

WebWhispers

Internet Laryngectomy Support

September 1999

Welcome New Members!

The following new members joined us in the month of August. Welcome aboard!

Patrick Denenny

Marshall, MI
patd112@aol.com

Lynn Elliott

Dallas, TX
LLE1@prodigy.net

Margie Encinas

Sunland, CA
ME29411@aol.com

John Fisher

Gonzales, TX
fisher@gvec.net

Chuck Howe

Woodward, IA
Marthar@netins.net

Gerardus Janssen

Curacao, N.A.
gerjanss@interneeds.net

Sandra Sue Knight

Potter Valley, CA
sknight@tomatoweb.com

Barton Lehr

St. Peters, MO
blehr01@earthlink.net

Continue on Page 2

Smile At Those Who Are Rude To You!

By Herb Simon

Dear Kathy and Don,

Hi, my name is Herb Simon and I am a laryngectomee (since June 1995) from Silver Spring, MD. I just read your letter and can empathize with what has happened to Don, particularly when people at work laughed and mimicked his esophageal speech.

I'm not sure exactly what Don's job is or what he does. However, I do feel that his personality should (or will eventually) be the same as it was when he is fully recovered from the operation and regains his self-confidence.

If you folks are spiritual (as I am), you can tap into the strength and wisdom offered from that source. I think the best way to pursue this is to overcome it by neutralizing it and eliminating most of it by your own positive actions (take the bull by the horns). I will elaborate later in this message. I think it's safe to say that all laryngectomees have faced similar situations at one time or another. How we react to them is what's important.

You mentioned that people in line at COSTCO stopped and stared when Don talked using an artificial larynx shortly after his surgery. As far as this type of situation is concerned, I think the best way to react to that is with a SMILE. A smile is the best weapon and/or neutralizer for this kind of behavior. This type of thing happens frequently: the looks and the head turning when you're in public. If people are not looking at you and they hear a strange or alien sound, their knee-jerk reaction is to look in the direction of the sound in bewilderment. SMILE and you immediately put them at ease. Sometimes I will even tell someone that I am fine or okay (all the while SMILING at them).

Unfortunately, there will probably always be people that respond in an IMMATURE way, such as the people that have caused Don's recent humiliation. This is something that we just need to accept as an event that will possibly be on going. We need to adjust (or strengthen ourselves) and learn to move on with our lives and not let it bother us. Here are a couple of tips that I offer to Don that have worked for me in business:

1. SMILE as you speak. Maybe this is not possible with esophageal speech (ES). I speak with a Servox electrolarynx (EL). I speak very clearly and in business I am assertive (as I was before the operation).

Herb Simon, Successful Real Estate Salesman, at our Reno Rendezvous



Continue on Page 2

Welcome New Members

Dave and Margie LeBlanc

Beaumont, TX
ezletter@tx-is.net

Richard and Marylou LeMond

Lafayette, LA
mlemond@deatel.net

Myra Lipsey

Marshall, MI
mlipsey221@aol.com

Steve Martin

Indianapolis, IN
smartin697@aol.com

Stan Mruk

Exeter, PA
smruk454@aol.com

Jack Nolin

Pemrke, NH
nolin3ath@aol.com

Robert Poyner

Pocono Lake, PA
kathypat@epix.net

Liz Richmond

Lancashire, UK
tim@redmond1.freemove.co.uk

Susan Schippmann

San Francisco, CA
SUSANLS1@aol.com

Steve Verngren

Downington, PA
SMVBirds@aol.com

William O. Willham

Danville, KY
wow@mis.net

Smile (Continued)

When I detect some uncertainty or strange looks or laughter from those I am addressing, I will look them straight in the eye, smile and ask, "Can you understand me?" I know that I need to be the strong one. I also know that I am focused on my goal and if they are not capable of dealing with me, that I will move on to someone who is. It's the nature of what I do anyway (Real Estate sales).

2. Another consideration might be for Don to use his EL in business for the time being until he has completely mastered ES. I know of some laryngectomees who can use esophageal or tracheoesophageal speech and who also use the EL at certain times. The reason I suggest the possibility of trying the EL at work is because when you lift the EL up to your neck to speak, there is no question, even before you say anything that you are going to sound different. If you smile and maintain eye contact at the same time, you will diminish or maybe even totally eliminate the responses that cause humiliation to you. I have personally found this to be very effective.

If you live near a laryngectomee Club that has a Loaner Closet or contact Darlene Parker, Secretary of WebWhispers, you may want to borrow a Servox for a week or so and see how that works for you. I am not a Servox salesman. However, I believe that in most laryngectomees, it produces the clearest, most understandable sound and tone, which is what we are trying to achieve. It is our responsibility as laryngectomees to make it as easy as possible for others to be able to hear and understand us.

3. Join a local support group if you haven't already. As great as WebWhispers is, it's still better to be able to meet and share with others in person. Try to go to next year's IAL Annual Meeting and Voice Institute. It will do you a world of good.

It sounds to me as if you are progressing at a great pace. You are experiencing growing pains, much the same as a youngster does in growing up. This is a new you. "You have to crawl before you can walk." You are learning about yourself and unfortunately in some cases, about others. This is just a stage you are going through. I feel certain that with all the excellent input from WebWhispers and your personal God-given dynamic will to succeed, you will look back on the humiliation you have just suffered as a learning experience. Try to turn this negative experience into a positive one. Everything happens for a reason. You would probably not have chosen these people who caused you this humiliation as friends even before your operation!

You have joined a very special group of people. I wish you the best and hope that this is helpful to you both.

God Bless You
Herb Simon

PS This is just a personal opinion, but I think that going the ADA (Americans With Disabilities) route is a negative approach. It will just keep the hurt from the humiliation alive and you will have to rehash it and relive it for a long time.

Think Positive and act Positive and you will arrive at your goal with the least amount of stress on both of you. The time you will have to spend pursuing the ADA route, could be spent doing positive things like mastering ES, and just plain enjoying your time together — "smelling the roses" if you so choose.

Herb Simon can be reached at H457@aol.com.

NO! NO! NO! NO!

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

Some laryngectomees are under the misunderstanding that the 20 French diameter prosthesis is used primarily in the case of "... leaks around the smaller 16 French size." That idea is just plain wrong! The only real reason to go to a larger diameter prosthesis is to increase the airflow

If there is leakage AROUND the prosthesis, it is due to one of two reasons:

1. The prosthesis is too long and "pistons" in the tract, causing it to dilate; or

2. There is something wrong with the health of the tissue around the puncture so that it doesn't close down around the prosthesis.

The tissue may be compromised for a variety of reasons. These include heavy radiation, especially if it is directly to the stoma; diabetes; thyroid problems; malnutrition; alcoholism; or persistent/recurrent disease including cancer elsewhere in the body.

I make this point because I have seen too many situations in which a Clinician has attempted to solve such a leakage problem by inserting a larger diameter prosthesis. Usually, the larger diameter prosthesis causes even more irritation to the tissue, making the problem worse instead of better.

The first thing to determine in the case of leakage AROUND the prosthesis is if the prosthesis is the right length. That means observing the prosthesis while swallowing to see if pistoning is occurring and then measuring the tract without the prosthesis to get the right size. It should not be "assumed" that the prosthesis is too long and automatically go to a shorter size because you can lose the puncture if the prosthesis is too short.

If the length is correct, then you can assume the problem is that the tissue is not healthy. In that case, the Clinician needs to find out WHY it is not healthy. That means checking for the medical problems listed above.

Having said all of this, there is an advantage to having a larger FLANGE (not a larger stem) when there is a leak around the prosthesis. The larger flange works like a washer to improve the seal against the wall. Silicone retention collars are available for this very purpose. They can be added to the even smaller diameter 16 French prosthesis.

Carla DeLassus Gress can be reached at carlag@email.his.ucfs.edu

E-Mail Addresses for IAL

The Indianapolis office of the IAL has been relocated to Maryland. The new address is:

7822 Ivymount Terrace
Potomac, MD 20854

Voice: (301) 983-9323

Fax: (301) 983-4397

The new Maryland IAL office can now be reached by e-mail at:

IntAL@starpower.net

For the first time, all IAL Officers can also be reached directly by e-mail at the following addresses:

George Ackerman, President

ackerman@pangea.ca

Jack Henslee, Vice President

jhenslee@softcom.net

Jack Keilsohn, Treasurer

keilsoh1@ix.netcom.com

Barbara Nitschneider, Secretary

Nitsch2@aol.com

Courage

By Theodore Roosevelt
April 10, 1899.

It is not the critic who counts, not the man who points out how the strong man stumbled or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena; whose face is marred by dust and sweat and blood; who strives valiantly; who errs and comes up short again and again; who knows the great enthusiasms, the great devotions, and spends himself in a worthy cause, who knows in the end the triumph of high achievements; and who at the worst, if he fails, at least fails while daring greatly; so that his place shall never be with those cold and timid souls who know neither defeat nor victory.

Submitted by Jewell Hoffman who can be reached at jewellsh@yahoo.com.



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
Terry Duga Treasurer
Darlene Parker Secretary

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.

Detroit Club Celebrates 50th Anniversary!

Early in June, the Anamilo Club of Detroit celebrated its 50th year of service to the laryngectomy population of the Metropolitan Detroit area.

The Detroit Club was founded in 1949 under the sponsorship of the Michigan Cancer Foundation, now known as the Karmanos Cancer Institute. The idea originated with two patients who attended Esophageal Speech School in New York where they encountered the first Anamilo Club, which had been started earlier that year by a physician after his own diagnosis of cancer of the larynx. The name "Anamilo" had been chosen due to its Greek roots meaning, "to speak again."

In Detroit, the organizers expanded the focus of the Club to include the addition of a part time free Speech School and the development of a service entitled "The Sounding Board Program." Sounding Board volunteers were rehabilitated laryngectomy patients who, after attending an intensive training program, visited newly diagnosed hospitalized patients. Their purpose was to offer hope and encouragement. The free Speech School became a full time venture in 1953.

The Anamilo Club of Detroit was a Charter Member of the IAL. Detroit also hosted the first national IAL convention in 1954. Bill Ruby, the Club's President, serves on the IAL's Board and his wife, Nancy, just began her term as President of the IAL Auxiliary.

WebWhispers' Loaner Closet Open to Other IAL Clubs

If your local Club has at least one member who is also a members of WebWhispers Nu-Voice Club, then the Loaner Closet of the largest laryngectomy support group on the Internet is now open to your members.

WebWhispers has been building up an inventory of equipment, particularly electrolarynxes, in its Loaner Closet. The Club has received a number of inquiries for loaner electrolarynx units from individuals who were not WebWhispers members. Generally, the Club's Officers were not in a position to know anything about these nonmembers who were requesting the use of relatively expensive equipment. However, discussions during and after the IAL Annual Meeting in Reno with many WebWhispers members from local Clubs lead to the conclusion that these members and their colleagues would be in a position to know about the legitimacy of needs coming from members of their own Clubs.

Following these discussions, WebWhispers Nu-Voice Club adopted the following approach for loaning electrolarynx units on a temporary basis to other Club members whose units require repair and/or to those who are awaiting receipt of Medicare, insurance or other funds to purchase a new unit:

WebWhispers will lend electrolarynx units from its Loaner Closet to those who are members of WW. It will also lend units to individuals who are members of a local laryngectomy support Club, at least one of whose members is ALSO a WW member who would be willing to certify the legitimate need of the recipient.

Under this arrangement, a WebWhispers member of a local Club would let Darlene Parker, WebWhispers' Secretary, know that "Charlie X" or "Suzy Y" needs a loaner unit for an approximate period of A weeks or even B months. If the Loaner Closet has a unit in stock, the Darlene would lend it out. If not, she would simply inform the member of the situation and let them go on from there.

WebWhispers would pay for shipping the unit, insured, to the recipient. This would cost about \$10.00 for Priority Mail and \$500.00 insurance value for shipments within the U.S. Overseas recipients would be asked to pay for the difference between \$10.00 and actual shipping costs to their destination. The recipient would be responsible for the entire cost of return shipment by the same way insured for the same amount.

WebWhispers would expect the recipient to return the unit in the same condition (except for normal wear and tear) in which it was sent. Units are usually placed on loan for a period not to exceed thirty (30) days but extensions are possible in appropriate circumstances.

At the current time, the limit would be one electrolarynx per Club outstanding at any given time. This could change as WebWhispers continues to build up its inventory of units.

Requests for loaner electrolarynx units should be submitted to:

Darlene Parker, Secretary
WebWhispers Nu-Voice Club
2202 Cambria
Dallas, TX 75214
Voice: (214) 827-9185
E-mail darlene1@airmail.net

 **Labor Day**