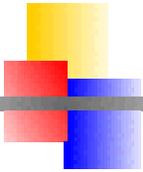


New Jersey
Carcinoid Cancer Network
Newsletter

September 2009

www.carcinoid.us or www.NJCarcinoidNetwork.org



We, in the Carcinoid Community have suffered a great loss in the recent passing of Monica Warner.

For the past two decades, Monica Warner has devoted herself to the Carcinoid Cancer Foundation. She has been instrumental in establishing support groups, educating physicians and aiding patients with current information.

Many of us have spoken to her personally over the years in seeking answers. She developed and maintained the CCF website. Mrs. Warner has been the driving force behind all the National and Local Carcinoid conferences.

Her compassion for Carcinoid patients drove her to form and expand the support groups that we now all belong to. Along with her husband, Dr. Richard Warner, she has brought Carcinoid to the forefront.

For all of her outstanding accomplishments with the Carcinoid community, it is still just a part of her many talents and achievements. Mrs. Warner held a private pilot's license, even learning to fly aerobatics (all after the age of 50)!

Monica was born in Sweden, and she spoke several languages fluently and loved to travel. She was a talented and artistic photographer and used this ability both personally and for the Carcinoid community. We



IN MEMORIAM
MONICA E. WARNER
May 16, 1937 – August 7, 2009

rarely saw Monica Warner without a camera in her hands. Her photography was recently recognized by National Geographic Society.

Most of her interests were shared with her husband. Dr. and Mrs. Warner had a rare and very special relationship. They shared their life together and had a unique and lasting bond that

was evident when you saw the two of them together.

Her passion and enthusiasm has been an inspiration to all of us and anyone she has come in contact with.

We will miss her greatly and honor her in our commitment to carry on her legacy within the Carcinoid Community.

*The New Jersey Carcinoid
Cancer Network*

**Upcoming
Dates**

Sept. 9th, 2009 – deadline to book Manahawkin Holiday Inn at discounted rate for the NJ Conference (see article on page 2).

Sept 13th, 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.

Sept 13th, 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.

October 17th, 2009- New Jersey Carcinoid Cancer Network lecture. Manahawkin, NJ. See article on page 2.



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For newsletter subscriptions, questions & submissions please contact:  
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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

When diagnosed with a rare disease, you find yourself having to become your own advocate. Let's face it, if you are one of a couple of Carcinoid patients that your local doctor has with this disease, he/she does not have the time to do the research needed to learn about your individual needs

That means that you, and your caregiver team, need to understand the basics of your disease and to stay informed about potential new treatments. Even those treatments that may not "be right" for you now, you may find that they may be appropriate at a later date. Staying informed is the best way to help yourself.

That is why the New Jersey Carcinoid Cancer Network is hosting a one day conference on October 17th. We have engaged two of the top carcinoid experts, as well as others, for this event.

If you have been around Carcinoid and Neuroendocrine Tumors (NETs) for any length of time, you know that Dr. Warner has been involved in Carcinoid his entire life. His experience and intuition cannot be duplicated.

Other US experts lovingly refer to him as "the Guru". Dr. Woltering (even with his large associate staff) has said that if he had carcinoid, he

would want Dr. Warner treating him.

Dr. Kjell Öberg is from one of the first, and best, world centers for Carcinoid at Uppsala, Sweden. Uppsala has pioneered many of the advances in diagnosis and treatment of this disease, and Dr. Öberg has long been recognized as a world expert.

Now, what if you had the opportunity to ask questions of these two greatest practitioners in Carcinoid, why would you not go?

Even if you went to New Orleans, Dr. Öberg is not on the agenda, but he and Dr. Warner will both 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 in our lineup is Nancy Gardner, RN, PhD. Nancy has a long history of working with carcinoid. She was with Dr. Kvols in Tampa and is now residing in NJ, working at Rutgers University. She has been involved with an investigation into familial factors of carcinoid. She will be talking about Sandostatin LAR and how you as a patient can get the best experience from your medical team.

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.

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.

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 may be made in check or via PayPal 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.

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.

Check with you tax professional, but under IRS code, for a patient attending a medical conference, reasonable costs to attend may be tax deductible.

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

## Remembering Monica

The Warner family has asked that anyone who would like to make a donation in honor of Monica's life can make them to the

Carcinoid Cancer Foundation #492  
333Mamaroneck Rd.  
White Plains, NY 10605

Notes or cards to Dr. Warner can also be sent to the Foundation.

We are happy to report that Dr. Warner is back to doing what he loves to do best...seeing patients and determining their best care.

Monica would want it that way.

## New Orleans Conference

Registration for the New Orleans patient conference is now filled and registration is now closed.

## Things To Do Near the NJ Conf.

In October, the traffic is lighter and the water still fairly warm. You can walk the beaches, or find any of the great eating places. Or choose from some of these activities:

October 10<sup>th</sup> kicks off the start of the annual LBI Surf Fishing Tournament with blues and stripers topping the catch. There are daily, weekly and monthly prizes. For more information check the website at <http://www.lbift.com>

The nearby Pine Barrens region offer some very unique ecology and plant and animal life. Kayak or canoe is a great way to explore the region and rentals are available near the conference site. You can also explore the salt marshes and backwaters with the same rentals.

There are also several good golf courses nearby...Sea Oaks is one of the premium courses. Ocean Acres and Atlantis are county run, keeping the cost very reasonable, but better quality than most county courses.

You can also visit the recently refurbished and relighted Barnegat Light. Built in 1859 the navigation aid was turned off in 1927, but this year, 150 years to the day after "old barney" was first lit, they replaced the glass & a new lamp.

October is also a great time to watch the park for migrating birds of many species, or just walk the park's 1/5 mile self guided nature trail. The park is open 9AM to 4:30 PM.

The SurfFlight Theater on LBI will be playing "Wait Until Dark" during the conference weekend. Check [www.surflight.org](http://www.surflight.org) for times and tickets.

Atlantic City shows and casinos are only about 30-40 minutes away from the conference site. (Please note: staying at some of the "cheaper" hotels in Atlantic City may seem like a bargain, but some of those places cater to the "3 hour rental" crowd, with the often attendant criminal activities.)

There are several "party" fishing boats running out of the area. It is too soon to know their schedule as of this writing. There are boats the run out of Barnegat Light, on the north end of the island, as well as beach Haven, on the south end. For more information check out [http://www.lbiviews.com/Boating/LBI %20Fishing and Charter Boats.htm](http://www.lbiviews.com/Boating/LBI%20Fishing%20and%20Charter%20Boats.htm)

If you are up to it, surfing is a popular pastime on the island. You can also visit the original store of Ron Jon surf shops. <http://www.longbeachislandsurfers.com/surf-lbi.html>

Viking Village, located at Barnegat Light, is a working fishing wharf with many small shops. Some of the freshest seafood can be bought here (a bit pricey, but worth it) as well as prepared dishes. [www.vikingvillage.net](http://www.vikingvillage.net) (Yes, if you have seen the Discovery Channel show "Swords, Life on the Line", you have seen some of the boats plying a living out of Viking Village) Bay Village at 9<sup>th</sup> & Bay in Beach Haven also offers many unique shopping opportunities. <http://www.bayvillagebi.com>

So, make the trip, and take your pick of things to do. **Remember to book your hotel room by Sept. 9<sup>th</sup> for the special rate.**

## Tips For Noids

Several years ago, in past newsletters, we printed some compilations of "tips" by various "noids". It has been a while, and there are enough newer people who may never have seen them, that they bear repeating. So here there are, updated to today's information.

The first was "**My 11 Point Start-up List**", written by the late Mary Ann Hicks.

1) Contact the Carcinoid Cancer Foundation - call the 800 number to get a list of the Carcinoid specialists. You will need a specialist to lead your local oncologist in your treatment, because, unless you are an exception, the local doctors will not even know how to spell Carcinoid. The main quality you need from your local oncol is a willingness to follow the lead of you and your specialist.

2) Know that you can FIRE your local doctor if he/she is not willing to provide you with the correct treatment. I was lucky and only had to fire my first oncologist. Well, I didn't actually fire him.....it's not wise to burn bridges, you never know when you may need them...I just found another one.

3) After you visit with the specialist, encourage your local oncol to call him and discuss your condition and treatment.

4) Read all you can about carcinoid. The first web sites I went to were: a) [www.carcinoid.org](http://www.carcinoid.org) the site for the Carcinoid Cancer Foundation. Read and re-read the transcripts from past symposiums by the specialists b) Susan Anderson's home

page which has links to many good sites, now [www.carcinoidinfo.info](http://www.carcinoidinfo.info)

5) It is important to note that a lot of the information you read will be out-of-date, so don't freak out at the statistics you see. If you're like most of us, the first thing you will look for are the statistics.

That's only natural when you have been diagnosed with a terminal illness. Most of the statistics you will see are based on old data. Look at the dates of the reference material. New drugs and procedures have been developed over the years, which have very positive bearing on our longevity.

6) I immediately started a notebook to carry with me when I visit my doctors. I don't need it as much now as at first, mainly because they (I now have 2) are too heavy to carry around (the notebooks, not the doctors -- LOL). One thing it did was make an impression on my doctors that I was going to be very proactive in my treatment, and my treatment was going to be a 'team effort right from the start.

7) You will be having lots of tests and procedures, and you should keep an updated profile to give to your doctors, and also to keep on your person and/or in your car in case of emergencies. Also obtain copies of all reports and tests to keep in your notebook.

8) This brings up one very important point which you should research more.....'Noids' should avoid ephinephrine, which is a normal medication given with novacaine at the dentists and

## Tips

(continued)

administered during surgical procedures. 'Epi' can cause a carcinoid crisis even if you have never had one. I know because I went into crisis during recovery from my surgery last December and the surgical team was not prepared for this. Sandostatin will control this crisis when it occurs. One exception I discovered, was that Epi is necessary in the case of allergic anaphylactic reactions (i.e. bee stings), so it cannot be avoided in this case, just be sure Sandostatin is available also.

9) There are 2 other support groups which you should also check out to see which ones you may prefer to subscribe to: a)

<http://groups.yahoo.com/group/Carcinoid/>. This group is closely moderated and is focused on technical and medical information sharing..

b) the ACOR group is more open to personal support than the Yahoo lists (more 'touchy-feely' if you know what I mean).

10) As soon as possible, attend a local support group function, or a national Carcinoid seminar. Hopefully someone in your general location will contact you.

11) Oops, I almost forgot. Don't sit around and isolate yourself. It is very easy to get depressed. I was given very good advice to get out and work with others as much as possible, and get your attention off of yourself whenever possible. I definitely do better emotionally and physically when I am busy with things outside of myself.

After Mary Ann, came Cynthia Marrs with her

### *"Things I Have Learned Since My Diagnosis"*

1-It's not all in my head. I can trust my instincts.

2-Someone else is in a far worse position than I am.

3-I'm not short on memory; I have a surplus of forgetfulness (Thank you Ellen DeGeneres)

4-How to spell diarrhea.

5-It's okay to ask for help.

6-It's okay to stand up for myself.

7-My daughter loves me.

8-God will many times give me more than I can handle. It is His loving way of reminding me that it isn't my job. I am not in charge.

9-Making sure the will and insurance are complete and correct is responsible.

Ordering the headstone is premature.

10-The most important one of all! I AM NOT ALONE!

*Here is a list of some general, practical things we have also learned over the years.*

1-Doctor's visits can be very stressful, especially initial consultations. These visits are often packed with strange and foreign information, and you may not remember or catch everything that will be said. When talking to your doctor it is a good idea to have someone with you to take notes or, with the doctor's permission tape record the conversation for later reference.

2-Start your own "photo album". If you have a test performed, especially imaging, ask to have an extra set of films made for you at the time the test is done. It is much easier to get the extra set then, rather than have to try to track them down when asked for them during a later consultation. Most places will not charge you if you get them at the time of the test.

Written reports may not be ready for a few days, but be sure to get a set of them as well. Ask the tech for an empty film box to carry and store them, or an artist's portfolio case works well

3-Keep a notebook of written reports. If you have a hard time getting the reports, any doctor can usually get them for you. We heard of one patient whose chiropractor was willing to have the reports faxed to his office and then gave them to the patient.

4-Keep a printed list of current medications, including dosages and frequency of dose. **Keep the list current!** Keep it with you at all times.

5-Keep a card in your wallet that indicates you are a carcinoid patient and that your carcinoid specialist should be contacted immediately if you suffer a sudden illness or injury. Remember that any traumatic event could result in carcinoid crisis, which may require Sandostatin® to be administered or other special care. Medical bracelets can also be helpful here.

6-Keep a journal of your symptoms, how you feel, and what medications or treatments you are currently on. You may even want to track what you have been eating. This may be helpful in treating symptoms and evaluating further treatments.

7-Keep a running list of questions, as they pop into your head, and take that list to the doctor for your next visit. Most doctors will appreciate the time saved by having questions prepared and not having to wait for you to think of your questions. Leave space on your question list to jot down the answers. Immediately upon return home, transcribe those questions and answers, while

they are still fresh in your mind. Check with your doctor, he may even appreciate you faxing your questions ahead so he has time to evaluate them and have the answers ready for your visit.

8-If your doctor discourages questions, or your suggestions, you may want to consider another doctor who is more responsive to you.

9-If you are taking Sandostatin LAR®, check with your doctor about what the recommended dose would be for a rescue shot, before you need actually one. Be sure to keep up to date about revising that dosage as your condition changes.

10-Sandostatin needs to be refrigerated and is not readily available, so if you are subject to carcinoid crisis, you may need to be aggressive in keeping it handy. We found a small wide mouth insulated container (such as a soup thermos), allows a vial to fit inside, with enough ice packed around it to last most of the day. Don't forget syringes and antiseptic or alcohol swabs in your "kit".

11-If flying, do not pack your Sandostatin® or "kit" in your checked luggage, as it may wind up lost or in another city. Before your trip, check with your airline for how they want you to package and/or present your medications and syringes at security checkpoints. Surprisingly, TSA does not even seem to flinch at seeing these, but you may want to alert them to what is in your carried bag.

12-You can carry a "kit" with a syringe of your dosage of Sandostatin® already drawn up and a couple alcohol wipes. It will fit in a travel toothbrush holder in a soft-sided cooler for those day trips.

# 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 | TBA                       |                                                       |
| 10:30 to 11:30 | Nancy Gardner, RN, PhD    | Sandostatin LAR & Patient Issues                      |
| 11:30 to 12:45 | Lunch                     | On or off-site                                        |
| 12:45 to 1:45  | Dr. Kjell Öberg           | “Advances in the Management of Neuroendocrine Tumors” |
| 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          |                                                            |                                                            |
|                             | <b>Total Amount Enclosed</b><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)