

New Voice News

New Voice Club of Broward County

Serving the tri-county area

www.newvoiceclub.org

March 2005

Mike Rosenkranz, Editor



NEXT
MEETING
Sunday
March 27th
2005

President
Carl Kilmer
(954) 472-0865
Carlkilmer@bellsouth.net

1st Vice President
Warren Goodman
(561) 737-9122

2nd Vice President
(854) 792-0832
Pat Hopping

Secretary:
Dottie Kilmer
(954) 472-0865

Treasurer:
Lenny Weinstein
1427 E Hillsboro Bv 529
Deerfield Bch, FL 33441
(954) 427-7043

Visitations & Liaison:
Earl Mogk
141 Eleuthera Dr
Dania Beach, FL 33004
(954) 929-0136

Directors:
Sidney Gellman

Earl Mogk
Bill Romanello

Mike Rosenkranz

Patty Sewell



Main Meetings Held at the Margate Community Center
6199 NW 10th Street, Margate, FL

12:00 1:00

4 blks N of Atlantic Blvd.
2 blks W of 441 (St. Rd. 7)

Rap Sessions Meeting & Program
Refreshments after Meeting



Lary, our friendly giraffe, hopes you have all paid your dues.

FLA News: Watch for the March edition of the FLA News. It will have the registration form for the Annual Meeting in Orlando on October 8th and 9th. These are corrected dates. The AM will be Saturday and Sunday, with the banquet on Sunday night. Registration will start on Friday afternoon. Follow this map to what is shaping up to be one of the best meetings we have ever had, in a great hotel in Florida's favorite playground. Last year we had the largest delegation at the meeting. Let's have an even larger delegation this year.



Remember: You don't stop laughing because you grow old. You grow old because you stop laughing.
Laughing on the inside works just as well.

Mail dues to Lenny Weinstein, Treas.
1427 E Hillsboro Blvd #529
Deerfield Beach, FL 33441
\$10 for two \$7 for one

*Ah me, 'tis spring
See the bird upon the wing
My word, how absurd
I thought the wing
was on the bird*



This is a gentle reminder that Spring is just around the corner. Pay close attention, or you may miss it. Spring is a short season in south Florida. Enjoy it while it lasts.

Plantation Relay for Life

Carraba's Italian Grill in Plantation hosted a Survivors' Luncheon on February 19th on behalf of the ACS Plantation Relay for Life. Close to seventy survivors were in attendance to hear great entertainment, eat a sumptuous luncheon, and learn a little more about the RFL. Representing the NVC were **Carl and Dottie Kilmer, Florence and Warren Goodman, Ruth and Bob Henegan, Joe Saliba, Helen McGiff and Mike Rosenkranz.** The Relay will be April 8th and 9th and is the major fundraiser for the ACS. We traditionally have a large turnout of our members who walk the first lap around the track. This is the survivors' lap and all are welcome to join us. **Check-in for the relay will start at 4 p.m. Friday, April 8th, with the opening ceremony set for 7 p.m.** Dinner will be served to survivors and their guests immediately following the survivors' lap. Pick up your registration form at any of our meetings.

CLUB NEWS

Sunshine: Sadly we have been informed of the passing of the wives of two of our members. **Alex Koukly's wife, Ellie**, passed away in December. **Sy Falk's wife, Thelma**, passed away on the 28th of January. I am sure I speak for all of us in extending our condolences to Alex and Sy. **Anne Kapiloff** is having a difficult recuperation at home following her recent hospital stay. **Pat Hopping** is scheduled for hip replacement surgery on April 6th. **Bernard Lalime** was hospitalized for seven days following a fall which resulted in a hairline fracture of the neck. He is now at home trying to figure out how to talk with an E/L while wearing a neck brace. Try finding a sweet spot through a neck brace. The good news is that **Mae Gerstenblith** is now back home enjoying her refurbished residence after her January adventure. Our treasurer **Len Weinstein** reports receiving another donation from **Marion McKelvey** in memory of **Bob Mazzei** who died three years ago. Congratulations to **Lynn Carrier** who recently celebrated her first wedding anniversary.

Pascale's meeting: No meeting. Pascale was out of town.
Penny's meeting: **Len Weinstein, Gary Morey** and **Larry Switzer** joined **Penny** and three couples from the H/N group in a discussion of Cancer Symptoms with the aid of a print-out from www.cancersymptoms.org. The website is designed for patients and caregivers to provide information on learning about and managing each of six common cancer treatment symptoms. This site has a wealth of information.

Lynn's meeting: **Aron Smith**, visiting from New Jersey, joined us. **Seymour Platt** reported he was given all kinds of supplies following his surgery but no instructions on their use or in the care of his stoma. **Len Weinstein** had trouble voicing for the past three weeks until a little light went on, he tried a longer prosthesis, and had instant voice. Lynn said she always measures before inserting a new prosthesis. **Bob Thomas** gave us his thoughts on the "Culture of Laryngectomy" in the February issue. Feedback was requested, but this was the first feedback. Also present were **Carl Kilmer, Gary Morey, Ralph and Doris Shadd, Paul and Florence Margolis, and Mike Rosenkranz**. **Lynn's next meeting will be on the 4th Thursday, March 24th**. This is only for March. Future meetings will be back on the third Thursday.

Margate meeting: **Bonnie Emerson**, our scheduled guest speaker, had to cancel her presentation due to an unplanned surgical procedure the day before our meeting. The surgery went well, Bonnie is okay, and her visit will be rescheduled. We had a very large turnout for the meeting, including first-timers Jerry and Ingrid Shapiro from the Kendall area of Miami. Jerry had his surgery at Sylvester on November 22nd. He and Ingrid were floundering until a chance meeting with Bernard Lalime put them in touch with our club. Earl Mogk reported on the ACS Advocacy trip. Florida has the second largest incidence of cancer diagnoses in the nation, and the ACS is requesting \$500 million in cancer research funding this year. This would be eligible for federal matching funds. Len Weinstein reported we have fifty-four paid-up members. The next meeting is at noon on Easter Sunday, March 27th.



March Birthdays



2nd Ana Maria Leveille	17th Sid Gellman
3rd Norman Leveille	18th Laura Winthrop
3rd Sam Schneiderman	24th Matty Matthews
4th Mike Rosenkranz	24th Joyce Robinson
12th Ralph Friedman	25th Earl Mogk
12th Linda Weiss	28th Karla McFarland
	29th Burl Blosser

Happy Birthday to All

UP-COMING EVENTS

? **FREE SPEECH THERAPY (1st Wednesday)**
(Coffee) with Pascale Bourne (Donuts)
Florida Medical Center - Auditorium
5000 W Oakland Park Blvd
Next Meeting - Wednesday March 2nd
10:30 – 11:30 a.m.
More information: (954) 735-6000 Ext 5307

? **FREE SPEECH THERAPY (4th Thursday in March)**
(coffee) With Lynn Carrier, CCC-SLP (cookies)
Boca Raton Community Hospital
DAVIS THERAPY CENTER
OAKS PLAZA - Glades Road at 13th Street
Next Meeting - Thursday, March 24th
10:30 – 11.30 a.m.
More information: (561) 955-5100 Ext 7430

UM/Sylvester/Deerfield

? **Tuesday, March 8th 1:30-3:00 p.m.**
Mort Silverblatt Head and Neck
Cancer Support Group
Facilitated by Penny Fisher

? **Wednesday March 9th, noon – 1:00 p.m.**
An Overview of Stomach and Esophageal
Cancers and Surgical Options
Eli Avisar, M.D. Assistant Professor
Division of Surgical Oncology

MARK YOUR CALENDARS

? **2005 IAL ANNUAL MEETING Boston, MA**
September 1-3 Boston Park Plaza Hotel
?
?
2005 FLA ANNUAL MEETING Orlando, FL
October 8-9 Sheraton Studio City Hotel

Anti - Tobacco

Duh, they must think our kids and grandkids are awfully dumb. Now they are marketing their cigarettes in flavors. What won't they think of next to create a new generation of laryngectomees.



Barbecue and Black Powder

by Logan Grayson

Hello to all! I was born sixty-five years ago in the little town of Ponca City in north central Oklahoma. I married my school sweetheart, Judy, when I was sixteen. We have one son, two daughters, thirteen grandchildren and another on the way, and sixteen great-grandchildren and another on the way....so far. Since we married so young, I had to find a job where I could care for Judy and our future family. I decided to join the service, but I had four uncles in the army during World War II, and heard them talk about sleeping on the ground and the food they had to eat, and I decided that when I went into the service I would go where I always had a bed and hot food. In 1957, at the age of seventeen, I joined a navy reserve unit in a town forty miles from me, went regular navy five months later, and retired in 1979 with twenty-three years of service.. We moved back to our home town to spend time with our families which we had left so many years before. I went to work for a Savings and Loan Association as their maintenance supervisor taking care of twenty-three buildings throughout Oklahoma. In 1995 they sold out to a large Savings and Loan in Nebraska, so I retired and started to enjoy life with my family.

I was diagnosed with throat cancer in 1997, and had a laryngectomy on February 7th, followed by thirty-one radiation treatments. So far, everything has been okay in all of my follow-up checkups, and Judy and I have spent a lot of time traveling and just enjoying our retirement. I found Webwhispers in 1998, and at that time I was the 103rd member to submit a biography. Living here in north central Oklahoma, I don't know what I would have done without Webwhispers. It was a year before I met another lary, and in eight years I believe I have only met five larys and talked to them face to face. A lot of things have changed for me for the better. We do a lot of family oriented things such as barbecue cooking in championship cook-offs throughout Oklahoma in which we have won a few first place ribbons. We do mountain man rendezvous (reenactments of the mountain man of the 1840's) where we shoot black powder rifle and pistol competi-

tions and tell tall tales and maybe even touch a shot of moonshine now and then. Of course, that's just a rumor. If I ever saw any of that myself, I'd have to report it to the Revenue Man. I have used the HME for about the last sixteen months. Prior to that I only used the foam filters. When my SLP found out I was doing black powder shooting, she gave me three boxes of HMEs and insisted I wear them when shooting. It seems she knew a little about shooting black powder and knew what your hands looked like after shooting up to twenty-five rounds a day, and told me not to put that dirty finger on my stoma. And yes, my HME is black when I get through shooting.

I met a feller on the Webwhispers forum three or four years ago by the name of Mike Rosenkranz, and have really enjoyed bantering back and forth with him as he is a hard act to follow and will get you in trouble in a heartbeat. He asked me to write an article of life as a lary in a small town in Oklahoma, and I thought who in the world would like to know what we do in this part of the country. But then what the heck, I enjoy my life as a lary as much as anybody else so why not? Here it is 2005 and I still enjoy my life as much as anybody else can whether lary or not. If you care to e-mail me, I am at loganlg@cableone.net My website is <http://myweb.cableone.net/loganlg/>

Larys and Clean Beds

An article in an issue of the *Headlines* newsletter some years back addressed one aspect of keeping the air reaching our lungs as clean as possible by discussing keeping our beds clean. In addition to changing the bed sheets and covers more often than we might have before becoming laryngectomees, there are some other things which might be considered.

We have learned that by becoming a laryngectomee the top half of our respiratory system has been cut off from the lower half. We lost the heating, humidifying and filtering effects of the nose, mouth and throat. Prior to the laryngectomy, the part of our respiratory system below the throat was considered to be medically "sterile" (germ-free under normal circumstances). This is no longer the case after becoming laryngectomees, so we are at greater risk for lung infections than before. Another interesting fact is that in non-laryngectomees their respiratory systems filtered and removed 90% of contaminants entering it within an hour. Now, the only thing between our lungs and the outside world is the short length of our tracheas and the mucus in it and in our lungs. That is the case unless we put something else in between them such as an HME (Heat/Moisture Exchange) fil-

ter, foam or cloth cover.

Another interesting fact which impacts many laryngectomees is that tobacco smoke kills respiratory cilia...the tiny microscopic hairs which propel mucus, and any contaminants trapped in it, upwards so we can cough it out. Without many respiratory cilia the conveyor-belt motion of the cilia is lost, and the only way we can get rid of the mucus is by forcefully coughing it out. This is why some laryngectomees need to use the irrigation (lavage) technique of using saline bullets or saline spray to introduce moisture into the trachea and lungs. This initiates the coughing necessary for them to clear their lungs. One way you can tell if you have adequately working cilia is if mucus "wicks" its way to the stoma, or there is always watery mucus just below the lip of the stoma.

At the insistence of the FDA (Food and Drug Administration), producers of HME filters advise laryngectomees to remove them during sleep. So if that advice is followed, laryngectomees only have foam and cloth filters to wear overnight. Wearing a stoma cover of some sort 24 hours per day is highly recommended by respiratory specialists who understand how the anatomy of laryngectomees has made us more vulnerable.

Although we are not aware of it, we human beings constantly shed skin. The outer layer dies and flakes off, to be replaced by new skin cells. Human skin (dandruff) is a major component of what we call household dust. And this dandruff accumulates in our bed sheets and blankets, and into mattresses. And the accumulation of dandruff attracts microscopic animals which feed on it - dust mites. Both human dandruff and dust mites are a source of allergic reactions for many. And if this material is breathed in, our systems must get rid of it. So reducing it, particularly around our beds, is a good idea.

As mentioned, a way to help the situation is to change the bed sheets and blankets weekly. Another suggestion is that while the bed sheets are off the bed it is a good idea to vacuum the top of the mattress, paying particular attention to the seams. Doing what we can to keep our stomas covered and reducing the contaminant load our respiratory systems must remove should make us all breathe a little easier.

Reprinted from the Webwhispers Journal, January 2003

From the Web

From a Webwhispers post by David Blevins on 12-27-04
TEP users ARE more prone to aspiration pneumonia than traditional esophageal or AI speakers since leaks occur around and through prostheses. While ES and AI speakers can certainly spill something down their stomas, TEP users are at a greater risk for aspiration pneumonia because of this connection between their esophagus, stoma and lungs.

One of my major concerns for some larys is their attempts to minimize or even eliminate their mucus flow. This is a major mistake. Mucus is probably among the biggest complaints larys have, perhaps second only to problems in voicing. Our having to manually eliminate mucus (before becoming larys it was handled automatically through swallowing, etc.) is certainly a major consequence of becoming a lary. But this vitally important role mucus plays in helping maintain the health of our airways reminds us that mucus is not really a problem, but the SOLUTION to help clean out our lungs, as well as a symptom that the air reaching our trachea and lungs is probably dirtier, colder and drier than our lungs want and that, therefore, we should do what we can to improve the quality of that air. We do that by wearing covers over our stomas and increasing the humidity of the air we breathe.

From the Mail

From Doris Littlefield, Subject: Emergency ID

Take a look at this website --www.roadid.com ---- it is a company that makes inexpensive ID's that can be a dog-tag type or a bracelet or anklet or shoe thing. They are good looking utilitarian kind - not jewelry - and very reasonably priced. I just ordered a dog-tag for myself with the necessary lary info on it - 6 lines of 23 spaces each. Cost for dogtag = \$24.99 stainless steel. It's a good alternative to the usual medic-alert bracelet and can carry a lot more needed emergency information.

My son in MA was out running at dawn and fell and knocked himself out on a cement curb and no one knew who he was! It all turned out OK and he only had a slight concussion but it was scary. So we found this website -- roadid.com and he ordered for himself and 3 kids who hike, ski, etc etc. But besides being a good idea for athletes, I think it's a great idea for larys to wear whenever we're out and about! Spread the word! DORIS

**I am not afraid of dying
I am only afraid of not having lived**