



**Metro NY**

# **Carcinoid Support Group**

**Newsletter**

August/September 2002

## **Upcoming Dates - Our Sister Groups**

**Arizona Carcinoid Team** - next meeting is October 26th. For more information contact Bob ([risbell@compuserve.com](mailto:risbell@compuserve.com))

**Southern California Carcinoid Fighters** - next meeting is September 7<sup>th</sup>. Guest speaker Dr. Eugene Woltering. For more information visit the group's web site (<http://www.sccfighters.org>)

**Capital Area Carcinoid Survivors** (Washington, DC) - next meeting September 14<sup>th</sup>. Guest speaker Dr. Marlene Haffner, Director of the Office of Orphan Products Development, FDA. For more information visit the group's web site (<http://members.aol.com/cacsva/index.htm>)

**South Texas Carcinoid Support Group** - San Antonio - next meeting October 19<sup>th</sup>. For more information contact Dawn ([txdawn62@SATX.RR.COM](mailto:txdawn62@SATX.RR.COM))

**Texas Carcinoid Support Group** - Houston - next meeting September 28<sup>th</sup>. For more information contact Dawn ([txdawn62@SATX.RR.COM](mailto:txdawn62@SATX.RR.COM))

There are new support groups continually starting up across the country. For the latest list of support groups visit the Foundation's web site ([www.carcinoid.org](http://www.carcinoid.org)) or Susan Anderson's web site (<http://home.att.net/~S.L.Anderson/support.htm>)

## **Wayne Tefs to Speak**



Our featured speaker at our September 29<sup>th</sup> regional meeting will be Wayne Tefs, author of rollercoaster: a cancer journey. Wayne writes about his experiences and emotions as he battles for an accurate diagnosis for his symptoms, then deals

with the reality of having cancer. The book chronicles his ups and downs as he tries to deal with the truth and learn how to live with Carcinoid.

The book is published by Turnstone Press and includes a jacket write up by Monica Warner of the Carcinoid Cancer Foundation. The book will be available for purchase at the meeting.

In addition to Wayne,

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## **Upcoming Dates**

**September 29, 2002** - Tri-State Meeting, Mount Sinai Hospital, New York. Featured Speakers will be Dr. Richard Warner, Dr. Lynn Ratner, and Wayne Tefs, author of the recent book rollercoaster: a cancer journey.

Please RSVP by September 24<sup>th</sup> to Sue Weiveris at 908-276-4873 or

[NoidFighter@aol.com](mailto:NoidFighter@aol.com)

There is no fee to attend this meeting, but space is limited so reply early. Refreshments will be served.

**October 20, 2002** - New Jersey Chapter meeting.

## **Things I've Learned or Remembered Since My Diagnosis**

The following was posted recently on the ACOR list by Cynthia Marrs ([YerRolodex@aol.com](mailto:YerRolodex@aol.com)) and is reprinted here with her permission.

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!

## **Newsletter Distribution**

As we announced in the last newsletter, this is the first issue that we are electronically sending to anyone with an email address.

If you received a paper copy of this newsletter in the mail even though you have an email address, it means we do not have your email address on file. Please provide your email address by sending a message to Sue ([NoidFighter@aol.com](mailto:NoidFighter@aol.com))

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## Newsletter

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You will then receive the next newsletter as an attachment to an email from [NoidFighter@aol.com](mailto:NoidFighter@aol.com). The file will be in Adobe (PDF) format. If you do not have Adobe Reader, you can download it for free, just go to [www.Adobe.com](http://www.Adobe.com), select the correct format for your computer and follow screen prompts.

We appreciate anyone who can receive the newsletter online as it is a significant cost savings.

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For Newsletter questions please contact:

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

## Friend to Friend - Nationwide Carcinoid Phone Support List

Our Nationwide Support List is up and running very successfully.

During the past few weeks we have fielded calls from people across the nation as they search for answers or just someone to relate to as they go through this. The response of people calling has been overwhelmingly positive, as has been the cooperation of everyone who has signed up to field calls. Support participants have also expressed positive feelings about being able to help others by sharing their experiences and knowledge.

In an effort to ensure everyone's right to privacy, the list maintains a policy of

contacting the support list participants and having them contact the original caller.

If someone desires to contact a fellow noid for support they should call the Carcinoid Cancer Foundation at 888-722-3132 (Tuesday – Thursday 9-5 eastern time) or Sue Weiveris at 908-276-4873 (Monday – Thursday 9-5 Eastern Time).

Information about the “Friend to Friend” program is also available on line at the Foundation's web site ([www.carcinoid.org](http://www.carcinoid.org)).

Please address any comments or suggestions about this program to Sue Weiveris ([NoidFighter@aol.com](mailto:NoidFighter@aol.com)).

## Tefs to Speak

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there will be an introduction by Dr. Richard Warner, Medical Director of the Carcinoid Cancer Foundation. A brief overview about clinical trials will be presented by Dr. Lynn Ratner, Assistant Clinical Professor, MSSM.

We will also have Carcinoid tee shirts available for sale. The meeting will conclude with refreshments and time for networking. Space is limited so respond as soon as possible to insure a seat.

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## Attention NJ Chapter Members

In an effort to better organize the group and assist in the necessary administrative responsibilities, we have created several committees.

The committees include

- ◆ Phone Chain/Home Support
- ◆ Hospitality/Transportation
- ◆ Treasury/Fundraising
- ◆ Newsletter/Publicity

You will find a sheet attached which gives a description of each committee along with the person in charge of the committee. If you can assist in any way, it would be greatly appreciated.

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## TX Group Makes News

Congratulations to Dawn Decker of the newly formed Texas support group. Dawn was recently featured in an article in the San Antonio Express-News. The article spoke of using the Internet to obtain Carcinoid information.

Thanks for helping to spread the word Dawn.

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## Caregiver's Corner

### A Look On The Lighter Side!

Submitted by Jim Weiveris ([caring4noids@aol.com](mailto:caring4noids@aol.com)).

For those who drive in to New York City for treatments or meetings, we offer these humorous tips for surviving the drive:

- When purchasing a new car, consider Metropolitan Transit Authority bus white or Taxi Cab yellow. That way you have a 50/50 chance that you will at least not have to touch the paint.
- Lane markings are merely a suggestion.
- Making a turn from the inside lane (such as right turn from right lane) is a sign of cowardice.
- Since there are no gas stations to ask for directions (even if you would), it helps to know that “Avenues” run North & South (Uptown & Downtown, respectively) and “Streets” run East and West (Cross-town).
- Turn signals are optional equipment and are rarely purchased.
- Beware of the divided roadway (such as Park Ave.) that you must stop for the red light on each side of the divider. The sign warning you of this is only slightly larger than a credit card, while the ticket is 4 inches by 6 inches.
- Most streets alternate their one-way direction on every other street, with some two-way streets. Don't mix them up.
- Don't get caught in a Fire Lane when a siren approaches. Most NYFD Fire Engines have several small cars trapped under them at any given time.
- You can drive across Central Park, but the police have no sense of humor if you don't use one of the paved transverse roadways (like 97<sup>th</sup> St.)
- In summary, driving in New York City takes bravado and caution, but with a little practice it can be done.
- Other suggested reading include “Do It Yourself Auto Body” by Tim Taylor. ©1995 Binford Press, Detroit, Michigan and “Jane's Book of Armored Vehicles”



# METRO NY CARCINOID SUPPORT GROUP

THIRD REGIONAL MEETING FOR CARCINOID PATIENTS  
CAREGIVERS, FAMILY AND FRIENDS

Theme: LIVING WITH CARCINOID

Introduction: Richard R.P. Warner MD,  
Medical Director, Carcinoid Cancer Foundation, Inc.

Keynote Speaker  
**WAYNE TEFS**  
author of "Rollercoaster; a cancer journey"

Topic:  
**Seeing UP when you're DOWN**

Additional guest speaker:  
Lynn H. Ratner MD, Assistant Clinical Professor (Oncology) MSSM  
Topic: Demystifying Clinical Trials (A brief explanation)

Refreshments, Networking

Date: **Sunday, September 29, 2002**  
Time: 2:00 – 4:30 p.m.  
Place: Mount Sinai Medical Center

Hatch Auditorium  
Second floor / Guggenheim Pavilion  
Madison Ave/100th Street  
New York, NY 10029

**RSVP By September 24**

Sue Weiveris 908-276-4873  
NoidFighter@aol.com

## DIRECTIONS

The Mount Sinai Hospital is located on Madison and Fifth Avenues, at 100th Street, on the Upper East Side of Manhattan.

**By Subway :** Take # 6 to 96th Street and Lexington Avenue. Walk west on 96th Street to Madison Avenue. Turn right and walk to 100th Street. Entrance to Mount Sinai Hospital is on left side of Madison Avenue.

**By Public Bus :** Take M1, M2, M3 or M4 Bus (Fifth Avenue Buses) traveling South to 99th Street Stop. Mount Sinai Hospital (Fifth Avenue Entrance) is located on 99th and Fifth Avenue.  
Take M1, M2, M3 or M4 Bus (Madison Avenue Buses) traveling North to 98th Street Stop. Mount Sinai Hospital (Madison Avenue Entrance) is located at 100th Street and Madison Avenue.

### **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.

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.

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.

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.

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.

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.

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.

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.