

WebWhispers

Internet Laryngectomy Support

January, 1999

Welcome New Members!

Lisa Born

Salem, MA
elsie1888@msn.com

Bruce & Elaine Bunnow

St. Louis, MO
ElaineBRB@aol.com

Duncan Bruce III

Conway, MA
dbruce@javanet.com

George Dolan

Tucson, AZ
gdolan@concentric.net

Paul Eickermann

North Pole, AK
gofor@mosquionet.com

Mark Finrock

Lauder Enterprises
San Antonio, TX
mark@voicestore.com

Marlin Hummel

Clackamas, OR
Rolandel@juno.com

John Johnston

Westville, NJ
jjohns2708@aol.com

Bob Kelley

Santa Clara, CA
Bob5436@aol.com

Continued on Page 2

A Laryngectomy Does Not Diminish Us!

By: Herb Simon

In my experience with laryngectomees since my own operation, I have come to realize that most of us are just like we were before the operation. We have the same strengths and the same weaknesses as we had before. All of us can do whatever we put our minds to if we have the faith and will to do it.

I sell real estate in Maryland and Virginia. I was diagnosed with cancer of the larynx in October, 1994 and underwent six weeks of radiation. My voice returned to normal for a short time until the cancer reappeared. I had a total laryngectomy in June, 1995.

At that time, I actually thought that I would never be a salesman again. I thought that without my natural voice, which was deep and resonant, I would be rendered ineffective. After my surgery, I grew physically stronger, but I was still suffering from a fear of the unknown about my new voiceless self. I was speaking with a Servox electrolarynx with an oral adapter. I was embarrassed when I went shopping and would use handwritten notes rather than draw attention from those within earshot. It didn't take me long to figure out that others didn't have a problem with the way I sounded. I was the one who had the problem!

I began going to the closest support group, the Nu Voice Club of Northern Virginia in August. That was a great boost to my morale. In September, I also joined the Laryngectomy Club of Montgomery County in Maryland. I highly recommend joining a support group to any laryngectomee, whatever his/her situation is. I am still an active member of both clubs today.

The first week in October was the first time I was able to speak with the Servox without the oral adapter. Suddenly, as if a miracle had occurred, I was able to speak and be perfectly clear and understandable to most people. My self confidence began to return. I returned to selling real estate on October 20, 1995 and made my first sale on the day before Thanksgiving. I sure had a lot to be thankful for! Once I had made all the adjustments and learned about my new self and produced my first sale, I completely let go of any fears about the future that may have remained. I still speak with a Servox and I continue to be successful in my profession.

One of the members of our Virginia Club sells new and used trucks at a Ford dealership in Northern Virginia has also picked up where he left off before his operation. He and I are still salesmen. Although we have lost our natural voices, we have not lost our knowledge of sales, our determination or our ability to communicate. We may sound different but what we say is much more important than how we say it. After most customers have talked to us for a while, they don't even think about how we sound.

Herb Simon lives in Silver Spring, MD and can be reached at H457@aol.com.

Welcome New Members!

Dawne Ledoux

Spring Hill, FL
dawnep@hitter.net

Peter McCole

Larchmont, NY
oleguy@email.msn.com

Karen V. Myers, M.A., CCC

San Antonio, TX
KVMYERS@stic.net

E. John Norris

Garland, TX
ejn@gte.net

Sally North

San Antonio, TX
mooser@texas.net

Kathy Porteau, Speech Pathologist

Toronto, Canada
kathy_porteau@cancercare.on.ca

Brian Russell

Johannesburg, South Africa
lyceum@global.co.za

Jim Sansing

Pensacola, FL
sansing@juno.com

Fred Thomas

Elmira, NY
thomas@hitter.net

Edna Tiernan

W. Des Moines, IA
MollysMum@aol.com

John D. Ure

Naples, FL
j.d.ure@worldnet.att.net

Michael R. Welsh

Rockhill Furnace, PA
mwelsh@penn.com

Botox in Speech Therapy

By Carla DeLassus Gress, Sc. D., CCC-SLP

Botox is an injectible medication which is used in a variety of disorders. It is essentially a toxin, derived from the organism that gives you botulism (food poisoning). Its action is to interrupt the transmission of a nerve impulse coming to the brain to activate a muscle. When a very small amount is injected directly into the muscle, it prevents it from contracting, resulting in a "weakened" but not totally paralyzed muscle. Its effects tend to last about three to six months, at which time another injection needs to be done. Occasionally its effects last permanently.

Botox is being used to help laryngectomees who are experiencing difficulties with tracheoesophageal speech. Some individuals have a spasm (over contraction) of the throat muscles which prevents the air from passing from the prosthesis to the vibrating area of the throat and then out the mouth. Injecting Botox into the throat muscles causes them to weaken, preventing the spasm. The voice is then more fluent because of the improved flow of air through the esophagus and pharynx.

The other ways to deal with the spasm which have been in use for considerably longer are a pharyngeal constrictor myotomy and pharyngeal plexus neurectomy. The myotomy is a surgical procedure in which the muscles are cut to prevent their contacting. This can be done at the time of the laryngectomy or anytime later. The neurectomy is a surgical procedure done at the time of laryngectomy in which the nerve controlling these muscles is cut on one side.

Botox is also sometimes injected into the vocal cords for a condition called spasmodic dysphonia in which the laryngeal muscles are in spasm and the voice sounds strained or strangled.

Carla DeLassus Gress, Sc. D., CCC-SLP is Associate Clinical Professor at the Mt. Zion Medical Center of the University of California at San Francisco and is a frequent contributor of very thoughtful commentary to our WebWhispers group. She can be reached at carlag@email.his.uscf.edu.

CAL Golf Tournament

Member interested in participating in a CAL-sponsored Golf Tournament at the 1999 IAL Annual Meeting in Reno, NV should contact **Jack Henslee** at **jhenslee@earthlink.com**. Jack is Host Committee Chairman.

Tentative plans call for an invitational open to both men and women with a shotgun start on the afternoon of Friday, July 16th. All attempts will be made to accommodate both handicapped and non-handicapped players with separate flights or a team format.

Let Jack know the names and the addresses of the players and their handicap status.

Tidewater Club Page

Frank Morgan has created a very attractive Home Page for his Tidewater Lost Chord Club. It is located at **<http://hometown.aol.com/silntknyt/advice/index.htm>**.

The Tidewater Lost Chord Club, founded in 1956, has an excellent reputation with the medical community in the Tidewater, VA area. At the request of the attending physician, the Club provides pre- and post-operative visits to new laryngectomees and their families.

For more information, contact Frank at **SilntKnyt@aol.com**.

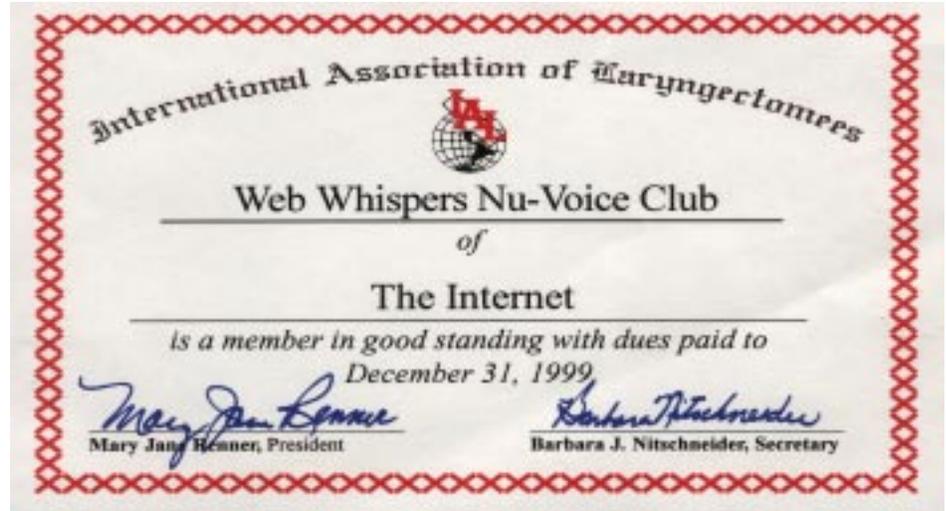
Thank You!

To all of our contributing members.

| | |
|------------------|------------------|
| Patsy Armstrong | Wayne Baker |
| Mary Bergquist | Ned Bienemann |
| Bob Blakeley | Grady Bradshaw |
| Ellen Byrne | Walter Canney |
| Joe Casey | Scotty Chandler |
| Philip Clemmons | Carter Cooper |
| Terry Duga | Rudy Dupler |
| Clinton Dutchler | Normal Edelman |
| John Edwards | Bob Fitz |
| Paul Galioni | J.J. Gaston |
| Lorents Gran | Logan Grayson |
| Dave Geiwe | Bob Hazell |
| Dutch Helms | Jack Henslee |
| Bob Herzog | Betty Hildebrant |
| Bob Hoover | Bob Hopkins |
| Jerry Hough | Max Hoyt |
| Barbara Lakatos | Jean Lakatos |
| Charles Lamar | Ron Langseth |
| Len Librizzi | Scott Lowery |

*Contributions to:
Terry G. Duga
6115 North Park
Indianapolis, IN 46620*

| | |
|-----------------------------|--------------------|
| Clyde Lush | Bernard Mellecker |
| Ron Martin | Frank Morgan |
| Ken Morris | Richard Panger |
| Darlene Parker | Belva Pearce |
| Marianne Peereboom-Kooijman | |
| Pat Petrone | Janet Pounds |
| Bob Radlow | |
| Red Rose Nu Voice Club | |
| Mary Alice Renison | Shirley Richardson |
| Pauline Rohm | Pat Wertz Sanders |
| Richard Scheele | Joe Schell |
| Herb Simon | Bobby Stanley |
| Harmon Swart | Diane Taliaferro |
| Chon Tamez | Richard Tunnard |
| Al Weitzel | Tor Wold |
| Kay Yetter | |



We Are Now an IAL Club!

WebWhispers Nu-Voice Club is proud to be formally affiliated with the International Association of Laryngectomees. We have paid our dues for 1999 and have received our IAL Membership Certificate.

WebWhispers joins over 270 IAL Clubs in North American and abroad. With over 235 members as of this writing, we are one of the largest IAL Clubs in the U.S. and we will be entitled to have eight delegates at the 1999 IAL Annual Meeting in Reno, NV next July 13th through 17th.

Per our Bylaws, delegates will be elected from and by the Voting Members. Further details of the election will be announced at a later time.

Please note that the IAL's regulations state that a delegate must be a laryngectomee and that a delegate can vote on behalf of only one IAL Club. As a result, those of us who will represent our local IAL Clubs in Reno will not be able to also vote as delegates for WebWhispers.

Those who believe they may be interested in being WebWhispers' delegates to the 1999 Reno meeting should contact **Darlene Parker**, Secretary, at **darlene@cyberramp.net**. Darlene will then begin to compile a list of interested and eligible candidates

Voting Members of WebWhispers will receive a wallet-size IAL Membership Card from Darlene in the very near future.

Membership in the IAL is a very important step forward for WebWhispers and we thank all of those who made this possible.

WebWhispers Nu-Voice Club



WebWhispers is the largest laryngectomee support group on the Internet and a member of the International Association of Laryngectomees.

The Club's officers for the 1998/1999 year are:

| | |
|----------------|-----------|
| Dutch Helms | Webmaster |
| Joe Casey | President |
| Darlene Parker | Secretary |
| Terry Duga | Treasurer |

WebWhispers welcomes all those diagnosed with cancer of the larynx or who have lost their voice for other reasons, their caregivers and friends and medical support personnel.

For information on membership, contact Dutch Helms at FantumTwo@aol.com.

Esophageal Speech

By: Bob Hoover

Esophageal speech is worth every effort you put into it. One of the most important words in learning this method is PRACTICE.

Esophageal speech takes time to learn. The biggest secret is practice, practice and more practice. I have been an esophageal speaker since 1995 and I use a Servox only as my back up method. To this day, I practice. The first thing I do every morning is go through the exercise of counting to loosen up the muscles in my throat.

The book "Self Help for the Laryngectomee" by Edmund Lauder is a must if you want to try to learn this method of speech on your own. It is available from Lauder Enterprises, Inc. at \$12.95 plus shipping and handling. Contact Jim Lauder at lauder@voicestore.com or **(800) 388-8642**.

To take esophageal speech to its maximum, you should have the help of a speech pathologist to make sure you don't pick up the various bad habits. Once you have learned the proper intake of air and how to control your air flow, you are on your way — but you need to constantly practice.

I considered a TEP but my speech pathologist advised me to stay with my esophageal speech and perhaps to consider the TEP at a future time. For now, I am happy with my esophageal speech and I encourage those who can learn it to do so. Please remember, however, that for reasons which your ENT or speech pathologist can best explain, not everyone is blessed with the ability to master this method.

Take care and God bless all.

Bob Hoover is President of Red Rose Nu Voice Club in Lancaster, PA. He can be reached at pahoov@lancanews.infi.net.

On Children...

When Bill and I went to a wedding after his surgery, a small group of children started following him around calling him Darth Vader. He loved it and showed them how his electrolarynx worked. They all paraded around after him at the reception.

When we left to go home, one of the little boys called out, "Bye, robot man!" It is amazing how children are able to cope so easily with these things, while adults are often so uncomfortable. Mary Alice Renison lives in Taos, NM and can be reached renison@newmex.com

*"Children are able
to cope so easily
with these things"*

When I was using the electrolarynx, I was in a store with my brother-in-law shopping for Christmas decorations. We were discussing just what we would need, when I noticed a boy about five or six years old looking at me and listening to me intently. Then he turned to his mother and said, "I want one of those for Christmas."

Tom Holcomb lives in Huntsville, TX and can be reached at tholcomb@lcc.net.

My seven year old grandson called me on the phone one Halloween night and asked if he could borrow my Servox. He was going to go to a Halloween party at school as Darth Vader. He just knew that if I would lend him my "voice," he would surely win the first prize.

Belva Pearce lives in Anchorage, AK and can be reached at rookie@msn.com.

Loaner Program

Under the leadership of **Darlene Parker**, Secretary, WebWhispers has created a Loaner Program.

Darlene currently has a number of Servox electrolarynx units which can be made available on a loan basis for up to three months to new laryngectomee. These units are also available for up to one month to those who need to send their existing unit to be repaired.

Those who are interested in taking advantage of the Loaner Program and also those who are able to contribute used equipment, supplies or books to the program should contact Darlene at darlene@cyberramp.net

Useful Data

Lauder Enterprises
Servox and Other Electrolarynxes and
Laryngectomee Supplies
@ (800) 338-8642 or
www.voicestore.com

Bivona Medical Technologies
OptiVox and Provox
@ (800) 348-6064

Bruce Medical Supply
@ (800) 348-6064

InHealth Technologies
Blom-Singer
@ (800) 447-5969 or
www.inhealth.com

Luminaud, Inc.
@ (800) 255-3408 or
www.luminaud.com

Medical West Healthcare Center
@ (800) 489-1888

Siemens
Manufacturer of Servox
@ (800) 333-9083
