



Metro NY

Carcinoid Support Group

Newsletter

June/July 2002

Fund Raising Efforts



The following is a message from Stephen Pazan, President of the Southern California Carcinoid Fighters.

The fight against carcinoid cancer is now being waged on a shoestring budget. Per-capita, our best estimates place our fund-raising far below that of better known non-profits. We would like to raise consciousness of this disease and raise money for carcinoid research, primarily through the Carcinoid Cancer Foundation

We at the Southern California Carcinoid Fighters are now collecting money for that purpose. Those who donate \$25 or more [to the Carcinoid Cancer Foundation] will be rewarded with this Hanes Beefy T-shirt, 100% cotton and the best quality made, with the inscription "Carcinoid Cancer Fighters" underneath the picture of the carcinoid fighter.

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Congratulations Dr. Warner



Dr. Richard R.P. Warner has been honored by The New York Cancer Society and The Fund for Blood and Cancer Research.

At their 50th anniversary dinner on June 4th, Dr. Warner was presented with

The Catharine Margaret Pasmantier Award for Outstanding Accomplishments and Distinguished Work with Carcinoid and Other Neuroendocrine Tumors.

We are all aware of the decades of research and treatment options Dr. Warner has been instrumental in implementing. We congratulate Dr. Warner on his recent award and humbly thank him for his dedication, care and compassion to Carcinoid patients everywhere.

Carpe Diem



It is with much sadness that we acknowledge the passing of a dear friend, Rosemary Finley.

Rosemary was among the national leaders for Carcinoid support and awareness. She was the founder of the Minnesota Carcinoid Support Group.

Rosemary was known for her determination and devotion not only in supporting patients and caregivers, but also for

making the word Carcinoid recognized around the country. Rosemary was always willing to talk to fellow noids. She provided encouragement and inspiration to newcomers and old-timers as well.

On a personal note, Rosemary was instrumental in helping us form the Metro NY Carcinoid Support Group. Through phone calls, emails and sharing of various ideas that she had tried and proven in Minnesota, Rosemary's insight was invaluable.

Rosemary will truly be missed. Her favorite expression was Carpe Diem (seize the day) and in her honor, maybe we can each try to remember to do just that. In addition, hopefully we will be able to continue the work she was so dedicated to.

Upcoming Dates

August 4, 2002 – 1:00-4:00 NJ Chapter Meeting. This meeting will be held at the home of Karen Antoshkiw. Karen has offered the use of her yard and pool for our barbecue. We will also have the opportunity to view the PBS program on tumor growth that was discussed at our last meeting. Please see the enclosed flyer or the Foundation's web site for more information about the meeting.

September 29, 2002 – Tri-State meeting. See the next newsletter or the Foundation's site.

Newsletter Distribution

Our success with this newsletter has caused us to change the way we will distribute the MNYCSG Newsletter. We currently have just under 200 recipients of the newsletter and the printing and mailing costs are mounting.

Starting with the next newsletter, we will e-mail the newsletter to all of those for whom we have an email address. You will get the newsletter as an attached file from Noidfighter@aol.com and

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Fund Raiser

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Anyone who follows the ACOR list knows that the T-shirts have raised questions among the general public. So, in addition to being a fundraiser they are furthering Carcinoid awareness; thus a "win/win" situation!

The Metro NY Carcinoid Support Group has purchased 30 T-shirts for resale to members, caregivers and friends.

The T-shirts will be available at the next NJ Chapter meeting being held on August 4th. They will also be available at the Tri-State meeting in September. Please contact Sue Weiveris (NoidFighter@aol.com) if you have any questions regarding the T-shirts.

We extend many thanks to Stephen and his group for taking on this wonderful project.

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the subject line will be (current month) Newsletter. 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, select the correct format for your computer and follow screen prompts.

If you have an e-mail address, but still wish to get a printed copy, you can print the Adobe version. If there is a problem with this procedure, please let us know and we will try to accommodate you. In addition, if there are any other problems, please let us know.

Pilot Study of the Nationwide Carcinoid Phone Support List

May 31st, marked the beginning of our nationwide telephone support list pilot study. The study is entitled "Friend to Friend". This project has been in the forming stages for a few months. We hope it will enable carcinoid patients nationwide to exchange information and share inspiration and support. The program is dedicated to the memory of Rosemary Finley, Founder of the Minnesota Carcinoid Support Group.

At this time there are 56 people representing 20 states, Canada and Puerto Rico included on the list. In an effort to ensure everyone's right to privacy, the pilot study will be conducted as follows:

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).

The caller will be asked where they live, their phone number and what type of information they are looking for. Type of information could include primary/mets sites, treatments received and Carcinoid specialists seen. Of course, some people may simply want

to connect with another person on a general interest level.

The call screener will record all the information and advise the caller that they should receive a return call within a few days.

The call screener will then contact one or two people on the support list who fit the needs of the original caller.

The support list person will receive all the information and be asked to make a call to the original caller. Obviously this should be accomplished within as short a time period as possible.

Once the support person contacts the original caller, it is up to the discretion of the support person as to whether they want to give out their phone number or e-mail address.

Information about the "Friend to Friend" program is also available on line at the Foundation's web site (www.carcinoid.org).

Remember that this is a pilot project, we encourage your comments and suggestions as we get this project off the ground. Please address any comments or suggestions to Sue Weiveris (NoidFighter@aol.com).

Transcripts

The Carcinoid Cancer Foundation is continually adding transcripts from various carcinoid lectures to their web site (www.carcinoid.org) If you are not in the habit of checking the site on a regular basis, it would be worth your while to do so.

The following is a list of some of the newest transcripts available:

- 2002 Annual Update and Review of Carcinoid Disease; Dr. Richard Warner; Jan '02
- Introduction to the Basic Science of Carcinoid; Dr. Eugene Woltering; Mar '02
- Current Concepts in the Medical Treatment of Carcinoid; Dr. Lowell Anthony; Mar '02
- Psychological Effects of Carcinoid Disease; Dr. Elizabeth Soliday & Dr. Suzanne Smith; Apr '02
- Coping with Carcinoid Diarrhea; Valerie Bennett, RN; Apr '02

In addition to the transcripts, there are always new and informative articles being added to the web site. We all appreciate the efforts made by the Foundation to keep us up to date on the latest Carcinoid data. Be sure to visit the web site when you have the opportunity.

For Newsletter questions please contact:

Sue Weiveris
Phone/Fax: 908-276-4873
E-Mail: NoidFighter@aol.com

Caregiver's Corner

We recognize the stress felt by caregivers as well as patients. We hope caregivers will find this section of value. Look for more caregiver articles in the future.

TIPS OF THE MONTH

From the National Family Caregivers Association
Tips for Family Caregivers

- 1 – Grieve for your losses, and then allow yourself to dream new dreams.
- 2 – Stand up for your rights as a caregiver and citizen.

For more information contact Jim (caring4noids@aol.com)