

## Investing in the Future

Last year, the New Jersey Chapter decided to help steer their own future care. They offered three local doctors to attend the Portland Conference, with the chapter paying some of the expenses as an added incentive.

The philosophy was two-fold. First, that we needed to get more local doctors better educated about Carcinoid and other NETs. Second, a recognition that the wide population of oncologists may be treating one or two patients each.

In an overall practice of several hundred patients, that percentage of the practice does not give much incentive (or benefit) to spend a lot of time learning about NETs. If a few doctors were selected and educated, patients could be consolidated and get better care by having more patients go to these (now) better educated oncologists.

To that end, the New Jersey chapter selected three local doctors who support group members recommended. For other support groups who might consider the same idea, here are some of the things we learned along the way.

Selections were based upon several factors:

- The willingness of the doctor to listen and learn
- The doctor's communication skill

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## The Yttrium 90 Treatment One Patient's Experience

I had never heard of Yttrium<sup>90</sup> or Carcinoid for that matter until I was diagnosed with liver metastasis of Carcinoid Cancer in July 2004. I would like to give a very brief background prior to having the Y<sup>90</sup> procedures.

After diagnosis it took 3 months to find the primary tumor, during which time I had multiple tests including a PET scan, a nuclear scan, and a Camera Endoscopy, among others. The Camera Endoscopy located the primary tumor in my small intestine lining.

I had the surgery in October 2004. The surgery included a resection of the small intestines, along with the removal of the primary tumor and one that had grown next to it. The surgeon also removed the gall bladder and performed Radio Frequency Ablation on 7 liver tumors and surgical removal of an 8<sup>th</sup> liver tumor which was sent out for lab testing. I went into Carcinoid Crisis during the

surgery where my blood pressure dropped very low and my heart was in arrhythmia. I needed much more Sandostatin which was administered. The surgery lasted 4 hours and I was in the hospital for 11 days of which 6 were spent in the Intensive Care Unit. I have been on Sandostatin since the diagnosis and ever since. My highest dosage is now LAR 50 every 3 weeks.

I have lived in the metropolitan New York area just about all my life. Within a year after my surgery I moved out to Colorado to be near my sister, who had flown out to New Jersey to take care of me during my surgery. My oncologist in Denver (Dr. Alan Cohn) had several Carcinoid patients and was familiar with the current treatments available. During the 2005 year my liver tumors were increasing in size with each CT scan. Dr. Cohn recommended the Y<sup>90</sup>

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## Upcoming Dates

**February 4<sup>th</sup>, 2007** - Pennsylvania Carcinoid Cancer Advocacy, Hershey, PA. 2 to 4 PM, Please RSVP to confirm meeting.

**February 17, 2007** - SEA 2007 Neuroendocrine and Carcinoid Cancer Patient Seminar at Glendale Adventist Medical Center, Glendale, CA. See article on page 2.

**March 4<sup>th</sup>, 2006** - New Jersey Chapter meeting at Crossroads Christian Fellowship. Union, NJ, 1:30 PM. Contact Jim Weiveris at 609-812-9294 or [Caring4Noids@aol.com](mailto:Caring4Noids@aol.com)

**Sept. 27 through 30<sup>th</sup>, 2007** - North American Annual Conference for Carcinoid and Neuroendocrine Tumors held in Norfolk, VA. Details will follow or visit (under construction) [www.carcinoidnetconference.org/](http://www.carcinoidnetconference.org/).

*Unless a special need arises, there will not be a February newsletter.*

## Corvette Club Honors Barbara Schuetz's Legacy



The wonderful members of the Lakes (Medford, NJ) Corvette Club followed through with a promise. On October 14<sup>th</sup>, they held their annual car show at the "Autumn in Moorsetown" fall festival. The event was a

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For newsletter questions & submissions please contact: Jim Weiveris  
Phone/Fax: 609-812-9294  
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## New Jersey Posts 2007 Schedule

January	7 <sup>th</sup>
February	no meeting
March	4 <sup>th</sup>
April	No NJ meeting, possible CCF Lecture
May	6 <sup>th</sup>
June	3 <sup>rd</sup>
July	no meeting
August	no meeting
September	9 <sup>th</sup> (3 <sup>rd</sup> is labor Day weekend)
October	No NJ meeting, Norfolk, VA Conference Sept. 27 - Sept. 30 <sup>th</sup> , 2007
November	Special event - To be announced
December	2 <sup>nd</sup>

- All meetings begin at 1:30 PM and are held at Crossroads Christian Fellowship, 2815 Morris Ave., Union, NJ 07083, unless otherwise noted. (Directions are available on our web site at [www.carcinoid.us](http://www.carcinoid.us).)
- Meetings are typically held on the first Sunday of designated months, unless there is a scheduling conflict.
- It is not necessary to RSVP to attend a meeting.
- In case of inclement weather, a decision will be made by 9:00 AM on the day of the meeting. Please call 609-812-9294 after 9:00 AM if the status is in doubt. If cancelled, the recording will be changed to advise of the cancellation.
- There is no fee to attend any meeting, unless otherwise noted.
- Patients and caregivers are welcome and encouraged to attend

### UNDERSTANDING NEUROENDOCRINE TUMORS:

#### What's New in Diagnosis and Treatment

**February 17, 2007  
Glendale, CA**

SEA is excited to announce the 2007 Neuroendocrine and Carcinoid Cancer Patient Seminar. It will be held at the Glendale Adventist Medical Center in Glendale, California, on Saturday, February 17, 2007.

SEA's seminar is an opportunity for carcinoid cancer survivors, their families, and friends to share in a day of education and camaraderie. Healthcare professionals who specialize in treating neuroendocrine and carcinoid cancer will speak on topics ranging from understanding neuroendocrine & carcinoid, new diagnostic procedures to treatment combinations to current research projects.

Seminar attendees have the opportunity to hear talks by neuroendocrine and carcinoid cancer specialists and ask them questions. Survivors and their families will have the opportunity to meet and talk to others with similar situations.

SEA provides this Neuroendocrine and Carcinoid Cancer Seminar at no charge to anyone who wishes to attend. Advance registration is requested.

For details please see our website at <http://www.sea4carcinoid.com/>

The flyer and registration form can be found at: <http://www.sea4carcinoid.com/pages/downloads/021706flyerC.pdf>

## Our Sister Groups

- Arizona Carcinoid Team** – Meets in Phoenix, For information contact, James at [act\\_mail@yahoo.com](mailto:act_mail@yahoo.com)
- Northern CA - NCF** meets in Fairfield. For information contact, Kathy at [karbanis@yahoo.com](mailto:karbanis@yahoo.com)
- Carcinoid One on One** meets in Orange, CA. For information contact, Terri at [Terris12@atti.net](mailto:Terris12@atti.net)
- SEA (Support Education & Awareness for Carcinoid Patients)** *Not affiliated with CalCF.* Meets in SanGabriel/San Fernando Valley area. For information contact, Nickolette at [sea4carcinoid@msn.com](mailto:sea4carcinoid@msn.com)
- South Bay Carcinoid Fighters (LA)** Meets in Redondo Beach, CA. Pat [carcinoidfighter@yahoo.com](mailto:carcinoidfighter@yahoo.com)
- Connecticut Carcinoid Initiative.** Meets in Rocky Hill. Contact, Bob [dglbg@juno.com](mailto:dglbg@juno.com)
- Capital Area Carcinoid Survivors** (Washington, DC) – For information visit the group's web site, <http://hometown.aol.com/cacs/va/>
- Florida** (informal group) Pam [prpowell@cfl.rr.com](mailto:prpowell@cfl.rr.com)
- Chicagoland Carcinoid Fighters** Meets in Gurnee, IL For information contact, Bob [robob444@netzero.net](mailto:robob444@netzero.net)
- 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](http://www.carcinoid-newengland.org)
- Michigan** - Meeting place may rotate. Contact Dave at [Dav2005@earthlink.net](mailto:Dav2005@earthlink.net)
- Minnesota Carcinoid Peer Support Group**, contact Jan Jackson [jaxon7@comcast.net](mailto:jaxon7@comcast.net), also covering western WI and surrounding areas
- New Mexico** – Meets near Belen. Contact Kathy, [WYHTAK@aol.com](mailto:WYHTAK@aol.com)
- Pacific North West** - For information contact, Corie at [cadean@NATPIPE.COM](mailto:cadean@NATPIPE.COM)
- Central Pennsylvania** - (Harrisburg/Hershey), For information contact, Teresa [CarcinoidSupport@juno.com](mailto:CarcinoidSupport@juno.com).
- Pennsylvania / Philadelphia** (Informal group) Contact Anne [StJohns56@aol.com](mailto:StJohns56@aol.com)
- Dallas, Texas** Contact Carol-Anne for information [CarolAnne52@gmail.com](mailto:CarolAnne52@gmail.com)
- Houston, TX** Contact Jan Peine, [jpeine@houston.rr.com](mailto:jpeine@houston.rr.com)
- Austin, TX** - For information contact, Ann Meyer [ameyer@swrcc.com](mailto:ameyer@swrcc.com)
- Canadian Carcinoid Cancer and NET Support Team** - Lower Ontario & Upper New York Sate - For information contact Maureen C. [maureenc@sympatico.ca](mailto:maureenc@sympatico.ca)
- Oregon Carcinoid Education and Advocacy Network. (OCEAN)** - For information contact Cynthia at [YerRolodex@aol.com](mailto:YerRolodex@aol.com) or [subscribe-OregonCarcinoid@yahoogroups.com](mailto:subscribe-OregonCarcinoid@yahoogroups.com)
- Oregon Chapter of Pacific Northwest Group** - contact Kari at [Kbrendtro@yahoo.com](mailto: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](http://www.carcinoid.org)), our web site ([www.carcinoid.us](http://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*

# Investing in the Future

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- The quality of the facility the doctor works from
- The ease of reaching that facility
- Other qualities you would desire in your doctor
- Age was considered only if a doctor was nearing retirement

There also were other questions to overcome, such as how much to contribute for each doctor. It was decided that the group would pay for the doctor's base hotel stay at the conference hotel for two days (the evening before and the evening after the one day seminar), the conference registration fee, and a stipend toward air fare, taxi, meals, or any other expenses the doctor incurred.

Some of the problems that developed were that after sending out the initial letters of invitation, only one doctor responded by the deadline set. At meetings, patients indicated that the doctors were still interested, so they were contacted again. By the time the second contact was made, the conference hotel had already been booked solid. We would suggest that you make a reservation at the time of invitation. You can usually cancel without penalty up to a certain date. Only the base hotel room cost (plus tax) was covered. This was to avoid the possibility of extra charges for meals, room services, etc. that can add up quickly.

Also consider making conference registration early, should the conference fill up (Portland came within only a few attendees of filling up). Refunds may/may not be available for cancellations.

Also considered was paying for the airfare. One of the recognized problems was what airport the doctor would like to fly out of (remember, we have 3 major airports within a small area), date & time of flights, airline preferred, seating class, etc. The logistics of trying to arrange that could have been overwhelming, and a missed connection could spoil the entire relationship.

We also considered having people be able to donate unused credit card mile bonuses. In investigating that, we found the restrictions, conditions and requirements to be different from card to card. Most also required that the recipient be a recognized non-profit (501(c)(3)) organization. Trying to coordinate it all would simply be too time consuming.

Part of the reason for having the doctor pay part of his/her way was a theory that they would then show a willingness in investing in their own future, not simply attending a "free conference".

One thing we did not clarify in our initial contact was who was to make the reservations (conference & hotel). Both require information from the doctor, but leaving it to the doctor means trying to reimburse for expenses (rather than pay directly to hotel or conference) or the reservation not being made soon enough, or at all. We would suggest setting up some form of communication to get the information needed and supply the doctor with confirmation information.

We decided upon a cash stipend of \$100 each. This

# PPIs May Have More Hazards

You can't watch TV without listening to a commercial for them... Those wonder drugs for persistent acid reflux... that class of drugs known as Proton Pump Inhibitors (PPIs).

Dr. Vinik believes the way they change Gastrin levels can cause problems (see webcast from the October, 2005 conference, at [www.carcinoid.org](http://www.carcinoid.org)), but the "Purple Pill" and others like it (Prevacid, Nexium & Prilosec) may have additional problems according to a recent study.

Published in the December 27<sup>th</sup> issue of JAMA (Journal of the American Medical Association, Vol. 296, No. 24) and also reported by the Associated Press, a British study indicates they may be responsible for increased bone fractures.

It appears the drug may interfere with absorption of bone-building calcium. This results in bone structures that are not as strong, and therefore more subject to breaking.

would bring out total cost per doctor to about \$425.00.

In return for attending, we agreed to work with the doctors that we sponsored, by suggesting these doctors to group members looking for doctors experienced and educated in NETs.

We have heard that the Norfolk, VA conference will again hold a seminar session for medical professionals. New Jersey plans on repeating this again this year. Perhaps your group would like to make a similar investment...

The study looked at the past statistical history of 145,000 patients over 50 years old who used a PPI for over one year. They then looked at how many of those patients had hip fractures and compared that with a similar group who did not use PPIs.

The concern is the widespread popularity of these drugs, often without clearly indicated reasons for use. The general perception is that they are essentially harmless. Untreated reflux can lead to esophageal erosion and possibly cancer.

The risk of hip fracture was approx. 44% higher than for the general population. The longer the use, the higher the risk. High dose users had a risk 2 1/2 times greater than non-users.

The same study found there was a slightly less risk with a class of drugs known as H2 blockers, such as Tagamet & Pepcid. Nexium is the 3<sup>rd</sup> largest selling drug in the world.

The study concluded there was an increased risk of hip fracture for those using long term PPI therapy, especially at high doses.

The study was conducted by several researchers including Drs Epstien, Yang, Lewis, and Metz from various departments at The University of Pennsylvania School of Medicine.

Men had a slightly higher risk of fracture according to the study, possibly because of women taking calcium supplements to avoid osteoporosis. More research is planned to determine if calcium rich diets or calcium supplements can avoid the problem.

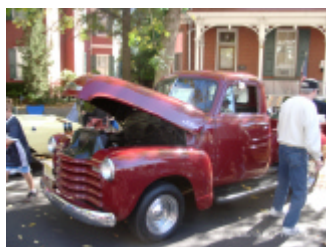
# Car Club Support

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smashing success. Clear skies and mild temperatures brought out car enthusiasts and entire families as well.

Over 200 cars showed up to display and compete in a variety of categories. Club members are prohibited from competing, but were there to help run the event.

Club President Virginia H. was found with Dick Schuetz, counting ballots for cars.



Their reception was heartfelt. Dick has remained active with the club even after the passing of his wife, Barbara, last year from Carcinoid.

The trophy display area boasted a sign about carcinoid. The club members are also well educated, thanks to Barbara.

As a result of the event, the club sent a significant donation to the Carcinoid Cancer Foundation, as a tribute to Barbara and her battle with Carcinoid.

Our thanks to the club for their support and continued efforts to spread the word about Carcinoid.



# Intraperitoneal Hyperthermic Chemotherapy

The title alone is a mouthful.

Sometimes you catch a glimpse of an article on something that just seems novel and interesting, even if it has no immediate direct application. TV Station WSOCTV in Charlotte, NC did a report on a procedure being used for cancers of the appendix, ovary and other abdominal cancers.

The procedure, called Intraperitoneal Hyperthermic Chemotherapy (IPHC, or "heated" chemo), has its dangers, but appears to have potential benefits. It is difficult to do properly, requiring close monitoring of the patient for overheating, blood loss, and changes in fluid & electrolyte levels.

The first part of the treatment involves surgical removal of as much, or all, of the cancer. Then after partially closing the abdomen four catheters are inserted. Through two of those catheters they pump a heated saline solution. The other two are used as drains.

The solution bathes the entire abdominal cavity and all the organs there. Once the saline reaches a very specific temperature, they inject chemotherapy drugs into the saline.

This bathes the internal organs in heated chemotherapy solution. After 90 minutes, they drain the

cavity and flush it with clean saline solution. They then remove the catheters and close the incision.

The heat works by itself to kill the cancer cells then also helps the chemo drugs get into the cancer. One IPHC treatment usually replaces several weeks of infused chemotherapy treatments. Also, because the drug is limited to specific area, doctors can use a higher dose than they would be able to normally use.

The treatment is considered an "aggressive" one, and is usually reserved as a treatment of last resort, although studies are being conducted to see if it should be a first line attack strategy.

Dr. Armando Sardi from The Institute for Cancer Care at Mercy Hospital (Baltimore, MD) has been leading the research and use of this technique.

So far, the results have been promising. One patient with a recurring ovarian cancer has lived an active life 3 years post procedure, even returning to work. Another has a nearly 12 year survival from cancer of the appendix.

At this time, there has been no reference to it being used for Neuroendocrine Tumors, but one can hope that with some modifications, who knows what the future may hold.

# The Yttrium 90 Treatment

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procedure and asked me to have a consultation with Dr. Charles Nutting. I phoned Dr. Warner in NY, as he had been consulting on my case since 2004. He knew of Dr. Nutting's work and had lectured with him on various occasions. The procedure was relatively new and initially used only as a last resort. I believe it was only approved in the US in 2002.

I met with the interventional radiologist (Dr. Charles Nutting) in November 2005. Dr. Nutting asked me to bring all my films from CT scans; he wanted to see the original films.

Dr. Nutting met with me and spent quite a bit of time explaining this procedure. The procedure was done on an outpatient basis. Through the femoral artery (in the groin) a very small tube is inserted, similar to having a stent for heart patients. This tube carries very tiny ceramic beads (10's of millions of them) about 1/3 the size of a strand of hair each containing a very high level of radiation – the Y<sup>90</sup>. The radiation has a half life of 64 ½ hours.

For the first 3 to 4 days you should not be too close to other people. Minimize the time spent near adults within 3 feet, stay away from children and pregnant women. After 2 weeks the radiation is completely out of your body. Dr. Nutting explained that the artery they would use would be a direct blood supply feed to the tumors. The radiation was so much more powerful than anything they currently can give with a machine and it is localized, directly targeted to the tumors.

Carcinoid tumors are “very vascular” and draw blood to them, thus drawing the radiation to or near them. But of

course we have to be careful that the particular artery does not go to any good tissue or other organs (like the stomach, heart, or lungs) so a pre-procedure is required.

I asked if I could experience the Carcinoid crisis from this procedure and Dr. Nutting said it was not likely but that I would be treated with Sandostatin during the procedure as a precaution. There is no pain during the procedure but you must stay awake.

This procedure had a very successful rate in shrinking the liver tumors and in some cases killing the nucleus of the tumors so they slowly die off. The most common side effects were extreme fatigue which can last up to 2 months. Also some patients experience nausea after the procedure which can last a day or two. Very rarely does a patient experience any other side effects (less than 1 or 2%). I questioned about the radiation leaking to other body organs. If that occurs, they treat those areas independently. I was told the procedure would last about 45 minutes.

Each patient is of course different and depending on their anatomy both lobes of the liver can be treated at one time. More commonly, patients have one lobe treated and return to have the second lobe treated, which was the case with my anatomy.

The Yttrium 90 is an extremely high level of radiation from a nuclear power plant. There were two places where the Y<sup>90</sup> could be ordered, Canada or Australia. Dr. Nutting said he orders the Y<sup>90</sup> from Australia. *[Editor's note: The beads are SirSpheres® made by Sirtex]* The beads are flown in the same day as the procedure.

In order to have this procedure done I had to consult with the Director of the Radiology Department in the hospital where the procedure would be performed. The Radiology Director must also be present in the room while the procedure is performed. I questioned why this was necessary and was told the director needed to be present to ensure handling protocol was followed (none of the Y<sup>90</sup> was dropped or inadvertently spilled). The Y<sup>90</sup> is very powerful stuff. The hospital I used was Swedish Medical Center in Denver.

I know I asked a lot of questions. My sister was with me during the consultation. It is really a good idea to have someone with you when you are speaking to the person who performs this procedure. My sister remembered a great deal more information from the consultation than I did. After having had the surgery for Carcinoid, this seemed relatively less invasive; although I still was nervous about having anything done.

When I met with the Director of Radiation for Swedish Hospital this was quite a long interview. We reviewed everything since my diagnosis of Carcinoid in 2004. There was also a great deal of paperwork that the Director was filling out during our consultation. *[Editor's note: There is another patient in the NJ Chapter Support Group who was due to have the procedure done at Mt. Sinai in NYC, but was postponed because the insurance company wanted additional information. This was on top of the paperwork for importing radioactive materials, etc. That experience may be a future article]*

I was scheduled for the pre-procedure in mid November of 2005. This was fairly easy, I was awake and, if I choose (which I did not), I could watch

everything on 3 big wide screen TV's. I looked the other way. The procedure was about 45 minutes and I returned to the waiting area. *[Editor's note: The pre-procedure is done almost the same as the actual treatment. Under image guidance (usually sonogram or CT) they snake the catheter from the femoral artery into the artery they intend to treat. They then inject a small amount of a radioactive dye into the catheter and watch to make sure it does not shunt to undesired areas]*

I had to remain lying down for a certain amount of time (maybe 2 or 3 hours) *[Editor's note: this is usually to make sure the femoral artery does not leak at the point of the catheter insertion].*

I was given lunch and I had no problem eating. After the specified waiting time, I was sent home. It was required that someone drive me to and from the procedure. On the way home I started vomiting. I just thought I ate too much, too fast after the procedure. This did not last too long and I felt fine that night and there after.

The pre-procedure tests indicated I was a candidate for the procedure but my anatomy required that one liver lobe be treated at a time. The right lobe is generally bigger than the left lobe and I had more tumors on the right side. We scheduled the Y<sup>90</sup> for the right lobe in mid December of 2005.

Based on the pre-procedure I really was not that worried. I thought I would just not eat much of anything afterward and just go home and rest. I was very anxious that morning. Dr. Nutting came to see me before it was time to start and was very reassuring. He also ordered some medication to help relax me. The Radiology Director also came to see me and said he would be present for the entire

procedure.

The actual treatment was the same as the pre procedure. I still did not look at the big TVs.

I was told when the Y<sup>90</sup> was injected and that did not seem to bother me. About half way through the procedure I started to feel like my chest was being crushed by a truck and it was hard to breath. I tried to express my distress and was given a little more medication which took care of it. I was again comfortable and the remainder of the procedure was completed. I had to again remain in a flat position for approximately 2 hours.

I had no trouble going home and was fine for a few hours. I just did not eat very much. However, around 7 PM I started to vomit uncontrollably. We phoned the hospital several times throughout the night. Various anti-nausea medications were prescribed but nothing was working. This went on for seven hours.

It became a retching cycle that we could not break. Around 2:00 in the morning we returned to the hospital and I was admitted for 2 days. This occurs in a very low percent of patients, 1-2% and was referred to as "post embolization syndrome". I was given IV medication for the nausea and dehydration which took time to get under control. The medication also let me sleep (thank goodness).

I was released after 2 days but continued to feel nauseous during the next couple of weeks and even during the next few months. My taste buds changed, things I liked before were no longer appealing to me, even coffee. I ate very little, lost a lot of weight, and slept for long periods of time.

My attitude towards the procedure changed, from one of optimism to regret. It was hard

to think of the possible long term benefit. It was recommended that the left lobe be treated approximately one month after the right. I would have time to feel better but at that time I was not ready to think about it. As I was one of the 1 – 2% who had experienced adverse side effects, I held off on treating the left lobe of my liver for many months.

Over time, I started to eat more and feel better. My follow up CT scans showed shrinkage of the tumors in the right lobe, but growth on the left. It was highly recommended I treat the left lobe and I was assured I would most likely not have such adverse side effects. This was because my left lobe was approximately 48% of the size of the right, thus needing less Y<sup>90</sup> beads. Additionally my right lobe was healthier. The Y<sup>90</sup> was working.

The doctors were well aware of how sick I was with the first procedure and were prepared to admit me over night so I could be treated intravenously should I get sick. I had the left lobe procedure on October 13, 2006. During the procedure I was somewhat sedated but not asleep. I vomited several times during the procedure and also experienced a symptom of Carcinoid Syndrome (flushing) which I did not have normally. With more Sandostatin, that subsided over the course of the remainder of the day.

I continued to feel nauseous and vomit after the procedure and throughout the time I was in the recovery area. Dr. Nutting visited me after the procedure and observed how sick I was so he discussed the procedure with my sister. The post-radiation scans showed all of the beads were in the right place and there were no problems with the procedure. The scan also showed significant improvement on the right lobe,

which was treated the previous year.

Most of the tumors in the right lobe had continued to shrink and it appeared the nucleuses were dying. This was very encouraging to Dr. Nutting. The nausea continued for one day and night. By 6 AM the following morning, I finally settled down and was able to drink some juice and later have some bland food. I had some chest pains and was taken for a stress test. The test showed no heart problems.

I continued to feel better after the procedure that day but was kept overnight, again for observation. I went home on the third day. Again my sister took care of me since I was not allowed to drive home. I did not get sick during the ride home or over the next few days. I was tired but not nauseous over the next few weeks.

With both procedures I had to take steroids for approximately one week. The second procedure was much better as far as the side effects I had experienced. I did not feel nearly as tired as I did for the first procedure.

The recommended follow up was to have a CT scan in 3 months and again in 6 months to compare the size of the tumors. Dr. Nutting was very attentive to my concerns and had called me at home several times when I had more concerns. His assistant was very helpful in making all the arrangements for me after I decided to go ahead with the procedures.

I have returned to the Metro NY area and am now scheduled to have my first CT scan since the second procedure. The tumors can continue to shrink over the year following the procedure.

It is also possible to repeat the procedure should there be a need to in some cases. If I had

to do the procedure again, I would have Dr. Nutting do it at Swedish Medical Center in Denver. He is familiar with my anatomy and history. Dr. Nutting also had lectured with Dr. Warner and is becoming very active in Carcinoid research. Dr Nutting returned phone calls and questions promptly and was very attentive to my concerns. He is a very personable and professional doctor who has experience in this area. I would recommend him if this procedure is an option and is being considered.

*Special thanks to Joanne from the NJ Chapter Support Group who wrote this article based upon her experience (and her sister). Joanne may be contacted at [jj0810@yahoo.com](mailto:jj0810@yahoo.com).*

## SirSpheres Study

According to a Business News press release in the Genetic Engineering News, Dr. Andrew Kennedy is expected to announce the findings of a recent study regarding the SirSpheres Treatments. The announcement is taking place at the 2007 American Society of Clinical Oncology (ASCO) Gastrointestinal Symposium in Orlando, FL.

Dr. Kennedy is expected to announce that patients who get the SirSpheres Y90 treatment may be able to receive multiple treatments. In a study of 38 patients, 11 of whom were Carcinoid patients, they found that two series of treatments presented no problems to the liver, with one patient getting 3 rounds of treatment.

There are currently approx. 60 doctors, at 65 medical facilities, in the US using SirSpheres, which was approved by the FDA in 2002.