



## The New Voice News



**New Voice Club of South Florida**  
Serving Broward, Palm Beach and Miami-Dade  
[www.newvoiceclub.org](http://www.newvoiceclub.org)

**April 2008**

**Editor:**  
Mike Rosenkranz  
(954) 236-0980  
[smike24@comcast.net](mailto:smike24@comcast.net)

**~ Next Meeting Sunday, April 20th, Noon to 2 p.m. ~**  
**Conference Center at Holy Cross Hospital**

**4725 N. Federal Hwy, Ft. Lauderdale, FL (south of Commercial Blvd)**

**Noon: Rap Sessions Followed by Light Refreshments 1:00: Meeting and Program**

From I-95, east on Commercial Blvd to Federal Hwy (U.S.1) Turn R (south) on Federal Hwy to 47th St. (1st street after the Holy Cross Main Entrance). Turn R onto 47th Street to the Ortho Parking Lot on your right. Park anywhere in the parking lot. Conference Center is the building to the right.

Look for New Voice Club Banner

**President:**  
Warren Goodman  
(561) 737-9122

**1st Vice President:**  
Allan Smith  
(954) 724-1971

**2nd Vice President:**  
Ralph Friedman  
(561) 495-8644

**Secretary:**  
Ruth Henegan  
(954) 968-3198

**Treasurer:**  
Lenny Weinstein  
1427 E. Hillsboro Bv #529  
Deerfield Beach, FL 33441  
(954) 427-7043

**Visitation & Liaison:**  
Earl Mogk  
141 Eleuthera Drive  
Dania Beach, FL 33004  
(954) 929-0136  
[earlmogk@wmconnect.com](mailto:earlmogk@wmconnect.com)

**Directors:**  
Howard Grabowski  
Earl Mogk  
Gary Morey  
Mike Rosenkranz  
Patty Sewell  
Richard Willenborg

### In Memoriam



We lost one of the stalwarts of the New Voice Club March 7<sup>th</sup> when Gene Kimble passed away. Gene was dedicated to the club, from giving up his director's seat to allow Gary Morey to serve, to grabbing Jim Israel off the golf course and taking him to a meeting before Jim's laryngectomy. A member of the New Voice Club since 1995, Gene was an active, willing worker always ready to help. He will be sorely missed and fondly remembered.

### A Message from the President

Wow! What a wonderful program we had at our March meeting. Thanks to Al Smith, our 1<sup>st</sup> VP who arranges the programs for our club, we had the pleasure of hearing from Karen Niosi of the Fort Lauderdale Fire Rescue Service. She obviously did a lot of research about larynx and showed us what they would be doing in cases of emergency treatment. And to top that off, she told us she would be forwarding her information to other units in Broward County. It was truly great. Another great pleasure was seeing a lot of folks who had not previously been to our meetings at the Conference Center at Holy Cross Hospital. It sure was gratifying. A very big thanks go to John and Jo Collier for providing the food for our luncheon. Jo really outdid herself with a wonderful quiche and fruit salad that was really appreciated by our members. .

During her program, Ms. Niosi described a **new enhanced 911 system**, that allows emergency operators to respond to your home after a call, **even if you are unable to speak**. She will research if your city uses this system if you are interested. Ms Niosi distributed **free emergency medical information kits** that conveniently attach to the front of a refrigerator or other metal appliance, and contain a blank form for personalizing your information, as well as laryngectomy stickers and cards. The kit makes it easier for rescue personnel to instantly know medical history, medications, allergies, and how to contact physicians and family. Contact Gary Morey [gemorey@hotmail.com](mailto:gemorey@hotmail.com) or call him at (954) 463-2461 if you are interested in either registering with your city's

*Cont'd on page four*





# What's Doing Around Town

**Penny's meeting:** Dr. Stanley Althoff, PhD, led an in-depth discussion on March 11<sup>th</sup> of the issues involved in Relationships During and After Cancer Therapy. Dr. Althoff maintains a private practice in West Palm Beach and consults at UMSylvester Cancer Center in Deerfield Beach where the presentation and discussion took place at the monthly meeting facilitated by Penny Fisher. Topics included expectation management, plus modification of character style and moving forward with recovery. Sadly, the only two in attendance were regulars Lenny and Gary. Penny goes to great lengths to present interesting and valuable programs each month, and it is rather embarrassing that only two members showed up for the meeting. Penny will present a program on Xerostomia (dry mouth) at her April 8<sup>th</sup> meeting, and it would be gratifying if more of our members are on hand for that very important presentation.

**Main Meeting:** We had thirty-four members and guests at our March 16<sup>th</sup> meeting, a very fine turnout, but those who were not there missed an excellent opportunity to learn the latest techniques in resuscitation. Karen Niosi of the Ft. Lauderdale EMS Bureau/Training provided a hands-on demonstration in the use of an ambu-bag plus compressions to resuscitate someone. It is essential that we larys all learn to use an ambu-bag due to our inability to breathe into someone's mouth. Ralph Friedman provided a delicious cake in celebration of his 86<sup>th</sup> birthday. Jo Collier provided a fabulous homemade quiche and fresh fruit bowl. We welcomed back Robert Iglesias who was having a problem with his loaner EL. Problem was resolved by Lenny, our resident fixer-upper.

**Lynn's meeting:** Three newer members joined us. Ken Smith is speaking much better with his TEP, George Fowler from Boynton Beach needed some information, and John DiPeri from New Jersey, who winters in Florida, gained valuable tips about TEP and stoma care.

The **Plantation Relay for Life** kicked off with the Survivor's Luncheon at Carrabba's Italian Grill. Representing our club were Joe Saliba, Helen McGiff, Warren and Flori Goodman, Mike and Sue Rosenkranz, and Lenny Weinstein and his grandson Brian, Brian has been doing stellar service as our interim webmaster for the past several months, posting the Newsletter and making all needed changes in the website. We owe him a debt of gratitude for his great work

# Upcoming Events

**Main Meeting**  
**3rd Sunday of each month**  
**Next meeting April 20th Noon-2 p.m.**

Rap Sessions at noon  
 Facilitator: Pascale Bourne MA, CCC-SLP

Light refreshments at 12:45 p.m.  
 Meeting and Program at 1:00 p.m.

**Conference Center - Holy Cross Hospital**  
 4725 North Federal Highway, Ft. Lauderdale  
 (U.S. 1 just south of Commercial Blvd.)

**More information: Christina at (954) 267-7770**  
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**Support Group Meeting**  
**Boca Raton Community Hospital**  
**Davis Therapy Center**  
 Oaks Plaza, Glades Road at 13th Street  
 Facilitator: Lynn Carrier MS, CCC-SLP

**3rd Thursday of each month**  
**Next Meeting - April 17th**  
 10:30 - 11:30 a.m.  
**More information: (561) 395-7100 Ext 7430**  
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**Veterans Administration Medical Center**  
 7305 N. Military Trail  
 West Palm Beach, FL 33410  
 Loren Blumenthal, M.S.P.A., CCC-SLP  
 Veterans Laryngectomee Group  
 (Veterans & family members only)

**2nd Thursday of each month**  
**Next Meeting - April 10th**  
 11a.m. - 12 noon  
**More information (561) 422-6237**  
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**UMSylvester/Deerfield**  
**Comprehensive Cancer Center**  
 1192 East Newport Center Drive, Suite 100,  
 Deerfield Beach

**Facilitator: Penny Fisher MS, RN, CORLN**  
**Mort Silverblatt SPOHNC Support Group**  
**2nd Tuesday of each month**  
**Next Meeting - April 8th**  
 1:30 - 3:00 p.m.

**XEROSTOMIA - What to do for a dry mouth?**  
**More information (305) 243-4952**

# Some Cancer Patients Turn to 'Coaches'

By MARILYNN MARCHIONE AP Medical Writer February 18, 2008

Bad advice, or just too much of it, can compound the trauma and damage done by the disease itself, cancer patients often find. Friends and relatives are important for support, but when these untrained people act as cancer coaches, they can sway people to make poor decisions about their care.

This includes survivors, whose opinions are highly valued by patients suddenly facing the scary diagnosis. They may know a lot about cancer, but can do harm if they project their own experiences onto someone else, who may have a different form of the disease that needs different treatment.

Survivors also may be out of touch with changes in the field, where genetic discoveries are rapidly reshaping notions of who needs chemotherapy and what kind.

- What's the solution? -

Many advocacy groups and hospitals are using "professional" coaches - trained volunteers or paid workers who can objectively help new patients navigate the maze of information and options.

The American Cancer Society started a patient navigator program a few years ago that now operates in 87 locations and is planning to expand. The National Breast Cancer Coalition also trains coaches, and big treatment hospitals like the University of Texas' M.D. Anderson Cancer Center are increasingly using them for breast, prostate, lung and other types of cancer.

Attendance set records in December at one of the top training programs, held during the San Antonio Breast Cancer Symposium. More than 240 breast cancer survivors spent late nights at the convention center, taking notes as scientists schooled them on the latest research.

These women go home to volunteer in hospitals and support groups where they staff hotlines, meet with new patients and teach other coaches what they learned. Demand for this training is so great that the Alamo Breast Cancer Foundation gets grants from the Avon Foundation and nine drug companies to subsidize some attendees, but still can't meet the need. Dozens are turned down each year.

To find a coach or navigator, patients can ask their doctors, local cancer hospitals or groups like the cancer society for help. Brann, feeling a need for unbiased help, found a coach by calling the Cancer Resource Center of the Finger Lakes, where associate director Bob Riter provided it. "People are usually too free about giving advice," said Riter (pronounced RITT-er), a survivor of male breast cancer and graduate of the San Antonio program.

**"We never tell people what to do. We provide information, and we help them think out loud."**

Whether amateur or professional, a good cancer coach should offer these things, experts say:

Support- an ear to listen, a shoulder to cry on, a hand to hold.

Resources- reliable information or help getting it, and only if the patient wants it.

Objectivity- a willingness to help patients discover what is best for them, rather than to validate the coach's own cancer battle and choices.

**"There's a big difference in saying, 'This is what I did' and 'Here's what you should do,'" Riter said.**

Elderly people are especially vulnerable to having their decisions usurped, he added. "Sometimes middle-aged kids impose what they want to do on their parents" without asking what the parent wants. No hard numbers exist on how many cancer patients bring professional coaches or informal ones - a relative or friend - to doctor appointments where treatments are discussed.

"The person coming with you can either be an asset or a liability," said Meg Gaines, a lawyer and ovarian cancer survivor who runs the Center for Patient Partnerships, an advocacy resource at the University of Wisconsin-Madison. It is good if the coach can ask questions, gather information and take notes for the shell-shocked patient to use later, she said. It is bad if the coach interferes with the patient's decisions.

Doctors often find themselves in the middle, fighting for the patient's trust. Some choices come down to personal values and risk tolerance, said Dr. C. Kent Osborne, a breast cancer specialist at Baylor College of Medicine in Houston.

Whether to have chemotherapy is an example. Some women want to avoid it at all cost. Others "don't want to leave any stone unturned," and demand it even if it has harmful side effects and only a 1 percent chance of helping, he said.

As for patients being swayed by others, "a lot of that occurs when they're not in the doctor's office and they go back to their home and their community," Osborne said. "Then well-meaning friends might say, 'Well, gee, I was treated with this and you should get that,' or 'Aunt Molly got this and you should get that, too,' not understanding that every patient is different."

Patients can fall into the same trap when they coach each other, Gaines said. "This is the potential downside of support groups -- you don't have expertise around the room," she said. "Someone may be describing her own treatment and others will think, 'My doctor didn't tell me that,'" possibly because their cancer is different. Mary Michaud, policy director at the Wisconsin center, warns: "Beware of people



# April Birthdays

6th Max Brown	20th Tony Talmich
10th Robert Iglesias	21st Elaine Brown
14th Wini Mogk	21st John Myers
16th Leon Essebag	22nd Sue Beatty
19th Gloria Smith	27th George Fowler
20th Trenia Blosser	27th Micki Lindenbaum

## Happy Birthday to All

*(cont'd from page one)*

911 emergency system or receiving one of these free emergency medical information kits. He will get the requested information to you.

The Plantation Relay for Life which our club always attends in good numbers will take place April 11<sup>th</sup> at 6 PM in Plantation's Central Park. Plan to be there no later than 5 to register in time for the Survivors' Dinner which starts the event. I sure would like to see a grand turnout. Attending one of these relays is quite a wonderful experience.

Our Visitation Committee continues to be active. Recently, Gary and Lenny visited a new lary who was having difficulty adapting to his neck-breather status, and Earl and Mike visited a lary-to-be prior to his surgery. He was too distraught to talk to us, so Earl will try again at the hospital following the surgery. If at first you don't succeed.....

I look forward to seeing you all at our April meeting..

*Warren Goodman*

Recently seen in a newsletter from a laryngectomee club up north, "After two consecutive Wednesdays of nasty weather, we were finally able to hold our first business meeting since December."

What is **our** excuse? Is our weather too good?

We're extremely fortunate in South Florida to have a wide array of available resources. We are provided with continuing education and information that is important to new and experienced laryngectomees alike. It is embarrassing when professionals like Dr. Althoff and Karen Niosi of Ft. Lauderdale Emergency Medical Services alter their schedules to accommodate us only to be met with disappointing attendance at their presentations.

## Tips from the Library at webwhispers.org

### MOISTURE

Adequate fluid intake is the first essential step

You will breathe easier, cough out thinner mucus with less effort, and have a cleaner, healthier stoma if you will irrigate, use a humidifier, and keep your stoma covered to avoid losing moisture each time you exhale. If you are away from your humidifier, carry a small spray bottle with clean water and use it to spray your stoma and your stoma cover. Keeping this area moist is the secret to avoid any crusting (dried mucus in and around the stoma) and to keep any bits of dried mucus or blood from solidifying inside your trachea. If you are crusting or coughing up dried bits, add moisture.

(Check our Post-Op Section for more hints on moisture or humidifying)

### SOFTEN DRIED MUCUS FIRST

I found out the hard way that you should first soften dried mucus which can accumulate around your stoma before trying to remove it with tweezers. You can really irritate your skin if you pull dried mucus from the stoma area without first softening and loosening it. If you shower or bathe in the morning, let the water vapor or steam soften dried mucus before removing it with your tweezers. Warm water on a dampened washcloth will also do the trick. For those who have the TEP prosthesis, the tweezers are also handy to use along with a tiny brush and modified hypodermic style syringe/pipet (a small syringe device or thin tube fitted with suction bulb) to keep the prosthesis clean.

### GUAIFENESIN

Used for keeping mucus thin.

From the Internet >>Guaifenesin is an expectorant, a medication that promotes elimination of mucus from the lungs. The expectorant effects of guaifenesin promote elimination of mucus by thinning the mucus and lubricating the irritated respiratory tract. Guaifenesin is an ingredient in many over-the-counter cough and cold products.(e.g. Plain Robitussin, Humibid, Mucinex). Guaifenesin was first approved by the FDA in 1952.<<

Some laryngectomees take this on a regular basis and in varying amounts. Most everyone takes it when they have a "cold" in one cough syrup or another. Please take it with enough water to make it effective. It's purpose of liquefying mucus needs the water and you may find that less medication with water works better than a lot of medication without extra water