



The New Voice News



New Voice Club of Broward County
Serving the tri-county area
www.newvoiceclub.org

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A Message from your President

Wow! What a great meeting we had on February 18th. We had a very nice turnout and the pleasure of having Tony Talmich, a longtime member from Miami. He spoke so beautifully with his electro larynx and then demonstrated how a hands-free unit works. Nancy, a physical therapist from HealthSouth, showed us some very helpful stretching exercises that most of us really need. Both presentations made for a great meeting.

The format of our meeting has changed. The rap sessions now run from noon to 12:30. A light lunch will be served at 12:30, followed by our program at 1:00. So you folks out there who do not attend our meetings because they may have interfered with your normal lunch time, we now make life easier. And talking about making life easier, that is what our group is all about. There are so many of us who really attribute our ability to speak understandably directly to the club..

We were again graced with five young ladies (SLP students from Nova) who stayed with us for the entire meeting. This was their first exposure to laryngectomees, so once again we have managed to spread the word. Folks, all the above is to keep you posted on what is going on, with the hope that you will join us each month for an afternoon of information and relaxation.

Warren Goodman

Our Members Speak

My name is Richard Willenborg, born in Wheaton Ill. in 1941 on Sept. 27th. Moved to Florida in 1947, and have lived here since. I had a good life as a child and enjoyed it. Started to smoke at an early age, twelve years old, and smoked for the next forty years. Approximately fifteen years ago, I was told that I had cancer in my mouth, and subsequently had to have surgery to remove the cancer, followed by radiation. Everything went fine – except, of course, I continued to smoke and drink. Ten years later, I had a sore throat which turned out to be cancer. I had to have surgery again to remove my larynx and lymph nodes by Dr. Weed from UM Sylvester which was successful. Six months later I had a TEP and prosthesis installed and everything went okay

A year went by, and I was not informed to have any follow-up exams, so I went to my doctor who ordered an MRI. At that time, they saw a spot on my right lung which turned out to be cancer. I had surgery once again, and they removed my lower right lobe. So far, I am doing my normal activities, and I found a lot of support from the New Voice Club by discussing problems with the change of lifestyle and associated problems. The group helped by making suggestions on how to accept and deal with day to day situations, and gave very informative advice. I am still active and getting along very well and doing most of my normal activities. If you have a positive attitude, things will go well for you. Good luck.

Richard Willenborg

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What's Doing Around Town

At Pascale's meeting last month, a small group of dedicated members discussed various issues experienced by individual laryngectomees. The group was then treated to a viewing of John Lubelski's video which fully explained the technique and equipment he had invented to enable him to swim on and below the water's surface. The device is comprised of the top half of a diver's wetsuit, fitted with a variable size tracheostomy tube connected to an oral fitting. Mr. Lubelski showed how it is possible for a total neck breather, using his invention, to hold his breath while submerged, and to, once again, be able to carefully enjoy immersion in the water.

Penny Fisher prepared a program about the causes and relief of upper respiratory infections (especially colds), which are so common in the Head and Neck Cancer patient and present unique problems for dealing with complications. This was followed by a discussion about xerostomia (dry mouth and mucous membranes) initiated by a recent radiotherapy patient who had difficulty relieving the symptoms.

Unfortunately, Lynn Carrier was unable to facilitate the Boca group last month as she, herself, had an upper respiratory infection. However, the laryngectomees attending, conducted a lively discussion on a variety of topics, including various stoma coverings and attachments. Myrna Glassberg shared her experience attending the Super bowl last month, compliments of a neighbor with whom she had become acquainted during her morning walks.

A large group of over thirty members attended the NVC main monthly meeting, and were treated to a presentation by Tony Talmich who demonstrated his talents with the TruTone electrolarynx, and his invention of the hands-free device to activate it and enable full expression without the need to use his hands, freeing them for other activities. Congratulations to Tony and Laura on their upcoming nuptials next month! We then enjoyed a presentation by Nancy, a HealthSouth physical therapist, who explained the needs, techniques and benefits of neck stretching exercises, especially for relief of post-surgical stiffness and soreness. Attend these meetings and be an informed laryngectomee. You never know when what you learn will be needed by you or a fellow member.

The lower half of page one of this Newsletter is the place we reserve for Our Members Speak which features contributions from fellow members. Items are needed for this feature, and we welcome your individual contributions, up to a full page in length. It may be biographical, a humorous incident, a personal experience, your thoughts on being a lary, what the club has meant to you....whatever you care to write.

We are soliciting new ideas for club projects and all offers to become an active worker. We have a large membership, but few active volunteers. Please contact Mike Rosenkranz with your ideas, and your offer to become an active worker. His phone number and email address are at the top of page one.

Upcoming Events

Main Meeting 3rd Sunday of each month

Next meeting March 18th 12 - 2 p.m.

Rap Sessions at 12 Light refreshments at 12:30

Meeting and Program at 1

HealthSouth Rehabilitation Hospital

4399 Nob Hill Road, Sunrise, FL 33351

(SW corner of Nob Hill and NW 44th St)

(between Commercial and Oakland Park Blvd)

Look for the New Voice Club Banner

Free Speech Therapy

HealthSouth Rehabilitation Hospital

4399 Nob Hill Road, Sunrise, FL 33351

Miriam Paul, MA, CCC-SLP

Pascale Bourne MA, CCC-SLP

1st Wednesday of each month

Next Meeting - March 7th

"Swallowing Disorders"

10:30 - 11:30 a.m.

More information: (954) 746-1340

Free Speech Therapy

Boca Raton Community Hospital

Davis Therapy Center

Oaks Plaza, Glades Road at 13th Street

Lynn Carrier MS, CCC-SLP

3rd Thursday of each month

Next Meeting - March 15th

10:30 - 11:30 a.m.

More information: (561) 955-2100 Ext 7430

Veterans Medical Center

7305 N. Military Trail

West Palm Beach, FL 33410

Loreen Blumenthal, M.S.P.A., CCC-SLP

Veterans Laryngectomee Group

(Veterans & family members only)

2nd Thursday of each month

Next Meeting - March 8th

11a.m. - 12 noon

More information (561) 422-6237

UMSylvester/Deerfield

Comprehensive Cancer Center

1192 East Newport Center Drive, Suite 100,

Deerfield Beach

Penny Fisher MS, RN, CORLN

Mort Silverblatt Head and Neck

Cancer Support Group

2nd Tuesday of each month

Next Meeting - March 13th

"Swallowing in Head & Neck Cancer Survivors"

1:30 - 3:00 p.m.

More information (305) 243-4952

Don't Let The Turkeys Get You Down

Some things never completely go away it seems, no matter how much progress we think we've made over the years.

Following my laryngectomy, TEP was not yet available, and EL was necessary, though far from my chosen goal of esophageal speech. While healing, going through radiation and resuming my family responsibilities, I used an electro-larynx. My employer deleted my job from the budget. My fellow employee/friends told me it's the machine...he thinks a concierge using it would be off-putting to the public. When I challenged him, I was offered another part time job as the coffee shop cashier. No offense to cashiers, but I couldn't see how that was easier for me to handle with the EL in one hand...or less off-putting to the same hotel guests?

Next I decided to take a very seasonal job wrapping gifts in our best department store. Since half of my family had already left the nest, I had fewer packages to wrap at home. My wrapping station was in the middle of the store. People (including the store's general manager) would stop to watch me wrap unusual packages; such as a six-sided hat box. After the holiday rush, much to my disappointment, I was not hired permanently, or even kept on to help with year end inventory. It was the EL, and the assumption that the public would not like it...again. Sometime later the newspaper carried a full page article about this same man, celebrating him as a war hero and told about his disabilities. Apparently he didn't learn a thing.

While shopping at the haberdasher's that my husband and grown sons used, I related what had been going on with the other local merchant and hotel/conference center. He had known me for several years as I selected clothing and gifts for my family. He invited me back to his office and told me about their second store that would include a ladies shop in a huge new shopping center that was opening soon. Would I be interested in a position as a wardrobe consultant? EL and all. Of course I took the offer. It went well. The customer's children loved to find out about the EL. The local newspaper ran a full page article about me (photos and all) with my R2D2 robot sounding EL. Bless "Star Wars"!

The trouble started when I began to master esophageal speech and the bloom was off the rose called EL. The woman who was my supervisor took me aside and bluntly told me to continue using the "thing" or quit. Well, ...when someone tells me "my way or the highway" my choice is very simple. I'll take the highway every time. After all, my primary job is to take care of

my life, not the store's profits. I was looking for a job when I found this one. The downtown manager was very disappointed that the ladies division had taken this stand with me, but understood my choice.

A regular customer had offered me an opportunity, and slipped her card into my suit pocket a few weeks before this turn of events. I called for an appointment, and ended up with a business of my own as an art and room accessories decorator. The public loved my work and the EL was not a problem; not even once. Three years later another business opportunity was offered and I soon had a second business of my own.

All the while I was teaching alaryngeal speech on the side on request. Eventually that rose to the surface as my main occupation, the other two fell into the background and soon I just maintained my connection to former customers addressing their needs.

The point I want to share with you, and our WW friends, is this is a new day. Now you have the ADA (American Disabilities Act) behind you for employment and volunteer work. (Oh, I forgot to mention that following hospice training for 10 weeks, they never once asked me to visit anyone because I "would not be understood, and it would be too depressing for the patients".)

Please, keep on keeping on! You will find your niche. Somebody out there needs what you have to offer. You will know it when it feels right to you. Good luck and good health as you continue responding to the needs of others. Go back to some of the things you did pre-op for leads. I worked as a volunteer in my children's grade school library, and in 'language skills tutoring'. From that connection I ended up speaking to health classes about laryngectomy rehabilitation. The kids loved learning to use my EL during our sessions. They ask the best questions. Priceless.

From a WebWhispers Post by Elizabeth Finchem

I am not handicapped, I am inconvenienced. We have all been through many trials, it's just this one is more obvious. Let's rejoice in our lives and help others cope with their less obvious problems. *From a WebWhispers post by David in Raleigh, NC*

MARK YOUR CALENDARS

UMSylvester/Deerfield

Tuesday March 13th at 1:30 P.M.

**Swallowing in the Head and Neck Cancer Survivor
Presented by Dr. Donna Lundy**

Tuesday, April 17th Presented by Penny Fisher

Head and Neck Cancer Awareness week

12 noon conference Head and Neck Cancer 2007

1:30 p.m. Continued discussion at support group

Reservations required: 1 (800) 545-2292



March Birthdays

2nd Ana Maria Leveille 18th Laura Winthrop
 3rd Norman Leveille 24th Ron Coquelin
 3rd Sam Schneiderman 24th Joyce Robinson
 4th Mike Rosenkranz 25th Earl Mogk
 6th Janet Hernandez 28th Karla McFarland
 12th Ralph Friedman 29th Burl Blosser
 17th Sid Gellman 30th Dorothy Kurainowicz
 31st Theresa Smith

Happy Birthday to All

Talking on the Telephone

How many of you are really comfortable answering and speaking on the telephone? What if there were an emergency in your home and you had to call for help?

Here are some tips to aid effective communication

- * Choose two or more friends who understand your speech face-to-face, and ask them to practice with you on the telephone.
- * Hold the mouthpiece of the phone next to your lips, no farther than one inch away. Never let the mouthpiece drop below your chin or it will transmit breathing noise from your stoma or EL vibration.
- * Be sure to speak slowly and more distinctly than ever. Remember, your listener cannot read your lips over the phone!
- * Use short, precise phrases as needed, or choose different words to convey your thoughts, and be willing to repeat phrases as needed.
- * Consider a good quality speaker phone

Kathleen Wesson, MA, CCC

Musings from the Editor

January 6th was the 8th anniversary of my lary surgery, and I have been speaking with an EL for all those years. The only time I think of my voice as robotic is when I am having fun with a telemarketer and informing him I am the family robot and the family is not accepting calls at this time.

I never have a problem with my voice. Occasionally, others have a problem with it, but that is their problem, not mine. When that occurs, I will over-enunciate and speak slowly, and that invariably solves their problem. Yes, I have had people hang up on me, but I simply hit the redial button and try again. Yes, I have had people who do not understand a word I may use, so I will use different words so they can understand what I am saying. It is my way of educating those who are unfamiliar with our manner of speaking.

Mike Rosenkranz

Cancer Surgery Without Incision



Anyone diagnosed with cancer knows receiving treatment can be terrifying. But the worst may be throat and neck cancer. In this case, surgery leaves patients with disfiguring scars and speech problems. Now, as 7's Diana Diaz shows us, there may be an oral cancer answer.

WSVN -- For Joan McCauley, this is unfortunately not her first time in a hospital bed. Twenty years ago, she had tongue cancer surgery.

Joan McCauley: "The recovery from my first surgery for tongue cancer was -- it was very raw. It was a raw area. It was tender, and it was painful, to be honest." Now, Joan's having the same surgery again. "This is the last one, hopefully."

But this time, a robot will be doing much of the work. Dr. Gregory Weinstein: "The back of the tongue, we're cutting right now."

While surgeons used to cut across the throat to remove the tumor, now the new robot works inside Joan's mouth, so the only incisions are small and the side effects minimal.

Dr. Weinstein: "Now, we do remove the entire tumor, but we don't have to do things such as wide incisions on the neck, or breaking or splitting the jaw bone and moving the tongue aside."

The procedure works best with two doctors - one at the console, the other by the patient's side. They can then maneuver the robot's three multi-jointed arms and watch the surgery on a 3-D computer monitor

Dr. Weinstein: "The robot allows me to move my hands like a joystick on the robotic console, and it's as if my hands were made this small, and I could get them right into the mouth to do the operation."

For patients, the robot also means losing less blood. Plus, they're able to talk and swallow easier because there's no cutting.

Dr. Weinstein: "We're now able to do the surgery with decreased side effects."

Joan couldn't be happier. Not only was her surgery successful, but her life will soon be returning to normal.

By the way, doctors are also able to perform the procedure in less time. Whereas the surgery used to take 15 hours, it now takes about three with the robot.

Reported by Diana Diaz

FOR MORE INFORMATION: University of Pennsylvania
1-800-789-PENN