New Jersey
Carcinoid Cancer Network
Newsletter
November 2009
www.NJCarcinoidNetwork.org

NJ Conference a Success

On October 17th, the first ever Carcinoid Conference to be held in New Jersey took place in Manahawkin. Despite pounding winds, heavy rain and unseasonably cold temperatures, approx. 80 people arrived to hear lectures from Dr. Warner, Nancy Gardner and Dr. Oberg.

Overall, the conference was a huge success. The feedback surveys held mostly praise for the entire event with many gracious comments about how informative it had been. The only negatives were the hotel sound system and the hotel restaurant not being prepared (despite several advance notices to them from the conference planners).

There was a brief presentation about the Carcinoid Cancer Foundation of White Plains, NY, who is responsible for the start of all of the current support groups in the US and many abroad. A special tribute was extended on the loss of Monica Warner, with recognition being presented in her memory to Dr. Warner.

Dr. Warner lead off the lectures with his typically informative, and easily understood, explanations of the disease, with current diagnostic and treatment protocols.

Dr. Warner addresses the group

Nancy Gardner

Nancy Gardner was our next lecturer. Nancy gave a rousing talk on being your own advocate, and provided a great deal of information about Sandostatin LAR. Some of the comments were that those attending seemed to not expect too much from her lecture, but were amazed at how informative it had been.

After lunch, Dr. Oberg rounded out the lectures with more, detailed information on carcinoid. He explained some of the treatment differences between the United States and European programs, explaining what benefits could be found. While Dr. Oberg's lecture was more technical, it was widely

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NJ Mourns

With our first conference, this fall was a time of joy. It was also a time of sadness as we suffered the loss of Bob Quinn in September.

Bob, with his wife Janice by his side, was at virtually every meeting since his diagnosis in 2004. During that time, Bob persevered not just through carcinoid, but also a suspected skin cancer, and was determined to make life his priority. Bob and Janice had also planned to attend the patient conference in New Orleans this year.

In June, Bob was found to have another cancer, a bile duct cancer, this one much more aggressive. Bob and Janice were both dedicated toward helping others with Carcinoid, with Janice volunteering to be the secretary for the New Jersey group. It seemed that both had a special panache for life, especially when celebrated together.

All of us at the NJ Carcinoid Network share in the loss to the Quinn family and offer our deepest sympathies. We mourn the loss of Bob, while we admire his spirit and determination.

We are especially humbled that the Quinn family has chosen the New Jersey Carcinoid Cancer Network to receive donations to honor and celebrate Bob's life.

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Upcoming Dates

Dec. 6th , 2009 – New Jersey Carcinoid Cancer Network meeting at Crossroads Christian Fellowship. Union, NJ, 1:30 PM. Directions on website or contact Jim Weiveris at 609-812-9294 or Caring4Noids@aol.com **(Full 2010 NJ schedule posted on page 3)**

Jan 10th, 2010 - NY Support Group meeting. Long Island, Verify dates at www.carcinoidaware.org or call 516-781-7814.

April 11th, 2010 – Carcinoid Cancer Foundation lecture at Mt. Sinai Hospital, New York City. DATE IS TENTATIVE!

DVD and web release videos of the New Orleans 2009 conference are being held up due to technical difficulties. They will be released as soon as possible.

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For newsletter subscriptions, questions & submissions please contact:
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New Jersey Conference

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praised for the level of excellence and information.

After completion of the lectures, there was an open Question and Answer session, with all the lecturer's participating on the panel. This has always been a popular part of these conferences and we allowed extra time to accommodate as many questions as possible. In over 90 minutes, questions from 30 of the note cards submitted with questions were answered (we only did not get to about 10). Many of the questions were multi-part, and answered by more than one member of the panel.

"Hi, I'm from the government and I am here to help you" – Just Kidding!
Thanks to Paul, Linda and Kathy for taking on welcoming duties

Kathy McKenna donated several hand knitted "zebra" items and these were raffled, with the proceeds going to the Carcinoid Cancer Foundation. American Medical ID also provided two $35 gift certificates toward a medical bracelet from their catalog. Thanks to all our other sponsors for their donations (Novartis Oncology, Carcinoid Cancer Awareness Network, the Carcinoid Cancer Foundation, and Inter Science Institute)

Dr. Oberg

These lectures were not recorded. We are already considering another conference, possibly at another location. Date and place will be set up later.

A special thanks to all those behind the scene volunteers who made this run as smoothly as possible…from making hotel room arrangements, to transportation for the lecturers, to the folks who greeted you at the door.

Thanks to all who attended, and for your comments to help make the next one even better.

Bob Quinn

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From Bob's obituary in the Star Ledger:

Robert Patrick Quinn of Sparta passed to Our Lord on Wednesday, Sept. 23, 2009, at his home with his loving family at his side. "Bob", who was 73 years old, was born in Newark to Patrick and Jean Quinn. Family and friends will always remember how his passion for love, life and song knew no boundaries. He passed after a valiant battle with carcinoid cancer.

Bob graduated from St. Peter's College, Jersey City, with a B.S. in chemistry. He resided in Sparta since 1968, previously of Naval Air Station Patuxent River, Md. He served his country as a career naval officer for 23 years, attaining the distinguished rank of captain.

Following military service, he was an American Airlines pilot for 29 years, retiring as a captain in 1996. He was a communicant of Our Lady of the Lake R.C. Church in Sparta. A loving patriarch and proficient aviator, Bob is survived by his beloved wife, Janice I. Quinn (nee McDonnell); son, Stephen and wife Nancy of Pennsylvania, son, Michael and wife Barbara of Kentucky, and son, Peter and wife Barbara of New Jersey, daughter, Susan and husband Colonel William Ellis of Virginia, son, Timothy and wife Lisa of New Jersey, and daughter, Patricia and husband Clint Olsem of California; 17 grandchildren; sister, Geraldine Opalak and husband Joseph; brother-in-law, Bishop Charles McDonnell; many nieces and nephews.

In lieu of flowers, the family asks donations to be directed to N.J. Carcinoid Cancer Network, 9 Maplewood Dr., Little Egg Harbor, N.J. 08087 or Pope John Angels Fund, 28 Andover Road, Sparta, N.J. 07871

Bob with his 3 year old grandson, Cormac

NJ 2010 Regular Meetings

Jan. 10th
Mar. 7th
May 2nd
Jun. 6th
Sep. 12th
Oct. 3rd
Nov. 7th
Dec. 5th

- 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 from our website at www.NJCarcinoidNetwork.org, or upon request.
- 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 about holding the meeting 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. (Please note that we look at the entire state/regional weather to consider those that travel distances…so if in doubt, we suggest you call)
- There is no fee to attend any meeting, unless otherwise stated.
- Patients and caregivers are encouraged to attend.

Carcinoid Cancer Foundation Looks Toward the Future

Keith R.P. Warner, President of Highland Water LLC in Denver, Colorado, has been named Chief Executive Officer of the Carcinoid Cancer Foundation (CCF). The appointment was announced by Richard R.P. Warner, M.D., Medical Director of the Foundation, who said, "I am delighted that CCF's Board of Directors has selected my son for the position of CEO. The Foundation was founded by my family and patients in the late 1960s to enable me to continue my research on this rare cancer. With Keith Warner's appointment, the legacy of the Foundation will continue. His background in business and administration makes him the ideal CEO for the fifth decade and beyond of the Carcinoid Cancer Foundation."

Keith Warner
Photo by Droolphoto.com

The oldest foundation of its kind in the United States, the Carcinoid Cancer Foundation has earned worldwide recognition as a resource for patients, medical professionals, and researchers. CCF's mission focuses on three distinct areas: research, conducting prospective and retrospective studies, as well as funding neuroendocrine tumor/carcinoid cancer research by physicians and scientists; awareness and education for the patient and medical communities; and support/advocacy, primarily for the patient community.

According to Keith Warner, "I am personally committed to changing the statistic that over 90% of all carcinoid/NET patients are initially incorrectly diagnosed and treated for the wrong disease. We must bring greater awareness to these rare cancers as we all look towards the day there is a cure for carcinoid/NET patients. I am very excited about the future of the Carcinoid Cancer Foundation as we work with carcinoid/NET patients, the medical and healthcare communities, corporations and foundations, and our Board of Directors."

An entrepreneur, Mr. Warner has founded or acquired a number of companies ranging from the wine industry to management consulting. Since 2004 he has been President of Highland Water LLC, a supplier of industrial, commercial, and water treatment systems. He founded Strategicore Consulting, for which he provided extensive management consulting services to various technology, product, and service companies, including Pristine Health, a venture capital group; All Star Kids Fitness Center; and Stassen North America, a private label tea/herb manufacturer. He was Co-Founder and President of the Rocky Mountain Spice Company, a spice importer/food manufacturer, and Co-Founder and Vice President of Ready Care Industries, a distributor/manufacturer of locker room beauty care products. He has also worked for a Wall Street money management firm and in commercial real estate.

Mr. Warner earned a Bachelor of Science degree in Business Administration from the University of Denver and a Master's degree in Business Administration, with a concentration in marketing and finance, from Boston University, with national honors recognition. He resides in Denver, Colorado.

Main conference room at the 2009 New Orleans Conference

New Orleans 2009 Conference Lectures Notes

Please note that these edited and cryptic records are those taken by one person and that not all points of any lecture are covered. Due to the possibility in error or interpretation, it is highly advised to seek a professional medical opinion before relying on treatments from these notes. These notes are provided only to give you some insight in to which ideas you may want to seek further follow-up information & discuss with your doctor . It is suggested that you use these notes as index to topics of interest and then refer to the recorded video of that lecture when they become available.

Please refer to notes from prior conferences, as some ideas presented are built upon prior lectures. These notes can be found in past newsletters from the Metro New York Carcinoid Support Group at www.carcinoid.us Due to the use of concurrent (simultaneous) lectures approx. 1/3 of the information covered could not be attended to take notes.

Dr. Guido Rindi – "What do you need to do for an accurate diagnosis? Why are the European and U.S staging schemes so different?"

Poorly differentiated is usually endocrine carcinoma

Well differentiated is usually Carcinoid of GEP

Different markers are found in different parts of the cell

Typical *vs.* Atypical criteria varies between tumors, based upon primary location

Need to describe using TNM criteria

T = tumor size, wall invasion, site

N = Node involved of uninvolved

M = metastases, to location and extent

Fine Needle Aspiration provides poor sample – use core biopsy

Most tests can still be done on preserved tissue

Ki-67 is greatly helpful in determining treatment

Dr. Thomas O'Dorisio – "NET Blood and Urine Markers: Does it make a difference what lab you use? What about Octreotide and Lanreotide plasma levels?"

Distribution of NETs

25% lung

56% Carcinoid

17% Insulinomas

15% PPomas

11,000 to 12,000 new cases per year in U.S.

110,000 to 120,000 patients currently living

Nature of NETs

Derived from neural crest origin

Arise mostly in gut

Episodic secretion

On and off

Makes hormone at inappropriate times

Predelict to liver (via portal vein)

Regulated mostly by Samatostatin SST2 receptor

60% have liver metastases upon diagnosis

Chromogranin A (CgA) is a "pro hormone" that is easily cleaved into better markers such as Pancreastatin

CgA and Synaptophysin (SYN) staining is positive on ALL NETs, despite principal hormone or primary location

Ki-67 staining

<2% is well differentiated

2 – 15% is moderately differentiated

>25% is poorly differentiated

Not homogeneous, can vary from slice to slice within a tumor

Tumors usually make about 50% too much of a good thing

Octreotide should always be used when tumors are clinically active

Foregut tumors

5HIAA is not helpful

CgA works better

May travel to breast or bone, vs. liver

Midgut tumors

5HIAA and CgA are good markers

Substance P also good marker

Classic wheeze, flush diarrhea and cardiac issues often present

Hindgut tumors

May produce CgA

More benign

Clinically silent and aggressive but rarely metastasize

5HIAA is usually not elevated if tumor burden in liver is below 20-30%

SSRIs can elevate test results

CgA test can raise with renal insufficiency, hypertension or use of PPIs (must be off 4-8 weeks), resulting in false positives

Stay with same lab for a test

In the U.S there are 5 lab assays approved and no way to convert results to be able to compare to follow a trend)

Pancreastatin is 100x more sensitive than CgA

Sandostatin LAR levels

First day produces large peak

2nd day drops level to very slow

Begins to rise until the 10th day where it will remain fairly steady

Somatuline

Peaks by 2nd day and remains steady

Dr. Robert Nagourney – "Drug Resistance Testing"

Cancer is not excessive cell growth

It is cells that die too little

Cancer cells divide at the same rate as normal cells (about every 3 months)

Cancers hijack the death / survival proteins within cells

If DNA is damaged – cell "reads" DNA and decides whether to "total" (destroy) it or let it reproduce

Expose cells to stress (deny food, oxygen, etc.), then cell often dies

Effect of treatment will often show cell death within hours to a couple of days from exposure

Idea is to increase cell death – not inhibit cell growth

Biosystematics is answer to cancer cure, not genetics

Cancer cells do not live in isolation. They live among other cells and we must treat accordingly

Testing should be done on tissue samples as they are found within the body "micro spheroid"

Patients who got drugs that responded in the test tube had approx. 75% response rate, while patient without tissue testing had response rates in single digits (avg. was 81% vs. 13%)

Doctors tend to have a "favorite" drug combination, but patient responses can vary from those favorites

Prognostics indicate the risk for recurrence of disease

Predictives show likelihood of response to a specific treatment

Genomics can be useful in prognostics, but not predictive

Genotype is not equal to phenotype

You can have the DNA for blue eyes, but the phenotype gives the blue eyes

This is determined not by the gene, but by the development process

Dr. Mary Hardy – "Over the counter vitamin supplements & alternatives therapies: How to assess safety & efficacy"

Diet supplements need to be VERY carefully individualized

Use of supplements by patients increases 8 fold after diagnosis

Goals

Reduce cancer risk

Boost immune System

Symptom management

Risk reduction in other illnesses

Heart

Osteoporosis

Wrong supplements can interfere with treatments and damage organs

Red Flags of bad supplements

If it is too good to be true, it probably is

"Secret ingredients"

Overpromising

Not willing to discuss with medical peers/team

Very expensive

Anecdotal evidence only

"Never harmful"

Very dismissive of medical system

Know good brands by understanding quality control

Look at label quality (does it look like it was printed in someone's garage?) and information (is the information complete and accurate, in common terms)-compare to name brands

Line between food or supplement is blurring

Ginger helps nausea

Food rarely causes problem – supplements can, because there is more of it

Low vitamin D is showing to be very common

Current recommended levels may be too low

Finding reliable info

Friend and family are most common

Can be inaccurate

Internet

Clerk at health food store

Identify a reliable expert

Question and Answer – Nagourney, Hardy, Rindi, T. O'Dorisio, Hardy & Go

Pancreastatin changes can precede CT shown changes by 3 months

Mitotic count and Ki-67 are two different tests

Quality of nutrients in large, commercial-farm products has declined in the last 25 years

Measure Vit. D 25 Hydroxy, which is total body level

Use calcium citrate to supplement

Do not use Tums® to supplement. Tums® neutralizes the acid needed to process it

Ga68 is about 3 months away from testing at Iowa

Fish Oil supplements need to come from "cleaned" sources to reduce mercury intake

Secondary low thyroid is common after about one year of Sandostatin use, resulting in fatigue

Pam Ryan, RN - "How to prepare for your expert opinion appointment"

You have to be you own advocate to make sure things get done and paperwork sent

Collect

Operative Reports

What was done, removed, found and how

Pathology reports

Tissue testing and staining

Radiological reports

CT

MRI (if liver)

Octreoscan

24 hour scan is all that is usually needed

Biological Markers

CgA, NkA, Pancreastatin, 5HIAA

Blood work within 3 months, scans within 6 months

Dr. Yi-Zarn Wang – "Sentinel Lymph Node Biopsies of the small bowel & pancreas: How does this direct surgical resection?"

Carcinoid is like a delinquent child

It does not read books, nor obey the laws

Typical response to a Stage IV cancer

Not much we can do, treatment or symptom control

If we can't remove it all, we don't bother to remove anything at all

30% of Carcinoids will get a secondary cancer

Tumor spreads to other locations via lymph system, over pre-determined pathways

Inject a dye or radiolabled isotope into the a tumor and watch it flow out of the tumor and find the most likely pathway and location of mets

May use Gamma probe, not Gamma knife

Led to surprising findings of lymph/mesentery involvement further from tumor than expected with good tissue in between

Tumor cells are like taking a highway, they bypass good tumor until they find an "off-ramp" to exit

Use of dye mapping allows removal of tumor and further mets, but allows good tissue to remain (can spare ileo-cecal valve)

Dr. Phillip Boudreaux – "How to use the Intra-Operative Gamma detector to find hot nodes and hidden tumors deposits"

Timing of injection is critical

Too soon and too much background "noise"

Too late and you get a weak signal

Seven days after Octreoscan is best

24-36 hours after MIBG scan

Must have good uptake in pre-operative studies

Dr. Marybeth Hughes – "The results of a clinical trial of isolated liver perfusion"

PHP is in phase II trials-needs to have one more patient to complete phase II trial

In patients with all tumor surgically removed, 76% have later liver mets

NET response rate is 86%

Procedure can be repeated

Dr. Susan O'Dorisio – "Genetics and risk for Carcinoid"

Why should a patient learn about genetics?

Understand my disease

Obtain genetic counseling, if needed

Converse with doctors better

Obtain help from insurance carrier

Educate family

Advocate for self and children

Stay up to date

Chromosomes

Humans have 46 – genes reside on chromosome

Extra chromosome can make a difference

Loss of a piece of chromosome does not cause cancer, but may make you more susceptible

Loss of one piece of chromosome, coupled with loss on another, can cause cancer

11q22 is address of Somatostatin receptor SST2

Carcinoid risk for relatives

Location	Number	Child -ren	Sibling
Colon	7/2424	2.7x	1.9x
Small intestine	11/2424	11.8x	9.3x
Lung	2/2424	2.6x	n/a

23 people out of 2424 people had a child or sibling who developed Carcinoid

Swedish study in Swedish population, Hirp, et. Al. 2009

Scientific name for a "hit" is a mutation

Mutations can increase gene activity

Mutations can decrease gene activity

Mutations can completely knock out the function of a gene

Sporadic cancer – two acquired mutations

Hereditary cancer – one inherited and one acquired mutation

Question and Answer – S. O'Dorisio, Hughes, Boudreaux, Wang, Ryan, Woltering & Choti

Genetic testing for NETs is difficult because there is no large population to establish a "norm" denominator

Genetic testing can affect lifetime ability for life and health insurance

Somatuline Depot usually needs 120 mg, every 14 days and takes 6 months for optimum levels, but resulting levels are higher

Radio Frequency Ablation max size depends on several factors, adjacent tissue and ducts can be cooled with saline solution

After PRRT – need to restage and re-evaluate to see if previously impossible procedures are now possible

Increase in tumor size may indicate (a need for) an increase in LAR dose – functional and non-functional

Decadron may help break down LAR receptor resistance

Anti-rejection medications in liver transplant do not seem to show an increase in growth of cancers

New mTOR based anti-rejection drug coming out soon

NIH is running a trial taking adult children of carcinoid patients and doing blood work and Octreoscan and finding many mid-gut children

Lung carcinoids are more prevalent in young (less than 30 years old) – more aggressive, unknown why

Dr. Eugene Woltering – "What's hot in the Woltering lab? Can you do a clinical trial in a test tube?"

A tumor can not grow larger than 2 cm without adding blood vessels

Biological

Chinese sweet leaf tea

Black Raspberry (freeze dried fruit)

Noni Juice prevents angiogenesis

For some patients whose tumors do not have receptors, you can still use Somatostatin analogues because the blood vessels that supply the tumors have receptors

Primary tumor is different than lymph node tumor which is different from distant mets

You must treat all 3 to prevent recurrence

Must tailor treatment for each person

Epothilone B is more universally effective than others available or in testing

Dose level may be critical

Dr. Andrew Kennedy – "Liver directed therapies: Bland vs. chemo vs. radioembolization"

First choice is surgical debulking, which is beneficial if or if not symptomatic

Tumors have 3 times more blood vessels than normal tissue and tumor blood

vessels can have a larger diameter

Radiation in liver can show tumor death 4 weeks to 9 months after treatment

As tumor gets larger, center of tumor starts to die off due to lack of effective blood supply and rim grows with blood vessels on the outside

Perform Yttrium 90 first, and then perform Hepatic Arterial Chemoembolization. Can be done in reverse order.

Dr. Lowell Anthony – "Research drug trials: the role in Carcinoid, Islet cell and other NETs, what is useful and what is not"

There is no upper dose limit to Octreotide Acetate

In 20 years, cancer death rate in adults has not changed that much

Pediatric cancer has had more success

5% of adults participate in clinical trials

Insurance may not cover all patient costs associated in a clinical trial

Average cost to develop a new drug in the US is about $700 million

That includes the cost for hundreds of drugs that are tried and don't work to become a winner

A researcher who can spot a drug that will not work well, early in the process, can save a drug company big money

Dr. Saju Joseph – "Role of liver transplantation in NETs: Autotransplant techniques and implications"

Five year survival for liver transplants is about 70%

NETs and transplant results

One year survival = 75%

Five year survival – 40%

Very few will be disease free

Higher failure rate with Islet cell and foregut

Midgut carcinoids have a 78% survival rate

General population is 92% five year survival

Islet cell has a 40% five year survival

Values have been improving

to show a five year survival is based upon techniques that were available 5 years ago

newer stuff is always coming out and is believed to be better

Liver and pancreatic surgeries are very tricky

Limits of treatment

Toxicity

Resistance

Non-operable liver disease

Tumor biology

Auto transplantation

Traditional surgery is limited by physical access

Takes liver out of body and then work on liver outside of the body (think workbench)

Ice it down while out

Bleeding is reduced (increases visibility)

Pack liver with pressure upon replacing, then remove packing the next day and close patient

Leigh-Anne Burns, RD – "Nutritional support for NETs: Managing diarrhea with diet modification and use of pancreatic enzymes, Cholestyramine & anti-diarrheal medications"

Lactose intolerance is inability to absorb lactose

Sorbitol, used as a preservative in gummy bears, can cause diarrhea in quantity

Intestinal water secretion exceeds ability to absorb

Tumor associated secretory diarrhea (NETs are different from most diarrheas)

Gastrinomas

VIPomas

Carcinoid

Short bowel can also cause diarrhea

Calories from

Carbohydrates

Fats

Proteins

Results in

Formed stool

Runny

Fatty

Assessment of problems

Time from ingestion to stool

Stool type (explosive)

Floating or foul smelling

Dietary factors

Caffeine

Fructose (quantities that exceed gut ability to absorb)

Milk products

Factors increasing motility

Activity

Stress

Foods

Concentrated sweets

Mix solids and liquids

Extreme hots and colds

Fiber types

Cholestyramine

Used when bile salts are thought to be playing a role

Keep records

Helps evaluation

Assessment of treatment effectiveness (comparison)

Question and Answer – Burns, Joseph, Anthony, Kennedy and Woltering

Liver regenerates in about 6 weeks

Regenerated tissue has a different look

Yttrium 90 does slightly scar liver at tumor locations but does not preclude future surgery

"Peppered" liver is best treated with bland embolization or radionucleotide approach – problem is the cumulative, collateral damage to many places (Kennedy) – Woltering prefers a chemoembolization but admits the toxicity problems

Sugar ingestion is not affecting tumors

Studying to see if high sugar leads to

insulin release leads to growth

Histamine release is usually from foregut tumors

Reconstruction of ileo cecal valve is not possible and the removal is not that problematic to warrant an attempt

Use of anti-angiogenics (black raspberry powder) with heart disease does not allow new, helpful blood vessels to grow for the heart

Dr. David Bushnell – "What are the ways to scan for NETs? PET, MRI, CT & Nuclear Medicine scanning"

Timing of contrast administration to image is important

Gallium 68 will probably replace Octreoscan

Do not take Over The Counter decongestants before MIBG scan

123 I MIBG *vs.* In 111 Pentreotide

10% had tumors that only showed on MIBG

20% had tumors that showed only on Octreoscan

Small role for PET in NETs

If tumors do not image on Octreoscan, but do image on PET, patient may have poorer prognosis

Open MRI images may be inferior result (distance from unit to tissue)

Dr. Stanley Goldsmith – "PET scans, Gallium scans, F-18 DOPA scans"

Wide variation of Spect and Spect/CT image quality

Not all PET is FDG-PET

Material	half life	requires
18 Flora	112 min	Commercial and Cyclotron
68 Gallium	68 min	Commercial and Generator
11 Carbon	20 min	In house cyclotron (5HTP PET)

Must learn to differentiate image of normal pancreas from problem pancreas

Dr. Edward Coleman – "I-123, I-131 MIBG – Scans, therapy, results"

Newer MIBG material (molecular insight), every molecule has 131 In attached

Even with Iodine blocking, thyroid can still get some, tolerable exposure during treatment

Nausea may start 8-12 hours after infusion and last up to 4 days

Blood counts drop after 2 weeks, but not severely

Dr. Richard Campeau - "Bone Metastases – Strnium-89, Samarium-153, Biophosphates"

Bone metastases can cause more problems than just pain

15- to 20 of Carcinoids have bone mets, but not all have pain

Traditional pain management has many side effects and can have significant costs

Management of bone mets requires multi-modal approach

Biophosphates

Radiopharmaceuticals

Dr. Richard Baum

Yttrium 90 therapy

PET/CT using Gallium 68 takes only 20 minutes for a whole body scan

Shows mets in heart well (normal angiogram after angina did not reveal it)

SUV = Standardized Uptake Values

With Gallium 68 can assign a number value to uptake amount

External Beam Radiation on NETs is useless (except for painful bone mets)

Need a multi-disciplinary team, selecting individualized therapy

long term, low dose & combined use of Yttrium 90 and Lutetium 177

Dr. Abe Delpassand

No radiopharmaceutical is 100% selective

Advantages

Can "test drive" at a lower dose

Cross fire effect

Radiation goes through cells and to others to which it is not directly attached

About 90 patients treated with Indium 111 high dose

10% had partial response of disease

75% had stable disease

15% had progression of disease

81% had at least a 25% increase in their functional living index

Average time to disease progression is about 19 months

Status of Lutetium 177 therapy

Awaiting testing on European formula

Expect first patient to be treated before end of 2009

Dr. Jan Müller

Yttrium 90

2 to 3 treatment cycles, 8 to 12 weeks apart

Life quality improvements

Diarrhea, 83%

Flushing, 48%

Asthma, 63%

Pain, 71%

Survival time – 50% had 5 year survival

Must stay in hospital 3 days

Can travel about city

Can fly after 3 days

Question and Answer Session – Müller, Delpassand, Baum, Campeau, Coleman, Goldsmith, Bushnell & O'Dorisio

Your scan should be read by someone with experience in your disease

U.S. needs to follow European Union standards of measurement labels and nomenclature

MIBG therapy should be used for patient with progressive disease that is not responding to other treatment

Repeated uses of MIBG does not have declining response in subsequent treatments

Yttrium 90 can be repeated if needed

Surgery is still the first line of treatment

Do not write into the FDA directly to complain about lack of an approval. That effort only ticked off the FDA workers (who are required to review each letter) so they took their time reviewing the applications and paperwork.