

WebWhispers

Internet Laryngectomy Support

December, 1998

Welcome New Members!

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A Letter to Lisa

By Patsy Armstrong

When I had my surgery last year, I was given several options. They found my tumor on Monday. My voice box was completely encapsulated and the airway was nearly blocked. The surgeon operated on Wednesday. All I remember is that he told me that a total laryngectomy with radiation afterwards was the only option that had any kind of a "guarantee". He said this was the only hope of getting it all.

I know that I am happy to be alive. Voice as I once knew it and thought was so important (I was a motor mouth) is not as important. Life is. And life is what you make of it.

Like Paul Galioni, I work in a community college. My full time job is taking care of the equipment in the Computer Science Department. I taught computer classes part time and teaching — not the equipment — was the job I loved.

I am 54. I was 42 when I started college and my jobs grew from that. I was able to teach part time after getting my Associate's degree. I was working on my Master's so that I could apply for a full time teaching position but a Master's degree is not that important anymore.

I still take care of equipment and I still teach part time. Last January, I taught a Microcomputer Hardware and Operating Systems class using the Servox. I was scared to death and didn't want to teach it but my Supervisor was very wise. He knew I had to do it then or I would probably never do it. When you get bucked off a horse, you need to get back on right then or you never will. It went well. I had great students. This semester, I am teaching an On Line class and plan to continue doing this. One reason is that I don't seem to have the energy any more to work 40 hours a week and teach three or four classes — or maybe my priorities are different and I want to spend more time with my family than before.

If I had to make the decision again, it would be the same. I do everything now that I did before the surgery. I shop, work, play, and visit just like before. At first I had some trouble with my husband. He was a little over protective. If he had had his way, I would never have left the house again. "Stay here where you are safe and nothing can happen to you." I told him if I did that, what was the reason for surviving cancer? I was never the stay at home type.

I don't know if this will help your mother make a decision or not but I thought I'd give you my two cents worth. My quality of life is just as good as before. I eat out a lot. I have begun calling Western Sizzlin' my kitchen. As Paul Galioni said, it is a change of lifestyles and there are adjustments but it can be done.

Patsy Armstrong lives in Mt. Pleasant, TX and can be reached at parmstro@e-tex.com

Useful Data

Airline Reservations

- www.travelocity.com

Blom-Singer Products

- InHealth Technologies @
(800) 447-5969

Laryngectomee Products

- Bruce Medical Supply @
(800) 348-6064
- Lauder Enterprises @
(800) 338-8642
- Luminaud, Inc. @
(800) 255-3408

NiMH Batteries for the Electrolarynx

- D & R Assoc. Inc. @
(800) 348-6064

OptiVox and Provox Products

- Bivona Medical Technologies @
(800) 348-6064

Servox Electrolarynx

- InHealth Technologies @
(800) 447-5969
- Bruce Medical Supply @
(800) 348-6064
- Lauder Enterprises @
(800) 338-8642

What's In a Name?

Starting a Club newsletter? Here are some names used by other Clubs.

ANAMEMO

Anamilo Speech Club

The Communicator

Tidewater Lost Chord Club

Let's Talk

New Voice Club of Pioneer Valley

New Voice News

New Voice Club of the Niagara Frontier

The Speaker

Dallas Lost Chord Club

Standard Prosthesis Rotation and Cleaning

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

If a laryngectomee is wearing a standard prosthesis and is capable of self-insertion, how often should the device be changed?

My own opinion is that a weekly rotation system combined with the use of hydrogen peroxide as the cleaning medium remains an inexpensive, easy way for controlling the yeast overgrowth which destroys the valve mechanism of the prosthesis.

When the voice prosthesis was originally developed, the standard recommendation was that it be removed once a day for cleaning and rotated with a spare device. This has worked for many individuals for many years. If your health professional is still telling you to change a standard prosthesis daily, it is not necessarily the wrong advice.

In the last eight years or so, there has been a strong effort here and in Europe to develop a prosthesis that did not have to be changed by the laryngectomee. Some individuals have poor dexterity and/or poor vision. Others just don't want to bother with daily changing.

This research resulted in extended-wear devices such as the InHealth Indwelling, the Provox and the Groningen, all of which are only removed when they are completely non-functioning and ready to be discarded.

The same research also revealed that many laryngectomees were not following the original guideline of daily changing of the standard device. A substantial number were "pushing the envelope" by not changing it for several weeks at a time — without serious consequences. The conclusion was that many people could wear the standard device as though it was a form of extended-wear device.

- The standard device has two advantages. It can be self-inserted by the wearer rather than requiring insertion by a health professional. It is less expensive than an extended-wear device.
- The major disadvantage is that a standard device has a thinner, smaller diameter retention collar. As a result, it is more prone to being accidentally dislodged than the a true extended-wear device.

Some health professionals believe that too frequent changing of a standard device can cause trauma to the tissue and promote the development of granulation tissue. However, health professionals also see granulation tissue in laryngectomees who use extended-wear devices. There appears to be more to granulation tissue than frequent changing alone.

A number of us recommend changing a standard device weekly and using hydrogen peroxide as the cleaning medium. When this approach is used, we do not see the growth of candida (yeast) on the prosthesis which has become a real problem with a prosthesis which is left in place for many weeks or for months at a time.

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.

Thank You!

To all of our contributing members.

Patsy Armstrong	Wayne Baker
Mary Bergquist	Ned Bienemann
Grady Bradshaw	Ellen Byrne
Walter Canney	Joe Casey
Scotty Chandler	Philip Clemmons
Carter Cooper	Terry Duga
Rudy Dupler	Clinton Dutchler
John Edwards	Bob Fitz
Paul Galioni	J.J. Gaston
Lorents Gran	Logan Grayson
Bob Hazell	Dutch Helms
Jack Henslee	Bob Herzog
Betty Hildebrant	Bob Hoover
Bob Hopkins	Jerry Hough
Max Hoyt	Barbara Lakatos
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Red Rose Nu Voice Club	
Mary Alice Renison	Shirley Richardson
Pauline Rohm	Pat Wertz Sanders
Richard Scheele	Joe Schell
Diane Taliaferro	Chon Tamez
Richard Tunnard	Al Weitzel
Kay Yetter	

To The Entire WebWhispers Group...



R.V. Park in Reno

The 1999 IAL Annual Meeting and Voice Institute will be held at the Peppermill Hotel & Casino in Reno. For those who are interested, the Peppermill has an adjacent R.V. park, the Silver Sage Campground.

John Edwards reports that Woodall's Campground Directory, 1998 edition, describes the Silver Sage Campground as follows:

SILVER SAGE RV PARK
(TOO NEW TO RATE)

Gated, Paved RV PARK in an urban area. Guests may use Peppermill Hotel's swimming pool and exercise room. From Junction of US 395 & Plumb Lane: Go 1 1/4 mi W on Plumb Lane, then 6/10 mi S on Virginia St (Business US 395). Entrance is on left.

FACILITIES: 43 sites. Most common site width is 24 feet. 43 full hookups, (30 & 50 amp receptacles), seasonal sites, a/c allowed, heater not allowed, cable TV, overnight phone hookups, handicap restroom facilities, laundry, public phone, traffic control gate.

No tents. Open all year. Big rigs welcome. Clubs welcome. Rate in 1997 was \$18-25 per vehicle. MC/VISA. Phone: **(702) 829-1919.**

Supporting Dr. Strome's Larynx Transplant Work

As many of you know, Dr. Marshall Strome and a team of his colleagues from the Cleveland Clinic Foundation performed the first successful U.S. larynx transplant last January.

Some of us asked if donations to the Cleveland Clinic Foundation could be directed specifically to the support of Dr. Strome's work. William Grimberg, Chairman of the Department of Institutional Advancement (i.e., fund raising) for the CCF has informed us that any individual who makes a donation or a gift can state in a letter to either Dr. Strome or Mr. Grimberg that the money is to be used to support Dr. Strome's work. The gift will then be deposited directly into Dr. Strome's Department Fund and will support further larynx transplant research.

Dr. Strome's address is:
Marshall Strome, M.D.
Chairman, Dept. of Otolaryngology
The Cleveland Clinic Foundation
9500 Euclid Avenue
Cleveland, OH 44195

Those interested in helping support this research can contact Mr. Grimberg at **GRIMBEW@cesmtp.ccf.org**.

WebWhispers Nu-Voice Club

WebWhispers is the largest laryngectomy support group on the Internet.

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**.

Changes

By Philip Clemmons

My laryngectomy resulted in a number of changes in my life.

- Not being able to smell as well as before can be a blessing at times. I don't have to worry about a lot of obnoxious odors that some folks do.
- I sing better now than I did before the surgery. I was terrible before. Now I have an excuse.
- When I do sing, I get to be real close to ladies. And that's a lot of fun.
- I can impress little kids — and slower big kids — with how long I can "hold my breath."
- I charge admission when I get ready to sneeze.

Having a voice did not make me who I was, any more than large breasts (or the lack thereof) make a woman who she is.

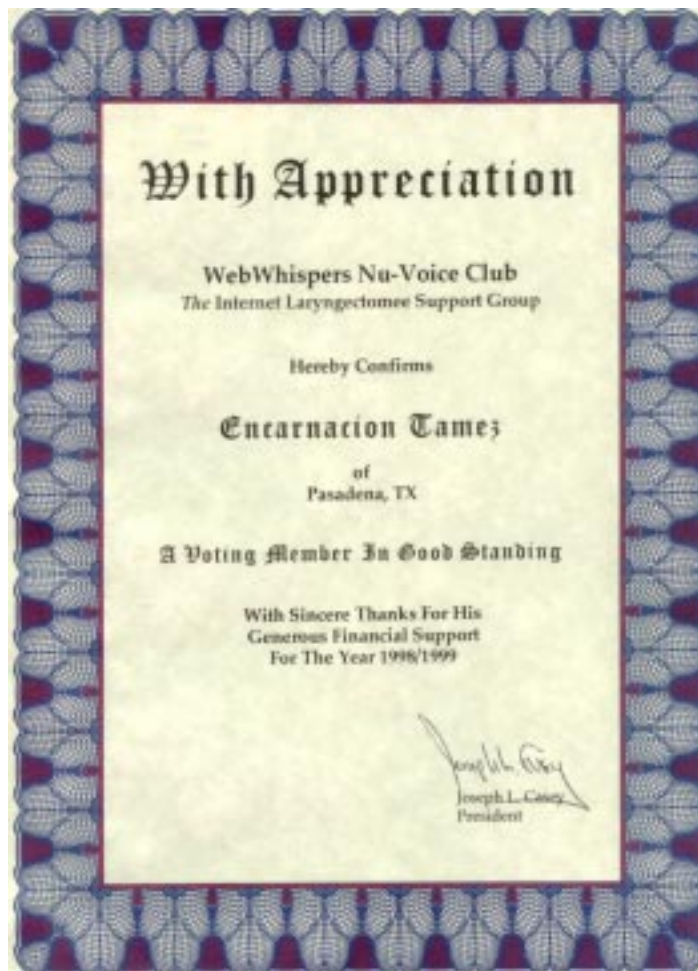
We need to get past the point that some part of our body is special. The parts that are special are our soul and our heart — not the physical heart but the spiritual one.

I often talk about what I've done or accomplished since my laryngectomy or of what my surgeon did. None of this would have been possible had God not given me the will to do what I've done and given Dr. Glenn Peters the skill which he has.

A long time ago I accepted that "Thy will be done." Then, I heard a "voice" tell me to not stand in the middle of the freeway, and to get busy and work my butt off.

See ya'll.
Phil

Phillip Clemmons is a businessman living in Cullman, AL. He can be reached at philip@elkriver.com



Membership Certificate

For those who have not yet seen one, our Membership Certificate is reproduced above. Thanks to Chon Tamez who scanned his Certificate into his computer and sent it back to me in JPEG format.

All WebWhispers members who make a voluntary contribution and who furnish their regular mail addresses will receive a Membership Certificate.

As a Cyber Club, we should be able to do everything electronically — but not quite yet. At this point, we have to depend on old-fashioned snail mail to accomplish the actual delivery of these Certificates.

Thanks again to the many members who have made voluntary contributions to WebWhispers. We are most appreciative.

On The Lighter Side

Part of my job entails going into court to conduct commitment hearings. I represent our State's Department of Mental Health. One hearing involved several lawyers representing the patient, his aged girlfriend, her relatives who were worried that she was being taken advantage of, and the State. I was using a small amplifier with neck microphone to allow my voice to be louder. During the patient's testimony, I suddenly realized that the amplifier was playing a local rock radio station. The judge and I exchanged glances and almost broke into laughter (the subject of the patient's testimony did not help matters much either). I quickly turned off the amplifier!

Terry Duga, WebWhispers' Treasurer, can be reached at tduga@atg.state.in.us