



# Metro NY Carcinoid Support Group Newsletter

Summer 2003

## Our Sister Groups

**Arizona Carcinoid Team** - For information contact Bob ([risbell@compuserve.com](mailto:risbell@compuserve.com))

**Southern California Carcinoid Fighters** – For information on specific chapters, please visit the group's web site. (<http://www.sccfighters.org>)

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

**Pacific North West** - For information contact Corie ([cadean@NATPIPE.COM](mailto:cadean@NATPIPE.COM))

**Pennsylvania / Philadelphia** - For information contact Karen ([KarenLKane@aol.com](mailto:KarenLKane@aol.com))

**North Texas** - For information contact Carol- Anne ([carolewilson@attbi.com](mailto:carolewilson@attbi.com)) or Harriet ([cmkelley@sprintmail.com](mailto:cmkelley@sprintmail.com))

**South Texas** – For information please contact Dawn ([txdawn62@SATX.RR.COM](mailto:txdawn62@SATX.RR.COM))

**Canada/Upper NY State** - Lower Ontario & Upper New York State - For information contact Maureen ([maureenc@sympatico.ca](mailto:maureenc@sympatico.ca))

**NEW – Boston Area** –The Dana- Farber Cancer Institute - contact Bridget Grant ([bridget\\_grant@dfci.harvard.edu](mailto:bridget_grant@dfci.harvard.edu))

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>).

## Tri-State Party Time



On June 1<sup>st</sup>, about 22 members of the Tri-State groups, friends & caregivers got together for a slightly different meeting. This meeting was a time to party. While we all enjoy each other's company, the focus today was on food and just chatting with one another.

We met at our usual NJ Chapter location (Crossroads Christian Fellowship in Union, NJ) but this time we added decorations and, most importantly, FOOD.

Thanks to the efforts of

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## Carcinoid Cancer Foundation Sponsors NYC Meeting

The Carcinoid Cancer Foundation will again sponsor a "Tri-state group" meeting in New York City. The topic for this meeting is The Multidisciplinary Team, What's new and what they do."

Topics will include an overview of Carcinoid and other NET's; Getting the most from your biopsy; Beyond surgical incision; Medical treatments; Drugs used for NET's and side effects; Role of nuclear

medicine and interventional radiology; Nutritional concerns with and without carcinoid syndrome.

The meeting will feature:

- Dr. Richard R. P. Warner, Internist, Gastroenterologist
- Dr. James A. Strauchen, pathologist
- Dr. Michail K. Shafir, oncology surgeon

## Upcoming Dates

**September 7th, 2003** – New Jersey Chapter meeting at Crossroads Christian Fellowship. Union, NJ, 1:30 p.m. Contact Maryann Ritter, (973) 252-7941 [marer57@optonline.net](mailto:marer57@optonline.net) OR Kathy Mazza, 732-842-3930, [tommazza@hotmail.com](mailto:tommazza@hotmail.com) to RSVP or if you have any questions.

**September 12th, 2003** – Metro NY First Annual Golf Outing to Support the Carcinoid Cancer Foundation. Contact Maryann Wahmann ([MommaHull@aol.com](mailto:MommaHull@aol.com)) or call 516-781-7814 if you have any questions.

**August 30<sup>th</sup> 2003** - The Illinois Support Group will meet on at 11:00 AM at the same place as the 1<sup>st</sup> meeting (Methodist Medical Center)

**October 05th, 2003** - Metro New York Group, Tri-State meeting, in collaboration with the Carcinoid Cancer Foundation presents The Multidisciplinary Team, what's new and what they do. 1:00 PM at Mt. Sinai Hospital in New York City (see article in this newsletter)

For Newsletter questions please contact:

Sue Weiveris  
Phone/Fax: 908-276-4873  
E-Mail: [NoidFighter@aol.com](mailto:NoidFighter@aol.com)

## Prescription Savings

A recent e-mail we got had information about a new report on television about prescription costs and how to save some money. The report had cited that some discount warehouse stores also have pharmacy departments and offer deep discounts on prescriptions. By law, you do not have to be a member to purchase prescriptions at these "member-only" facilities. Some pharmacies had reported mark-ups of over 3000% (that is not a typo) on some drugs. We have always been amazed at the costs of drugs and just a chat room inquiry one night found people paying from \$2000 to \$5000 for Sandostatin LAR, so you can see the wide range of costs.

Unfortunately, the e-mail was copyright protected, so it can not be directly quoted here, nor give credit to the author, but you get the idea. Check around for the best price on drugs.

## Two New Groups Sought

Recent e-mails have been asking for people interested in starting two new regional support groups.

One group would be in the Central Pennsylvania area, most likely meeting at the Hershey Medical Center. Hershey is in close proximity to Lancaster & Harrisburg. If you are interested, please contact Teresa Lanza at [teresalanza@juno.com](mailto:teresalanza@juno.com)

Another start-up is in the works in the Miami-Ft. Lauderdale area. No meeting location has been suggested yet but interested parties should contact Julia via e-mail at [Juldand@peoplepc.com](mailto:Juldand@peoplepc.com)

## Tri-State Banquet

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Chez Barbara Catering, several dishes were prepared for the group. Barbara Herrington, long-time friend/caregiver to Sue Weiveris performed double duty, both as a participating caregiver and also in assisting in set-up and keeping the trays full and hot. A special thanks to Barbara. Everything from lemon chicken, grilled vegetable lasagna to filet mignon and various desserts were there.

Conversations ran from each other's kids, to pets, to homes and vacations. (those are some discussions we overheard, I am sure there were more) There was, of course, just some inevitable discussion about Carcinoid and treatments, but this time, they were the exception.

We all had a great time, some of us ate too much, and most agreed to do it again.

## Metro NY Golf Outing Planned

The Carcinoid Support Group has scheduled their first annual Golf Outing to help raise money for the Carcinoid Cancer Foundation, which support carcinoid cancer research and education.

Under the direction of Maryann Wahmann & her husband, Bob, the Long Island chapter has taken on this ambitious project.

The date is Friday, September 12<sup>th</sup> at 12:45PM at the Douglaston Golf Course and Douglaston Manor, located in Flushing, NY.

The outing will have an afternoon of golf and an evening buffet. Shotgun start, hot dog & beer at the turn,

50/50 raffle, golf cart and great prizes (closest to pin, longest drive, low score) are just part of this day which also features a 3 hour open bar and buffet, including coffee and dessert. All for just \$175. If you are not up for golf, join us for the buffet at 7:00 PM for only \$65. For more information, contact Maryann or Bob at 516-781-7814 or via e-mail at [MommaHull@aol.com](mailto:MommaHull@aol.com)

Registration checks should be made payable to the Carcinoid Cancer Foundation.

Also needed are hole sponsors, raffle prize sponsors and volunteers to help out.

## Social Security Information

Last newsletter we asked readers to submit questions about Social Security Disability. We have since found the best way to handle these personal questions is to consult the local Social Security Office or the agency's web site at [www.ssa.gov](http://www.ssa.gov) for information.

## Have you missed a newsletter?

If you are thinking it has been a long time since you last saw a Metro NY Carcinoid Support Group newsletter, you may not have missed any. The last one published was April, 2003.

While we try to get information out on a more regular basis, various factors have teamed up against us recently. In the last few months we have dealt with a number of personal issues (cleaning out & selling one parent's house, cleaning and marketing and selling our house, building our new house, moving to a temporary apartment, Jim's "promotion" to civilian (retirement) and Sue's health issues and recent hospitalizations.

We will continue to do the best we can in the future, but can make no guarantees. Thanks for your patience and understanding.

## NYC Meeting

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- Dr. Lyn H. Ratner, oncologist
- Dr. F. Scott Nowakaoski, Interventional radiologist
- Dr. Jeffrey I. Mechanick, Nutrition & metabolism.

The date is Sunday, October 05, 2003, 1:00 PM to 4:30 PM at the Mount Sinai Medical Center, 2<sup>nd</sup> floor, Guggenheim Pavilion, Madison Ave. at 100<sup>th</sup> Street, New York, NY

As usual there will be time for networking and refreshments will be served.

For additional information, directions, or to RSVP by September 27<sup>th</sup>, please call Maryann Wahmann at 516-781-7814 or e-mail at [MommaHull@aol.com](mailto:MommaHull@aol.com)