



Norfolk Conference Information

If you haven't registered for the conference, WHAT ARE YOU WAITING FOR? No specific date has been posted, but registration will be closing soon.

The organizers (of any event) have to be able to close the registration to get a final count to the facility manager so they can prepare a proper sized room and meals. Then than also have to coordinate what rooms are available and what concurrent lectures will be placed in what room.

You can register on-line by going to www.carcinoidnetconference.org or by calling 757-486-2569. The registration fee of \$95 is worth more than just the included meals. Page 6 starts the agenda and list of expected lecturers, some of the best in the world.

Travel Alert

If you are planning on travelling from the Norfolk conference late on Sunday, September 30th and you want to take the Cape may-Lewes Ferry, then watch the weather on September 16th, or make your reservations for that segment soon.

There is a benefit motorcycle rally scheduled to take place on

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Webcasts on Carcinoid Cancer Foundation Website

The Carcinoid Cancer Foundation has added a bunch of new content to their already informative website at www.carcinoid.org. They now have many of the lectures from the Portland Conference available for viewing.

The Carcinoid Cancer Foundation has traditionally facilitated the taping of lectures at past patient

conferences. That includes the expense of taping, camera operators, equipment, securing permissions, editing and distributing.

For both the Portland and Philadelphia conferences, the Foundation has paid for the copies and distribution of the lectures to each of the many support groups. CDs of both

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Fighting Insurance

Sue (Weiveris) used to scream over the telephone at the insurance company that she "didn't know which was worse, having cancer or dealing with the insurance company" (that was the "cleaned up version".)

That may not have been the best way to get her point across, but the frustration sure is evident. That frustration hits probably everyone who is

dealing with a rare disease.

Laurie Todd is a rare cancer survivor (not Carcinoid) who has decided to share her experience in taking on the insurance companies, becoming known as "The Insurance Warrior." She has written a book "Fight Your Health Insurer and Win". In the book, she offers many

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Wayne Tefs Rides a Another Rollercoaster (this one by choice)

Some of you may recall Wayne Tefs. Wayne is a Canadian author who wrote a book on part of his Carcinoid experiences called "rollercoaster: a cancer journey". Wayne, accompanied by his wife, Kristen, spoke at the



Wayne Tefs in the Pyrenees, travelling the hard way

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Upcoming Dates

September 9th, 2007 - Long Island, NY Chapter meeting at Bellmore Library. Verify dates at www.carcinoidaware.org or call 516-781-7814

September 9th, 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

Sept. 27 through 30th, 2007 - North American Annual Conference for Carcinoid and Neuroendocrine Tumors held in Norfolk, VA. See article to left and on page 4, or visit www.carcinoidnetconference.org/.

November 4th, 2007 - Pennsylvania Carcinoid Cancer Network, Hershey, PA, 2 to 4 PM, Please RSVP to confirm meeting, CarcinoidSupport@juno.com

November 16th, 2007-
DATE CHANGED
CCAN Annual Dinner Dance, Long Island, NY. See article on page 2.

November 17th, 2007-
DATE CHANGED
CCAN Lecture, Long Island, NY. See article on page 2.



Wayne in 2002

Doctors Cancer Foundation Awards Grant

On May 10th, the Doctors Cancer Foundation held their annual "One Step Closer" banquet and benefit. The benefit dinner was held at the Willow Ridge Country Club in Harrison, NY.

What made this event special is that this year, their annual grant went to research for Neuroendocrine Tumors.

The Doctors Cancer Foundation awarded a \$50,000.00 grant to Dr. Herbert Chen who heads up the Endocrine Cancer Disease Group at the University of Wisconsin. The Doctors Cancer Foundation focus is on genetic research and other novel approaches to cancer.

Dr. Chen was selected for

his novel approach model and the apparent promise of success for his research.

Dr. Chen's Portland lectures can be viewed with the webcasts on the Carcinoid Cancer Foundation website (*see article on page 1*)

Special thanks to Dr. Bernhardt, his entire family (who work to put the event together), and the Doctors Cancer Foundation for their support of research for NETs.

We also have to thank Adam Sattler and his wife, Erica, who provided the "connection" for this grant going towards Carcinoid. Adam's mother (who passed away last year) was diagnosed with carcinoid.

CCAN Lecture & Dinner Dance

It is coming up to that time of year again. Time for the Annual Dinner Dance and Lecture, hosted by the Carcinoid Cancer Awareness Network, Inc. (CCAN).

The dates have changed from what was previously scheduled, as well as the lecture location.

The Dinner Dance will be held Friday evening, Nov. 16th at the Bellmore Knights of Columbus on Long Island. The lecture will be held the following day, Nov. 17th at the nearby Huntington Hilton Hotel, Melville, NY.

The Dinner/Dance will be from 7:00 PM to 11:00 PM and the cost per person is \$85.00. It includes an open bar, buffet style dinner (excellent food), cake, coffee, DJ, Dancing, & Raffles.

The 9:00 AM to 4:00 PM lecture, which includes lunch, will feature:

---Dr Hal Gerstein - Cancer Institute of Long Island, Great Neck, NY

---Dr Eugene Woltering - LSU Health Sciences Center, New Orleans, LA

--- Dr Lowell Anthony - LSU Health Sciences Center, New Orleans, LA

---Dr Thomas O'Dorisio - University Of Iowa Hospital and Clinics Iowa City, IA

---Dr Italo Zanzi - North Shore University Hospital, Manhasset, NY

The cost is \$ 20.00 If you attend both events, the combined cost is \$95.00

To attend, contact CCAN at call 516-781-7814 or e-mail Carcinoidaware@aol.com

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 karbanis@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 Glastonbury through this summer. Contact, Pat PStrongLaw@aol.com

Capital Area Carcinoid Survivors (Washington, DC) – For information visit the group's web site, <http://hometown.aol.com/cacs/ya/>

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 Day2005@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

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

Pennsylvania / Philadelphia (Informal group) Contact Anne StJohns56@aol.com

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

Houston, TX Contact Jan Peine, carcinoid@comcast.net

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

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

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

Washington (state) Chapter of Pacific Northwest Group - For information contact, Corie at cadean@NATPIPE.COM

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

Telephone numbers and personal addresses are not normally included for the security of those listed, whose information becomes "searchable" data through any Internet search engine, such as Google.

Carcinoid Cancer Foundation Webcasts

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have been distributed and DVD, high resolution versions, of the Portland Conference are currently "in the pipeline".

On the website are broadband, low-speed and audio only versions of the lectures. These are a great chance to review and find out "what did that doctor really say?" after time has clouded the memory. Or it could be a chance to hear about a new procedure from one of the experts who helped develop it.

Just visit the Carcinoid Cancer Foundation website at www.carcinoid.org, then click on the left hand margin section marked "Did you miss a conference? View videos, pictures, and read transcripts of lectures from past carcinoid conferences". Once on that page, you have to scroll down a little bit and just below the title banner "Webcasts of local and national Patient carcinoid/net Conferences", click where it says "click here".

That will take you to a hosted site, which the Foundation has contracted to actually host the content. You must be using Internet Explorer. Each lecture has available not only the camera shot of the lecturer, but the PowerPoint slide presentation follows the audio for that slide.

This year, the Foundation is making arrangements to tape some of the lectures using a new technology, which should make the taped sessions available sooner. Note that not all session or lectures can be taped, especially when there are multiple concurrent sessions, due to the cost of multiple equipment rentals.

That will hold true for the Norfolk Conference also. So don't rely upon being able to see a video tape, make the trip and get to Norfolk.

The lectures that are available from Portland are:

Disk 1 of 14 - Day 1, Session 1 (plenary) Viewing time: 2 hrs., 3 min.

A TEAM Approach to NET Disease Diagnosis And Management

A Panel Group Discussion with Selected Case Studies
Introduction & Chair: Eugene Woltering

Panel Members: Kjell Öberg, Bertram Wiedenmann, Guido Rindi,

Anthony Heaney, Patricia Pellikka, and Robert H. Reid

Disk 2 of 14 - Day 1, Session 2a (breakout) Viewing time: 1 hr., 23 min.

Carcinoid / NETs 101: For the Newly Diagnosed
Richard Warner, Kjell Öberg, and Edward Wolin

Disk 3 of 14 - Day 1, Session 2b (breakout) Viewing time: 1 hr., 1 minute

Unknown Primaries / Pediatric NETs

Bertram Wiedenmann and Sue O'Dorisio

Disk 4 of 14 - Day 1, Session 2c (breakout) Viewing time: 1 hr., 19 min.

Lung Carcinoid
Dan Grandberg and Lowell Anthony

Disk 5 of 14 - Day 1, Session 2d (breakout) Viewing time: 1 hr., 23 min.

Islet Cell, MEN1 and other 'Nomads'

Larry Kvols, Herbert Chen, Robert Jensen, and Stephen Marx

Disk 6 of 14 - Day 1, Session 2e (breakout) Viewing time: 1 hr., 5 min.

Secondary Diseases

Aaron Vinik, Thomas O'Dorisio, and Patricia Pellikka

Disk 7 of 14 - Day 1, Session 2f (breakout) Viewing time: 1 hr., 14 min.

Navigating Through Insurance Systems

Joe Koplun and Angela Lim

Disk 8 of 14 - Day 1, Session 3 (plenary) Viewing time: 1 hr., 14 min.

Pathology & Surgical Management of NETs

Introduction & Chair: Larry Kvols

Panel Members: Larry Kvols, Guido Rindi, Rodney Pommier,

Eugene Woltering, & Herbert Chen

Disk 9 of 14 - Day 1, Session 4 (plenary) Viewing time: 1 hr., 12 mins.

Diagnostic Imaging

Introduction & Chair: Stanley Goldsmith

Panelists: Bertram Wiedenmann, Robert H. Reid, and Kjell Öberg

Disk 10 of 14 - Day 1, Session 5 (plenary) Viewing time: 53 mins.

Monitoring NETs: Which Tests and How Often

Introduction & Chair: Edward Wolin

Panelists: Thomas O'Dorisio, Eugene Woltering, Aaron Vinik

Disk 11 of 14 - Day 2, Session 1 (plenary) Viewing time: 1 hr., 36 mins.

Targeted Therapies & Treatment Guidelines

Introduction & Chair: Rodney Pommier

Panelists: Lowell Anthony, Larry Kvols, James Yao, Matthew Kulke, and Herbert Chen

Disk 12 of 14 - Day 2, Session 2b (breakout)

Viewing time: 1 hr., 19 mins.
Living With Carcinoid/NET Disease:

Confronting Physical & Emotional Changes

Presenters: Giovanna Joyce Imbesi and Susan Hedlund
Note: There were other concurrent sessions, but they were not recorded.

Disk 13 of 14 - Day 2, Session 3 (plenary) Viewing time: 1 hr., 11 mins.

Current Treatments for Metastatic Disease

Introduction & Chair: Edward Wolin

Panelists: Kjell Öberg, James Yao, and Anthony Heaney

Disk 14 of 14 - Day 2, Session 4 (plenary) Viewing time: 1 hr., 14 mins.

Management of Liver Metastases

Introduction & Chair:

Anthony Heaney
Panelists: Douglas Coldwell, Rodney Pommier, and Robert H. Reid, Woltering, & Herbert Chen

CCF Awards Grant

The Doctors Cancer Foundation awarded a grant (to Dr. Chen, see story on page 2) for research on NETs in May. Among the applications for the grant given by the Doctors Cancer Foundation was a proposal by Dr. Muthusamy Kunnimalayaan, also from the University of Wisconsin.

While his proposal did not win, the Carcinoid Cancer Foundation liked his concept and CCF gave Dr. Kunnimalayaan a grant of \$10,000.00.

Insurance

Continued from Page 1

suggestions on how to deal with the insurance company, and what not to do (I think screaming and cursing fits as one of those).

The book covers more than just dealing with insurance. There are chapters on selecting a doctor, surviving a hospital stay, dealing with family members, and even dealing with Social Security Disability.

The book is available for \$14.95, plus \$5.00 shipping in the US. It can be ordered at her website, www.TheInsuranceWarrior.com or by calling 425-497-1858. Laurie is also available for public speaking engagements.

Laurie has given permission to reprint some of her information here. Thanks, Laurie.

Q: Why did my appeal letter fail?

A: First, it failed because you sent a LETTER to the insurer, not a LEGAL DOCUMENT. No letters, they are not substantial enough. You must prepare an imposing document with title page, table of contents, cover letter, bullet list of facts, attachments, and a blockbuster conclusion. Your appeal must intimidate by its very weight.

2. You tried to prove to the health insurer that you need this treatment to survive, this treatment would improve your life, you will suffer if you do not receive the treatment. **THEY DON'T CARE ABOUT ANY OF THAT!** A successful appeal is not an attempt to educate, it is an

attempt to intimidate. It is not a medical document, it is a legal document.

3. You went on about how agonizing it all is, your pain and suffering, how unfair, etc. A successful appeal contains no feeling words. The minute you show even the slightest bit of anger, weakness, or sarcasm, you have lost the chess game.

4. You have not proved your point with FACTS. You tell them that this is the only treatment that will save your life. Why should they believe you? Include the peer-reviewed articles, the qualifications of your doctor of choice.

5. You have not included a strong list of precedent. You can be pretty sure that, even if your health insurer calls your treatment-of-choice "experimental," they have paid for it before. Put out the call on your online patient support group, and find the precedent.

6. You didn't quote all of the non-sensical, ridiculous, untrue things which your in-network doctor said to you. Did your doctor say, "There IS no treatment for your disease," when you knew that there was? Did he say, "Your cancer is slow-growing, let's just watch and wait"? Did he tell you, "There IS such-and-such a treatment, but you wouldn't want to do THAT"? Did he refer you to a local specialist who had no interest and no experience with your disease? **DON'T TELL ME ABOUT IT, QUOTE THEM IN YOUR APPEAL!** These sorts of statements are very embarrassing to the insurer when they show up in your appeal document.

THE QUOTATION MARK IS THE MOST POWERFUL WEAPON WE HAVE.

7. You sent your appeal to only one person. Why should they pay any attention to you ... there is nobody to check up on them. Copy the Medical Director of the insurance company, copy insurance company executives. Copy the head of the local Medical Society, copy the accrediting body that they belong to. Whoever you can think of. You want your blockbuster appeal to land on many powerful desks at once, and you want them to start picking up the phone and calling each other.

THE "CC" IS THE SECOND MOST POWERFUL WEAPON WE HAVE.

8. You didn't do your research on your health insurer. We must totally know our opponent. Google, my friends ... dig up the dirt. Have there been any successful lawsuits against your insurer lately? Has the Attorney General of your state investigated them? You could pick out a few choice words or phrases, and drop them into your appeal ... just so that they know that you know. Or, you could include the Attorney General or the attorney on that successful lawsuit in your cc's.

9. You wrote your appeal from a position of weakness. We must come from a position of strength. Not begging for our treatment, but calmly guiding the insurer through the steps that let them know that we are well-informed, armed with facts,

ready to expose any and all mistakes that the insurer has made thus far in order to save our own lives.

Don't be afraid to confront your health insurer. If you don't confront them, **THEY WILL NOT PAY FOR YOUR TREATMENT.** They will never say "Yes" without being pushed, and you will die being nice to your insurance company. If you do confront them -- in a big, powerful way -- you can go on with the rest of your life, knowing that you have done your utmost to save it.

The written appeal is your hero's journey. It is your opportunity to take your power back ... at the time when you feel the most frightened and victimized. You are in the right, you will get your treatment paid for. It will be the best-paid work you will ever do. Furthermore, you can consider yourself to be your health insurer's best friend, as you have probably saved them at least a million dollars by getting to the treatment that actually gives you a chance at a good outcome.

Friend to Friend Program

Created in 2002, the friend to friend program is dedicated to the memory of Rosemary Finley, who was a friend to many newly diagnosed patients. The program operates nationwide at no charge.

One of the primary goals is to allow patients who are facing unknown procedures and

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rollercoaster: a cancer journey - Tefs Updated

September 29, 2002 lecture session at Mt. Sinai Hospital, sponsored by the Carcinoid Cancer Foundation.

In his e-mail, Wayne mentioned that the Pyrenees roads can have demanding vertical climbs of more than a mile over 10 miles of climbing then harrowing descents at speeds of 50 MPH

Thanks to Maureen Coleman, Wayne reconnected with us recently and here is some of what he has been up to.

Since we last crossed paths in 2003, I've been busy promoting Rollercoaster and, by extension, the public awareness of carcinoid cancer. I've had "episodes," as we all do, and frights, too, as have we all.

I've published another novel, 4X4 and a "docu-fiction," a mixture of fact and fiction about a doctor who had a grueling experience in Canada's frozen north. His survival story, living with a neck broken in two places in the back of his pickup truck for a month while his injuries healed enough for him to walk to safety, was an inspiration to me personally and, I hope, will also be to readers of Be Wolf. Survival is what we carcinoids are into.

We're also into having fun and making the most of each day. *Carpe diem* might be the motto on our next T-shirt. After the shock of diagnosis, we come to value our lives, to see each day as a gift, to fill our days with joy and pleasure as much as possible.

It's not always possible. Jobs and family obligations take up large chunks of our time, but these are often themselves enjoyable and provide us with

that sense of satisfaction and self-worth that is given a fairly hefty setback upon diagnosis. In that initial flush, we can feel weak, unimportant, marginalized to the sidelines of the work-a-day world.

In any case, as part of my own program of living with cancer, I've made a point of keeping physically active. Along with many of you, I've also changed my diet fairly radically, in line with the insightful suggestions of Monica Warner and others.

I see in the newsletter that many of you, like me, are daily taking a regime of vitamin, mineral, and other supplements. Richard Warner, in an interview in the newsletter "Rays of Hope" a decade or so ago pointed out the value of taking salmon oil capsules, a source of the omega fatty acids. They help in keeping the tricuspid valves of the heart limber, I believe. Things like that are part of my regime, as they constitute parts of many of yours.

In the past five or so years my wife and I have done a lot of cycling. It's a pleasant sport that you can participate in at various levels. We're serious and dedicated road cyclists. I

ride 3,000 – 7,500 miles every season.

But there's all kinds of ways to enjoy the sport, most of them a lot less demanding than those numbers might suggest. It's good for the cardio-vascular and a lovely way to see places on vacation.

In the photos accompanying, we're in France. We travel there as often as we can, just before or after the famous Tour de France. We ride portions of a number of the "stages" (daily rides) that the participants ride.

Motorists in France, Italy, and England, and I'm guessing other countries of Europe, too, are respectful of cyclists. It's a much bigger sport there, both at the professional and grass-roots levels. There are lovely valley roads, undulating hills, and outright murderous climbs. We did some of the latter this June. Very challenging but also great fun.

On the way up a steep ascent of a vertical mile over 5 to 10 miles we managed little more than 6 MpH, where our valley riding speed is about 20 MpH. Lots of sweating. But an enormous sense of accomplishment at the top.



Kristen

Norfolk Travel

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September 16th in Southern New Jersey and part of the rally includes travel on the ferry. The rain date is September 30th and the largest group is planned to take the 6PM ferry from Lewes, DE. The rally is to benefit autism.

To make your reservations, got to www.capemaylewesferry.com or call 1-800-643-3779.



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For newsletter questions & submissions please contact: Jim Weiveris  
Phone/Fax: 609-812-9294  
[Caring4Noids@aol.com](mailto:Caring4Noids@aol.com)  
Mailing address is:  
9 Maplewood Dr.  
Little Egg Harbor, NJ 08087  
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It's not for everyone. The sage advice is "Take it easy." Our bodies are under enormous stress dealing with the rampant new cells that threaten to take over. So I'm not suggesting that energetic exercise is for every one. Each of us must survive in our own way. But maybe, like me, you can seize the day, freewheeling on a bicycle.



Switchbacks

Norfolk Conference Agenda

The below agenda is taken from the website of the organizers and may be subject to change. Interpretation of the web site posting is also open to error. The agenda is continued on the following pages.

Thursday Sept. 26		9:30 AM	<i>Factors Regulating Neuroendocrine Cell Growth and Proliferation and Prospects For Therapeutic Intervention.</i> Aaron I. Vinik, MD, PhD, FCP, FACP
12:00 PM	Conference Opening		
1:00 PM to 5:00 PM	One on One Sessions		
12:45 PM	<i>Quality of Life is Determined by its Activities</i> Etta Vinik, MEd		9:30 am start and 2:30 pm start - One on One Patient Sessions- Two Time Selections Offered. Refer to Saturday schedule for details and the extended program schedule for details
1:15 PM	<i>Advanced Pain Management And Cancer - Options and Timing</i> Lisa Barr, MD	10:15 AM	Break
2:00 PM	<i>The Keys To A True Working Patient and Physician Team</i> Aaron I. Vinik, MD, PhD, FCP, MACP - Moderator Edward George, MD Martin J. Goldberg, MD David Johnson, MD Mark Sinesi, MD Richard Sokol, MD, FAAFP, ABFP James Stark, MD Harlan Vingan, MD Roger Perry, MD	10:30 AM	<i>Carcinoid Heart And Heart Valve Disease: Risks, Effects, Surgical Intervention Options, Correct Monitoring, And New Techniques</i> Martin J. Goldberg, MD Joseph Newton, MD
4:00 PM	Break	11:15 AM	<i>Surgical Intervention And Management of Neuroendocrine Tumors</i> Roger Perry, MD
4:30 PM	<i>Interventional Radiology, Isotopes, Nuclear Imaging, Microspheres, & More</i> Lester Johnson, MD, PhD Andrew Kennedy, MD, FACRO Robert Reid, MD, ChB, FRCPC Harlan Vingan, MD	12:00 PM	<i>Liver Health: Non-NET Liver Disease Impact</i> Michael J. Ryan, MD, FACP
6:00 PM	Conference Check in Closes, will resume Friday at 8:00 AM	12:45 PM	Break
6:30 PM	Nauticus Opening Evening Reception Radiotherapeutic Exhibits Aaron I. Vinik, MD, PhD, FCP, MACP Rear Admiral Cullison, MD	1:00 PM	Physician Specialty Lecture Series: Choice of One Lecture
	<i>The Seldom Seen Face Of Carcinoid And NETS—NETS in Children and Adolescents</i> Miss Katelyn Bledsoe Sue O'Dorisio, MD, PhD		<i>Islet Cell, Gastrinoma, Insulinoma, & More</i> Roger Perry, MD
	<i>Targeted Radio Nuclide Therapy</i> Ebrahim Delpassand, MD		<i>Immune System Problems for NETS</i> Paul Conkling, MD
	<i>Microsphere Therapy For NETS</i> Andrew Kennedy, MD, FACRO		<i>Carcinoid Arthritis Related Problems</i> Roger W. Lidman, MD, FACP, CCD
Friday, Sept. 28			<i>Skin Manifestations of NETS</i> Antoinette Hood, MD
6:30 AM	Daily Morning Zebra Stroll, Walk, Jog - Join Physio Therapy Specialists In Lobby		<i>NETS and Cholesterol: Controlling Lipids, Reducing Cardiac Risks</i> Richard A. Sokol, MD, FAAFP, ABFP
8:00 AM	Breakfast and CME Symposium Registration Check In		<i>NET Patients and Kidney Disorders</i> Paul F. Shellhammer, MD
8:30 AM	Welcome Introductions		<i>NETS Relationship with Type I Diabetes</i> John O'Brian, MD
9:00 AM	<i>Fiscal Conflicts In Healthcare</i> Ms. Jody Wagner, Secty of Finance Commonwealth of Virginia		<i>Incidence of Octreotide Related Type 2 Diabetes Among NETS: Treatment Impact and Options</i> M. Elizabeth Mason, MD
			<i>Diet and Fatty Livers: Impact on Nets</i> Leon-Paul Georges, MD
			<i>Octreotide: Digestive Impact</i> Michael J. Ryan, MD, FACP
		2:00 PM	Break
		2:30 PM	<i>Bronchial Carcinoid Case Studies: Typical and Atypical</i> Dan Granberg, MD, PhD, Moderator Nancy Fishback, MD Lester Johnson, MD, PhD Michael E. Lee, MD Frank A. Mitros, MD Joseph Newton, MD Richard A. Sokol, MD, FAAFP, ABFP

3:15 PM	<i>Seldom Discussed And Possible Systemic Effects Of Carcinoid Cancer And Octreotide Treatment</i> Gene Woltering, MD, FACS
4:00 PM	<i>Nutrition and NETS</i> Monica Warner, MS, RD, CDN Vay Liang W. (Bill) Go, MD
4:45 PM	Break
6:00 PM	Welcome Reception And Dinner <i>Targeted Radiotherapies for Neuroendocrine Tumors— Medical Need, Patient Criteria, and Clinical Experience</i> Evening Program Co-Chairs Aaron I. Vinik, MD, PhD, FCP, MACP, Larry Kvols, MD David Bushnell, MD R. Edward Coleman, MD Eric P. Krenning, MD, PhD Jan Muller-Brand, MD Robert Reid, MD, ChB, FRCPC
9:30 PM	Evening entertainment
Saturday, Sept. 30	
6:30 AM	Daily Morning Zebra Stroll, Walk, Jog. Join Physio Therapy Specialists In Lobby
8:00 AM	Breakfast CME - LOCAL Registration Check In
8:30 AM	Welcome - Introductions
8:45 AM	<i>Bone Metastasis Treatment: Current And Future Treatment</i> Theresa A. Guise, MD
9:30 AM	<i>GI Carcinoid and Non Carcinoid Case Study Panel</i> Gene Woltering, MD, FACS, Moderator Joel Randolph Hecht, MD Andrew Kennedy, MD, FACRO Frank A. Mitros, MD Tom O'Dorisio, MD Michael J. Ryan, MD, FACP Florencia Que, MD, FACS Robert Reid, MD, ChB, FRCPC
	9:30am OR 2:30pm - One on One Patient Sessions– Two Time Selections Offered - Refer to combined program schedule and patient brochure for details.
10:30 AM	Break
10:45 AM	Concurrent Sessions: Concentrated Area of Study Pathway Chosen During The Registration Process
	<i>Bronchial Carcinoid—Differences And Similarities - In Depth - Symptoms, Normal Progression Stages, And Special Circumstances</i> Dan Granberg, MD, PhD
	<i>Bone Metastasis In Bronchial Carcinoids: Special Implications</i> Theresa A. Guise, MD
	<i>Bronchial Carcinoid Testing Protocols At Diagnosis And Beyond</i> Dan Granberg, MD, PhD

	Newly Diagnosed Morning Session <i>Carcinoid NETS 101 - Understanding How And Why</i> Kjell Oberg, MD
	<i>Scheduling Basics - Optimum Imaging And Laboratory Cycles</i> Aaron I. Vinik, MD, PhD, FCP, MACP
	Standard Morning Session <i>The Complexities of Flushing</i> Edward Wolin, MD
	<i>Octreotide: Immediate Versus Slow Release Injections Versus Pump Combos</i> Thomas O'Dorisio, MD
	Organ Transplants: Specifics and NET Candidates Florencia Que, MD, FACS
12:45 PM	Break
1:00 PM	Specialty Lecture Series: Choice of One Lecture
	<i>Islet Cell, Gastrinoma, Insulinoma, & More</i> Roger Perry, MD
	<i>Immune System Problems for NETS</i> Paul Conkling, MD
	<i>Carcinoid Arthritis Related Problems</i> Roger W. Lidman, MD, FACP,CCD
	<i>Skin Manifestations of NETS</i> Antoinette Hood, MD
	<i>NET Patients and Kidney Disorders</i> Paul F. Shellhammer, MD
	<i>NETS and Cholesterol: Controlling Lipids, Reducing Cardiac Risks</i> Richard A. Sokol, MD, FAAFP, ABFP
	<i>Incidence of Octreotide Related Type 2 Diabetes Among NETS: Treatment Impact and Options</i> M. Elizabeth Mason, MD
	<i>Diet and Fatty Livers: The Impact on NETS</i> Leon-Paul Georges, MD
	<i>Octreotide: Digestive Impact</i> Michael J. Ryan, MD, FACP
	Round Table Patient Discussions *
	<i>The Primary Care Physician and NETS</i> Robert Blackwood, MD
	<i>Familial Carcinoid</i> Thomas O'Dorisio, MD
	<i>An Insider's Insight on NETS</i> Wendy Gillis, MS, RN, NP, CNS
	<i>NET Patient and Cancer Care</i> Rosemary Davidson, RN
	<i>Using the Internet As a Medical Resource</i> Linda Silversmith, PhD.
	Caregivers Only—Ask Any Question Dana Sussman, MA, LCP
	<i>Patient Advocacy Oriented Discussions</i> Maureen Coleman Nancy and Dave Hawkins Pam Powell Nicolette Way Carol-Anne Wilson Jim Weiveris Kathy Wright

Lanreotide Approved

In a press release in Brisbane, CA, Tercica announced approval from the U.S. Food and Drug Administration (FDA) for marketing Somatuline® Depot (lanreotide) injection 60, 90 and 120 mg/ml in the United States.

Somatuline® Depot is indicated for the long-term treatment of acromegaly in specific cases. Remember that Sandostatin (Octreotide, which is a somatostatin analogue) was originally approved for acromegaly. The FDA has also designated Somatuline® Depot as an orphan drug for acromegaly, giving the first manufacturer exclusive rights for 7 years. In October 2006, Ipsen granted to Tercica the development and commercialization rights for Somatuline® Depot in the United States and Canada.

The drug will be available in a pre-filled syringe eliminating any need for reconstitution and thus enabling of easy administration to patients. It is the only long-acting somatostatin analogue that does not require reconstitution prior to injection. This provides a significant ease in administration with easy injections and ready-to-go simplicity. The medication is actually a gel and the standard dose frequency is 28 days.

It is expected to be launched in the U.S. in approximately eight weeks.

While the current FDA approval does not specifically address use for Carcinoid, this product underwent further development in Europe in the treatment of symptoms associated with neuroendocrine tumors, especially Carcinoid.

Friend to Friend

Continued from page 4

circumstances to be able to talk to someone who has walked a similar path. This can be especially helpful in areas where no support group exists. Another concern is for the safety of those who have signed up to participate.

If you have ever been asked to sign up for our database, or for the Friend to Friend Program, you might wonder why we ask for so much information. First, ALL of the information is held in confidence. We do not share our data with any other group without your consent.

Then, the reason for so much information is so that we may match up the person asking something to a couple of people who most closely match that person's situation. Even factors such as age, location, treatment history, etc. are taken into account. That matches are never exact, but often close.

When someone calls for information, we ask them for their background and contact information. We then contact (usually up to 3) people on our list who are a close match and give that caller's information to them. This way we protect the identity of those who volunteer.

The number of requests we actually get is actually quite low, but it takes little cost for us to keep it going. If we can help just one person, we have made it all worthwhile.

If you are interested in becoming part of this program, send an e-mail to Caring4Noids@aol.com or call 609-812-9294 and we will end to the form to fill out and return.

Norfolk Agenda *(continued)*

	Other Topics Genetic Counseling For Cancer Clinical Trials - Assess Risks and Benefits Relaxation—The Importance To Nets Keeping Your Medical Records— Why and How The Politically Active Patient—Refer to posted Information for subjects and locations
2:00 PM	Break
2:30 PM	Concurrent Sessions Continue: Concentrated Area of Study Pathway Is Chosen At Registration
	Bronchial Carcinoid Afternoon Session <i>Surgical Options: Lobectomy or Resection, Robotics</i> Joseph Newton, MD
	<i>Current Bronchial Therapies and Therapy In Development</i> Dan Granberg, MD, PhD
	<i>Conventional SCLC Therapy: Benefits To Bronchial Carcinoids, Need For Reclassification</i> Michael E. Lee, MD
Newly Diagnosed Afternoon Session	An Interactive Question And Answer Session With A Team Of Experts Gene Woltering, MD, FACS, Moderator Edward Wolin, MD, Co-Moderator Frank A. Mitros, MD Manisha Shah, MD James Stark, MD Richard Warner, MD
Standard Afternoon Session	<i>MEN1, MEN2: The Specifics</i> Stephen Marx, MD
	<i>Unknown Primaries Versus Known Primaries: Treatment Differences</i> Kjell Oberg, MD
	<i>Secondary Traditional Cancers In NET Patients: Risks, Genetic Interface, Testing, and Disease Mgt</i> Tom O'Dorisio, MD
4:30 PM	Break
4:45 PM	<i>The Evolving Problems Managing Neuroendocrine Carcinomas</i> Walter Kocha, MD, PhD, FRCP
6:00 PM	Evening Reception and Dinner
7:30 PM	<i>Pipeline Medicines, Treatments, And Research In North America And Abroad</i> Q & A Moderator Aaron I. Vinik, MD, PhD, FCP, MACP Matt Kulke, MD James C. Yao, MD
9:30 PM	Introduction to CNETS Without Borders - The Art And Spirit Of Global Teamwork To Fight Neuroendocrine Tumors And Cancers
9:45 PM	Evening Entertainment