888-722-3132 (Tuesday – Thursday, 10 am – 4 pm)  
If no answer, leave a message and a CCF staff member will return your call.

2. **By E-mail:** Copy, complete and paste information from the form below and send to:  
carcinoid@optonline.net (with **MSH Carcinoid/NET Symposium** in the subject line)  
Send check by snail mail or pay online <http://tinyurl.com/bwbnwf>  
(click on Donation Designation)

3. **By Snail Mail:** Print, complete form and mail with check to:  
The Carcinoid Cancer Foundation, 333 Mamaroneck Avenue # 492, White Plains, NY 10605

Name \_\_\_\_\_ ( )

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Total number of attendees in my party (including me) \_\_\_\_\_

Their Name \_\_\_\_\_ ( )

Their Name \_\_\_\_\_ ( )

Their Name \_\_\_\_\_ ( )

Indicate in the parenthesis after each name if you and those in your party are a patient (P), Spouse (S), Family member (FM), Friend (F), Physician (MD), other health care professional (HCP), Other (O) please specify.

**A \$25.00 per person tax deductible fee is required at the time of registration payable either by check or online <http://tinyurl.com/bwbnwf>**

(click on Donation Designation drop down list and choose MSH conference)

## FOR FUTURE PLANNING

If you are a patient, we would be most appreciative if you could complete the following. This will help guide us when we select future symposium topics.

I would be interested in learning more about the following topics:

---

---

I would like to hear the following guest speakers:

---

---

In addition to the medical community, I would like to hear from patient guest speakers:

Yes\_\_\_\_\_

No\_\_\_\_\_

Newly diagnosed (yes or no)\_\_\_\_\_

Long-term survivors (yes or no)\_\_\_\_\_

If you are a patient or a patient caregiver, would you be interested in possibly participating in future symposia as a guest speaker:

Yes\_\_\_\_\_

No\_\_\_\_\_

I am a: Patient\_\_\_\_\_

Caregiver\_\_\_\_\_

**I would like to be on The Carcinoid Cancer Foundation's mailing list.**

Please add my name to your e-mail list. This is my e-mail address (please print):

---

**THANK YOU**