

New Voice News

New Voice Club of Broward County

Serving the tri-county area

www.newvoiceclub.org

February 2005

Mike Rosenkranz, Editor



NEXT
MEETING
Sunday
February 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

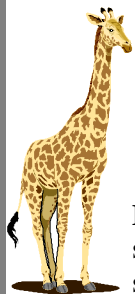
Patty Sewell

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

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

12:00 1:00

Rap Sessions Meeting & Program
Refreshments after Meeting



Best wishes to all for
a Happy Valentine's
Day from Lary, our
friendly giraffe.

MARK YOUR CALENDARS

Next Margate meeting
February 27th at noon

President's Message

FLA AM: Nothing is written in stone, (no contracts have been signed), but the 2005 Annual Meeting of the FLorida Laryngectomee Association is planned for the Sheraton Studio City Hotel, 5905 International Drive in Orlando.

www.sheratonstudiocity.com The dates are October 6th, 7th and 8th. It's a great venue, 302 oversized sleeping rooms with pillow-top mattresses, art deco decor, good meeting rooms, great entertainment, dining and shopping at your doorstep. The hotel is easy to get to, near the turnpike and I-4. Complimentary transportation is offered to Walt Disney World, Universal Studios and SeaWorld. The hotel has a fitness center and hair dressing salon in addition to a restaurant and lounge. Discount coupons will be available for local outlet malls. You can't register yet, but please plan on it. Look for Registration forms in the March FLA Newsletter.

Best wishes, Carl Kilmer, President

Bonnie Emerson, SLP, will demonstrate the Griffin Laboratories Tru-Tone, Sola-Tone, and TeliTalk speech aids at our February 27 meeting. Bonnie will adjust these instruments as needed, and help members with the application process for the TeliTalk, which is available to Florida residents through the FTRI. She will also be available for a brief

period at the end of the meeting to troubleshoot and answer individual questions. Most of us have taken advantage of this program. If you have not, now is the time to do it. The Teli-Talk is a great backup for your primary form of speech, and it's free.

Looking Back

Looking back just prior to my laryngectomy, it is very difficult to know just exactly what I was thinking. My doc had told me that he was going to make a fistula for me that would hold the TEP which I now use. Nobody really gave me any counseling to speak of. The only thing I did know was when I woke up I would no longer have my voice to use. Was I scared at the time? I guess I was. But the realization of waking up with no voice was very hard for me to comprehend. And then twelve hours later I did wake up, and had no voice. Darned if I didn't want to scream, but nothing came out. After the recovery room, they wheeled me into my regular room, and I started at that point to communicate with a pad of paper and a pen. It wasn't till after I got home from the hospital that Earl and Wini came to my house on Christmas Eve and Earl presented me with a Servox. I used it that night to say Merry Christmas to my wife, kids and grandkids. This was the beginning of being a lary for me.

Pat Hopping



CLUB NEWS

Our thanks for paying your dues. Checks payable to
New Voice Club of Broward should be mailed to:
Leonard Weinstein, Treasurer
(\$10 for two) **1427 E. Hillsboro Blvd # 529** (\$7 for one)
Deerfield Beach, FL 33441

Sunshine: Anne Kapiloff is recuperating at home following a long hospital and rehab confinement. Micki Lindenbaum is recovering from her mini-stroke and doing well with only a few minor problems. She is back to driving, and will be back to tennis and bowling shortly, but sometimes has difficulty remembering the right word. A lot of us have the same problem, and that is without having had a stroke. Mae Gerstenblith is well, but staying at an assisted living facility while repairs are completed to her apartment. A series of leaks necessitated the repairs. Thelma Falk, Sy's wife, is home from the hospital. She is bedridden with several critical problems. Ramon Cruz is doing better after multiple hospital stays. Our thoughts and prayers are with them. Pascale's meeting: Present were Elaine Brown, Lenny Weinstein, Earl and Wini Mogk, Al Smith, Pat Hopping, Gary Morey, Mike Rosenkranz, George Hill and his aunt, Elsie Schreiffer. This was the first meeting George had attended since his surgery, and he was speaking well with his loaner and an intra-oral attachment. Elaine has had problems with her prosthesis and is ready for a new one. Lenny announced that the club has received a generous donation from Broward ENT of Plantation. Pascale said Dr. Reed will give us advance notification of scheduled laryngectomies, which will allow us to see his patients pre-op. Penny's meeting: In Penny's absence, the meeting was facilitated by Marty Mash, who led a general discussion. Present were Lenny Weinstein, Gary Morey, Matty Matthews, Warren Goodman and another couple. Lynn's meeting: Doris Littlefield attended her first meeting in some time and said she is feeling much better. We had two first-timers, Francisco Suarez and his wife Bruni, and Anthony Russo and his wife Judith. Both men are TEP speakers, but Anthony was having trouble voicing. Lynn to the rescue, aided by many suggestions from those present who included Lenny Weinstein, Bob Thomas, Gary Morey, Paul and Florence Margolis, Seymour Platt, Carl Kilmer and Mike Rosenkranz. Margate meeting: Our guest speakers Tom and Dorothy Lennox of Luminaud, updated us on several new products, demonstrated their new 9V adapter for the Servox, supplied catalogs, sample stoma covers and tweezers, and gave prizes to the three lucky winners. Dorothy discussed several Medicare changes and the best way to file claims. We welcomed our newest members, Howard and Dian Grabowski. Howard's surgery was December 14th, and he will be using a TEP for his alaryngeal speech. We also welcomed Anthony and Judith Russo who had joined us at Lynn's meeting and were at the Margate meeting for the first time. The meeting ended with Gary Morey installing our new slate of officers.

February Birthdays

1st Rose Donovan	9th Larry Wiederhorn
3rd Hilda Demps	12th Sue Rosenkranz
7th James McGuire	13th Penny Fisher
7th Eugene Pinard	14th Fletcher Wimpey
7th Seymour Platt	21st Paul Margolis
9th Kathy McFadden	23rd Thelma Falk
9th Irma Schad	25th Betty Dyer
	28th Rita Verdiglione



Happy Birthday to All



UP-COMING EVENTS

SPECIAL NOTICE

**The February Meeting
facilitated by Pascale Bourne
has been cancelled**

**Her next meeting
Will be March 2nd at 10:30 a.m.
In the Florida Medical Center Auditorium**

FREE SPEECH THERAPY (1st Wednesday)

(Coffee) with Pascale Bourne (Donuts)
**Florida Medical Center - Auditorium
5000 W Oakland Park Blvd**

**March Meeting - Wednesday March 2nd
10:30 - 11:30 a.m.**

More information: (954) 735-6000 Ext 5307

FREE SPEECH THERAPY (3rd Thursday)

(Coffee) With Lynn Carrier, CCC-SLP (cookies)
**Boca Raton Community Hospital
DAVIS THERAPY CENTER**

**OAKS PLAZA - Glades Road at 13th Street
Next Meeting - Thursday, February 17th
10:30 - 11.30 a.m.**

More information: (561) 955-2100 Ext 7430

UM/Sylvester/Deerfield

Tuesday, February 8th 1:30-3:00 p.m.

**Mort Silverblatt Head and Neck
Cancer Support Group
Facilitated by Penny Fisher**

MARK YOUR CALENDARS

**2005 IAL ANNUAL MEETING Boston, MA
September 1-3 Boston Park Plaza Hotel**

**2005 FLA Annual Meeting Orlando, FL
October 6-8 Sheraton Studio City Hotel**

Anti-Tobacco

Earl Mogk is a one man anti-tobacco dynamo. I accompanied him on only two of the many days in which he carried his important message. On our first day he picked me up at 8:15 a.m. On that day, he addressed a dozen teenagers who had violated the Coral Springs ordinance on under-age smoking. On the second day, I was picked up at 7:15 a.m. On that day, he addressed about sixty recovering addicts at the Broward Addiction Recovery Center. By now, those of us who have been paying attention are well aware that cigarette smoking is an addiction. **Want to join the fight?** Contact the ACS at 954-564-0880 and tell them you want to be an anti-tobacco volunteer. You may also volunteer to join Earl on one of his talks. We do need more volunteers, so don't be bashful.

Mike Rosenkranz

This article is from the 10-18-04 issue of *ADVANCE* for Speech-Language Pathologists and Audiologists. The writer has requested feedback. Her study group consisted of seventeen laryngectomees. This News is mailed to over 110 laryngectomees, caregivers, and professionals. It will be interesting to compare the thoughts of our readers to the study's findings, so **Please Email your comments to Mike Rosenkranz, smike24@comcast.net or see him at a meeting.**

The Culture of Laryngectomy **Patients share beliefs and approach to living** By Linda K. Glazer, DSW

The concept of a "laryngectomy culture" first was introduced by David Myssiorek, MD, an otolaryngologist at Long Island Jewish Medical Center. A laryngectomy culture is a system of shared beliefs and an approach to living shared by patients who have undergone a laryngectomy. The concept of a laryngectomy culture has never been documented before, but we believe sharing this knowledge will enhance the feelings of validity and well-being of laryngectomees.

Individuals sharing this culture are not all alike. They represent a variety of demographic, socio-economic and religious backgrounds. However, they share common similarities after experiencing the invasive laryngectomy surgery.

At Long Island Jewish Medical Center we are especially concerned about sharing this information with laryngectomees who are elderly, socially isolated, and at risk for depression.

We hope that sharing this material will raise the self-esteem and quality of life of these patients as they realize their feelings are part of a culture and need not involve feelings of shame.

Some of the salient features observed by the laryngectomy culture involve appearance, socialization, holidays and events, religion, humor and sex.

It is very important for a laryngectomee to be neat and well groomed. Many patients wear stoma covers to complement their outfit, begin to exercise, and feel it is especially important to be proud of how they look.

Our members feel that socialization and connecting with others is necessary, fun and therapeutic. Social isolation is very negative and needs to be avoided.

Holidays and family events need to be recognized and celebrated, not avoided. Celebrations are not to be taken for granted; they often become more meaningful and special.

Many laryngectomees indicate they value religion even more than before their surgery. They find religion to be a valuable source of strength.

The laryngectomy culture values humor and encourages members to utilize their humor as a coping tool.

Finally, laryngectomees favor a positive yet cautious attitude toward sexual relations, and members encourage each other to maintain a healthy body image.

In addition to the laryngectomy culture, there are lifestyle attitudes that promote positive coping skills. These attitudes revolve around topics ranging from safety, communication and advocacy to clothing, finances and family issues.

Safety is always the first priority. It may mean carrying an emergency case with extra batteries, normal saline, tissues, a spare Servox[®], etc. Notifying their community fire department and police station about their condition is vital for emergency precautions. When in doubt, laryngectomees should go to the emergency room if they are having any difficulty breathing. While this seems so obvious, patients often feel embarrassed to do so.

Individuals must be tenacious if they are misunderstood when communicating. They should maintain eye contact to assist the listener.

Laryngectomees should not personalize a stare. Many people have never heard a laryngectomee speak or seen an electrolarynx. Some people may be frightened at first, especially if the laryngectomee has a loud cough. The individual should explain that he or she is a laryngectomee.

Laryngectomees need to be careful when traveling. They should carry a portable humidifier and explain to airport security and flight attendants what the Servox is. Before going through security, an individual should explain he or she is a laryngectomee. The flight attendant can be told that the passenger is a "neck breather."

Laryngectomees can obtain a decal from the American Cancer Society for their car. In the event of an accident, the decal will let emergency medical personnel know a person's neck breather status.

<p>Telephones need not be intimidating. Individuals should disregard instances when people think they are a machine and explain at the beginning of the conversation that they are laryngectomees. Care is needed when making clothing choices to make sure the stoma is always covered. Laryngectomees should wear cotton scarves rather than polyester, which does not breathe. When eating out, individuals should choose restaurants that are not very noisy. They should request a corner table, maintain eye contact, and avoid bending over and dancing immediately after eating. Laryngectomees should be proud of who they are and the fact that they have faced the challenge. They should share their strength with other laryngectomees. Their abilities on a good day may be exactly what the other person needs to keep going. Coping skills will help people deal with other losses in their life, such as health, finances and family. Their strength and ability to negotiate health systems and insurance companies will be utilized many times. Partners, spouses and children feel the pain of laryngectomees and share in their success. What hurts people with laryngectomy, scares them, and gives them strength is reflected and absorbed into their family's emotions as well. Laryngectomees should not forget the needs of their family. Their health issues may be even more intense, and their need to connect with the person is just as strong as that of a colleague. Finally, laryngectomees should maintain close contact with their support team, which consists of their surgeon, speech-language pathologist and mental health provider. Individuals will be more effective in confronting difficult and challenging situations if they have support from their team. In an effort to further explore the premise of the laryngectomy culture, the North Shore Long Island Jewish Health System conducted a survey of its laryngectomy groups. We utilized feedback from group members at the Long Island Jewish and Plainview locations. Although our sample consisted of just 17 people, the results reflect trends seen in a laryngectomy culture and the importance of a support group. In addition, the survey highlights the true sense of camaraderie that all of our respondents experience as well as a sense of shared identity. Most importantly, all respondents agreed it is very important to share the concept of a laryngectomy culture with a new laryngectomee.</p>	<p>When asked if they believe there is a laryngectomy culture, i.e., a series of beliefs shared by people who have had laryngectomy surgery, 13 respondents said yes. The same number said they believed another laryngectomee understands them better than their friends. All 17 members said becoming part of a laryngectomy group or culture had enhanced their life. All of the respondents believe there is a brotherhood or sisterhood bond among laryngectomees, and all feel an automatic sense of shared identity when they meet another laryngectomee. None of the 17 survey participants reported having a problem with the label "laryngectomee." A dozen respondents said there are personal issues regarding their laryngectomy that they would discuss with another laryngectomee before anyone else. The same number feels that the shared experience of being a laryngectomee leads to a greater level of trust among laryngectomees than one would have with the general public. Asked if they think their friendship with another laryngectomee is deeper and different than with their other friends, eight responded yes, while nine said no. Six survey participants said they feel more comfortable socializing with other laryngectomees than the general public, while 11 said they didn't. All 17 said sharing information about laryngectomy culture, such as common thoughts and perceptions, with a new laryngectomee would be helpful. In conclusion, we know there are variations within each culture stemming from socio-economic, demographic, employment and religious differences. However, the commonalities within a culture create an important bond. Having laryngectomy surgery is the beginning of a new chapter in a laryngectomee's life. Leading a positive lifestyle and coping with possible setbacks is a challenge that is more easily obtained with peer support and knowledge of the laryngectomy culture. On behalf of the laryngectomy community, I appreciate your support in sharing information about the laryngectomy culture as we strive together to enhance the quality of life for our patients. <i>Linda Glazer is on staff at Long Island Jewish Medical Center in New Hyde Park, NY. She can be contacted at LGlazer@LIJ.EDU</i></p> <p><i>This article has been reprinted with permission from ADVANCE Newsmagazines</i></p>
--	---