Metro New York Carcinoid Support Group

Newsletter

March 2007

www.carcinoid.us

Yttrium$^{90}$ Support Expands

In the last newsletter, Joanne was kind enough to share her story about her experience with the Y$^{90}$ treatment. That article has prompted response in many different ways.

Expected was the myriad of e-mails to Joanne. People who wanted to know a little bit more, people who wanted to share their experiences, and people just curious about the article have prompted response in many different ways.

Mea Culpa

In the last newsletter, I included an article on IPHC (Intraperitoneal Hyperthermic Chemotherapy). In that article, it may have appeared that it was a new procedure.

Thanks to the vigilance of Dr. Warner, let's straighten out the facts.

The procedure has actually been around for about 15 years. Dr. Sugarbaker (in the Baltimore area) has been doing quite a bit with this procedure. The results have been of only modest benefit, and only in cases with diffuse intraperitoneal involvement.

While a unique procedure, it does not seem to offer a great deal of promise.

My apologies for any confusion.

Carcinoid Cancer Foundation Lecture Announced

The Carcinoid Cancer Foundation has announced it will be hosting a lecture and group meeting on April 15th at the Mt. Sinai Hospital complex in New York City.

The featured speaker is Dr. Irvin M. Modlin, Professor of Surgery, Director - Gastric Surgical Pathobiology Research Group at Yale University School of Medicine in New Haven, CT. Dr. Modlin's topic title is "Carcinoids: The Slow Pace of Rapid Progress".

The program starts at 1:00 PM and will end at 5:30PM at the Goldwurm Auditorium, located at 98th St and Madison Ave (not the main hospital building, but just across Madison Ave).

Dr Warner will start off the afternoon with introductory comments. There will also be an extended question and answer panel of medical professionals from several disciplines and including Dr. Modlin.

The day will end with a session on becoming a part of a support/advocacy group. Here is your chance to learn more, people who wanted to know a little bit more, people who wanted to share their experiences, and people just curious about the article have prompted response in many different ways.

Are You Ready for Tax Time?

It's that "wonderful" time of the year again. Time when you start thinking about just how much money have you spent for your care. How much can you deduct? Where is that receipt for the parking deck at Mt. Sinai?

Taxpayers will have extra time to file and pay in 2007 because April 15 falls on a Sunday, and the following day, Monday, April 16, is Emancipation Day, a legal holiday in the District of Columbia.

Everyone knows that you can deduct bills for doctors, labs fees, hospital charges, and medications (that are not covered by insurance). That amount must be over 7.5% of your adjusted gross income. For example, if your adjusted gross income is $40,000.00, then you can deduct any uncovered medical expenses over $3,000.00.

There are some other deductions that you can take. Improvements to your home to accommodate your condition, as long as the main purpose is for medical care, may be deducted. Things such as wheelchairs, ramps, etc. may be deducted. Let your local accountant or tax expert discuss with you these issues.

Upcoming Dates

March 4th, 2007 - New Jersey Chapter meeting at Crossroads Christian Fellowship, Union, NJ, 1:30 PM. Contact Jim Weiveris at 609-812-9294 or Caring4Noids@aol.com

March 11th, 2007 - Long Island, NY Chapter meeting at Bellmore Library. Verify dates at www.carcinoidaware.org or call 516-781-7814

March 18th, 2007 - Pennsylvania Carcinoid Cancer Advocacy, "Conversation & Coffee" Hershey, PA. 2 to 4 PM, Please RSVP to confirm meeting.

April 15th, 2007 - Carcinoid Cancer Foundation lecture and meeting. See article to left & registration form on page 5


Sept. 27 through 30th, 2007 – North American Annual Conference for Carcinoid and Neuroendocrine Tumors held in Norfolk, VA. Details will follow or visit (under construction) www.carcinoidnetconference.org/

November 9th, 2007 - CCAN Annual Dinner Dance, Long Island, NY

November 10th, 2007 - CCAN Lecture, Long Island, NY

Continued on Page 3
Our Sister Groups

Arizona Carcinoid Team – Meets in Phoenix, For information contact, James at act_mail@yahoo.com

Northern CA - NCF meets in Fairfield. For information contact, Kathy at kabanis@yahoo.com

Carcinoid One on One meets in Orange, CA. For information contact, Terri at Terris12@att.net

SEA (Support Education & Awareness for Carcinoid Patients) Not affiliated with CalCF. Meets in San Gabriel/San Fernando Valley area. For information contact, Nickolette at sea4carcinoid@msn.com

South Bay Carcinoid Fighters (LA) Meets in Redondo Beach, CA. Pat carcinoidfighter@yahoo.com

Connecticut Carcinoid Initiative, Meets in Rocky Hill, Contact, Bob delby@juno.com

Capital Area Carcinoid Survivors (Washington, DC) – For information visit the group’s web site, http://hometown.aol.com/cacsva/

Florida (informal group) Pam prpowell@cfl.rr.com

Chicagoland Carcinoid Fighters Meets in Gurnee, IL contact pending

Boston Area – At the Dana-Farber Cancer Institute - contact Sarah Murphy, LICSW at 617-632-6463 or the New England Carcinoid Connection (NECC) at www.carcinoid-newengland.org

Michigan - Meeting place may rotate. Contact Dave at Dav2005@earthlink.net

Minnesota Carcinoid Peer Support Group, contact Jan Jackson jaxon7@msn.com, also covering western WI and surrounding areas

New Mexico – Meets near Belen. Contact Kathy, WYHTAK@aol.com

Pacific North West - For information contact, Corie at cadean@NATPIPE.COM

Central Pennsylvania - (Harrisburg/Hershey), For information contact, Teresa CarcinoidSupport@juno.com

Pennsylvania / Philadelphia (Informal group) Contact Anne SuJohns56@aol.com

Dallas, Texas Contact Carol-Anne for information CarolAnne52@gmail.com

Houston, TX Contact Jan Peine, jpine@houston.rr.com

Austin, TX - For information contact, Ann Meyer ameyer@swrec.com

Canadian Carcinoid Cancer and NET Support Team - Lower Ontario & Upper New York Sate - For information contact Maureen C. maureenc@sympatico.ca

Oregon Carcinoid Education and Advocacy Network. (OCEAN) - For information contact Cynthia at YerRolodex@aol.com or subscribe-OregonCarcinoid@yahoogroups.com

Oregon Chapter of Pacific Northwest Group - contact Kari at KBrendtro@yahoo.com

Some information reprinted here with the permission of the Carcinoid Cancer Foundation. Thank you.

For the latest list of support groups visit the Foundation’s web site (www.carcinoid.org), our web site (www.carcinoid.us) or Susan Anderson’s web site (http://www.carcinoidinfo.info/).

To list your group or update a listing, please send us a note

Memphis Area

Dave Hall was diagnosed with Carcinoid in Dec. 2000.

Dave wants to hear from anyone in the Memphis, TN area. He is interested in starting a support group, possibly at the Mid South Cancer Center, or to just have others to chat with.

Dave can be contacted at chefbear1@comcast.net

Daylight Saving Time

Daylight Saving Time now begins the second Sunday in March. So, on March 11th, don't forget to push those clocks ahead one hour before you go to sleep (or you will find yourself late for everything that morning).

We switch back the first Sunday in November (the 4th).

For those who live in Arizona and Hawaii, please disregard this public service announcement. 😊
Tax Time
Continued from Page 1

as the cost to add grab bars to your bath or shower may be allowed. Keep your deductions reasonable and the costs realistic. For example, you may have changed your door knobs to lever types because they are easier to open & close. However, choosing to use hardware that is gold-plated (yes, it does exist) may be considered unreasonable.

Home improvement deductions are offset by the value increase to your home resulting from the improvement. Take an example. Let's say you have enlarged a bathroom to make it wheelchair accessible and the improvement cost $15,000. The value of your home, because of that improvement, increased the home value by $10,000, then you can only deduct $5,000. You can include the costs for meals & lodging if the primary reason for being at that institution was for medical care.

 Lodgings and meals may not be lavish or extravagant under the circumstances. Lodging costs are limited to $50 per night, per person. That can include a person travelling with you, but meals are not included.

Insurance premiums, including Medicare part D, COBRA, and HMOs are deductible. Insurance for long term care policies are subject to limitations.

Maintenance and Personal Care services may be deductible, if the patient meets certain criteria as "chronically ill", and it is directed in providing assistance of a disability.

You can include the transportation and admission costs to attend medical conference regarding the care of yourself, spouse or dependant for a chronic illness. Meals while at that conference are not allowed. The majority of the time at the conference must be spent attending medical information sessions. (That means going to the annual Carcinoid/NET patient conference may be deductible within the limits set.)

Medications and prescriptions brought in from another country cannot be deducted. Transportation costs to/from (and which are essentially for) medical treatment are deductible for the patient and caregiver (the law specifies "parent who must go with a child"), if needed. As part of transportation costs they include, bus, taxi, train, ambulance services and air fares.

Car expenses to/from medical appointments may be deducted using actual expenses or the standard rate of $.18 per mile (round trip). Start adding up how many times you drove to the doctor and multiply that by the mileage. You may be surprised just how much it comes out to be. Parking fees and tolls can be deducted, even if taking the standard mileage deduction.

Wigs, if on doctor's advice and due to the medical condition or treatment (well, that leaves me out), and other prosthetic devices are also deductible.

Some of the things you can't deduct:

Baby sitting or child care services.

Health club dues or swimming pool memberships, even if prescribed by a doctor.

Non-prescription drugs, even if recommended by a doctor (like aspirin) are not deductible. Neither are nutritional supplements and herbs.

You cannot deduct daily use personal items, but can deduct the difference in cost for a special form item that is needed. For example, toothpaste is a personal item, but a special type (sensitive teeth, for example) costs more, and the difference in cost may be deducted.

How to treat reimbursements.

Only costs which are not reimbursed may be deducted. If you have an operation late in the year, and pay the surgeon's fee "up front", if the reimbursement check arrives after Jan. 1, you must show that reimbursement as income for the following year. (See IRS publication 525 for more information)

If your insurance reimbursements are greater than your expenses (some couples with multiple policies can have this happen), you must show that excess amount as income. This one gets real complicated about who paid the premiums (employer, patient, spouse….), etc.

Record Keeping (or "how to keep from getting indicted or slammed with penalties & interest later on"): The IRS suggests that you keep written records with the following information:

The name and address of each person you paid, the date and amount paid. You should also keep an itemized invoice or statement containing: 

Continued on Page 4
Tax Time
Continued from Page 3

• What medical care was received
• Who received the care
• Nature and purpose of any other medical expenses and who they were for
• The amount of the medical expenses and date of payment.

Also remember, if you turned 65 in 2006, you deserve a bigger standard deduction than younger folks.

For any tax questions, you can call the IRS at 1-800-829-1040 or get face to face information at IRS Taxpayer Assistance Centers (check your local telephone directory to find one near you). Just don't wait until the last minute, they can get real busy.

Keep in mind that you should have receipts for each expense claimed. Also keep in mind that getting "too creative" may get you in trouble. If audited, you may need some proof or documentation that the work on your home, the couch, that was really worth the amount claimed.

That audit can be years later, so get your documentation together now, and keep it with the copy of your return. Like trying to gather up copies of medical tests at a later date, it is far easier to get it all together now, and not scramble for it later. Also, just like the medical field, you may have to "educate" auditors about the special needs of Carcinoid patients.

For more information on medical deductions, check out IRS Publication 526, available at www.IRS.gov.

Specifically for any goods donated, you must use the "fair market value" of the item(s) which is "far less than" the price you originally paid for it.

To be considered, the donation must be to a qualified organization. Some nonprofits aren't qualified charities for tax purposes. IRS Publication 78 has a master list of qualified organizations. It's updated quarterly and can be found in many public libraries as well as the IRS website. For example, the MNYCSG is not a qualified non-profit organization, but the Carcinoid Cancer Foundation is qualified.

Expect to only be allowed the amount such an item would sell for at a thrift shop or similar. That does not mean you can't make the donation and help a worthy organization, just don't expect to be able to deduct what you paid for a 20 year old fur coat.

Also, donations to events like a dinner dance can only be deducted for the amount over the fair value of the event. Example, a $100 ticket to a dinner/dance may have a value of $45 for the meal, etc. You can only deduct the difference (here, $55).

If donating an auto, use the "blue book" value of that car sold as a "private party sale" not as a "dealer sale" (usually a higher value). Charities are required to issue detailed written acknowledgments on Form 1098-C to vehicle donors, the IRS also gets a copy. There are many other rules regarding vehicle donations.

For cash donations under $250 (per contribution, not for the year), some record of the transaction (your cancelled check, debit statement, credit card statement) will suffice. Written records (log entry or note) will suffice if they meet certain criteria.

Contributions of $250 or more will require a statement or letter from the receiving charity. As the donation amounts increase, the requirements for reporting also increase.

For more information on donations, see IRS publication 526, available at www.IRS.gov.

Of course, local & state laws may vary, proof of payment and medical necessity may be required for all deductions. Check with your local tax preparer before relying upon this article to claim a deduction.

This article is not intended to provide tax advice, but to merely suggest areas where patients and caregivers may want to investigate further and consult with a tax professional before applying for any deduction.
THE CARCINOID CANCER FOUNDATION presents

Carcinoids: The Slow Pace of Rapid Progress
A symposium for patients, family, friends, and healthcare professionals

Sunday, April 15, 2007
1:00 – 5:30 p.m.
Goldwurm Auditorium, 1st Floor, Icahn Institute
Mount Sinai Hospital, New York, NY

Introduction:
Richard R.P. Warner, M.D.
Clinical Professor of Medicine, Mount Sinai School of Medicine, NYC
Medical Director, Carcinoid Cancer Foundation, Inc.

Guest Speaker:
Irvin M. Modlin, M.D., Ph.D., F.R.C.S.
Professor, Department of Surgery
Director, Gastric Surgical Pathobiology Research Group
Yale University School of Medicine, New Haven, CT

Physician Panel: Mount Sinai Hospital Specialists

Refreshments

Become an Active Patient Advocate: Save a Life
Meet your local support group leaders and members
Together We Make a Difference

RSVP before April 5

↓ DIRECTIONS ↓
DIRECTIONS

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

Parking is available on 99th Street between Madison and Park Avenue.

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 98th 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 98th 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.

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 98th 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 98th 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.
REGISTRATION FORM

Carcinoids: The Slow Pace of Rapid Progress
Symposium at Mount Sinai Hospital, New York, NY
April 15, 2007, 1:00 - 5:30 pm

There is no charge to attend this symposium.

4 WAYS TO REGISTER: RSVP before April 5
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)

3. **By Fax**: Print, complete form and fax to: 914-683-0183

4. **By Snail Mail**: Complete form and mail to:
   The Carcinoid Cancer Foundation, Inc., 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.

**ATTENTION PATIENTS!!! PLEASE FILL OUT THE FOLLOWING CONFIDENTIAL INFORMATION:**

(over)
FOR FUTURE PLANNING AND FOR THE APRIL 15 SUPPORT/ADVOCACY SESSION

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 and also to organize the April 15 patient support/advocacy session.

I have carcinoid:    Yes ☐    No ☐

The location of my primary tumor(s) is ____________________________

Is your carcinoid:    typical ☐    atypical ☐

Do you have carcinoid syndrome?    Yes ☐    No ☐

I have another type of neuronendocrine tumor:    Yes ☐    No ☐

Please specify type ____________________________________________

Additional comments: ________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

THANK YOU