

WebWhispers

Internet Laryngectomy Support

November, 1998

New Members

The following new members have recently joined our WebWhispers group.

Jane Brown

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JaneBHome@aol.com

Sandy Brown

Florence, MA
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Logan Grayson

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Jim Lauder

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Richard Scheele

Port Townsend, WA
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Thanks From Linda...

Hello all,

Just a note to let you know that Paul is winding down his radiation treatments. He is really doing well. I understand these last few treatments will be more concentrated and the side effects will be a bit worse.

I wanted to let each of you know how much I appreciate your support and prayers. On the days Paul was so uncomfortable, it was so good to be able to tell him... let's try some ice chips, or perhaps sipping some chilled aloe. Having you guys around made me feel the same way I did when my mother came after my son was born. :-). It was very reassuring to know that you were out there — and the answer to my question was just an e-mail or a phone call away. The doctor had given us the big medical picture, but you were truly my support. Some days I have felt a bit lost, but every day... there you were! What a nice feeling!

I just can't thank you enough for all the public postings, the private e-mails and "cyber-cards." What a blessing you are!

So, to all of you, have a blessed day and take care!

Linda

And From Lori

To Dutch,

I am deeply appreciative of all the responses I have gotten from other people who have had their larynx partially and/or totally removed. My sincere gratitude to you and all the dear people who responded. I am no longer in despair, confused or afraid to face surgery on October 12.

Again thank you.

Lori

Your Responses Are Important

New and/or prospective laryngectomees have questions — lots of questions. A busy ENT, no matter how dedicated, can only answer some of those questions — and may not even know about the questions which come up after the patient leaves the office. Every request to our WebWhispers group is important. Keep those responses coming!

“Snowflakes are one of nature’s most fragile things — but just look what they can do when they stick together.”

CAL Newsletter

Useful Addresses

Airline Reservations

- www.travelocity.com

Books

- www.amazon.com

Blom-Singer Products

- InHealth Technologies @ www.inhealth.com

Laryngectomee Products

- Bruce Medical Supply @ (800) 348-6064
- Lauder Enterprises @ www.voicestore.com
- Luminaud, Inc. @ www.luminaud.com

Larkel Swimming Device

- Brooklyn Respiratory Home Care @ (718) 331-7769

OptiVox and Provox Products

- Bivona Medical Technologies @ (800) 348-6064

Reno/Lake Tahoe Area

- www.reno.net

Servox Electrolarynx

- Bruce Medical Supply @ (800) 348-6064
- InHealth Technologies @ www.inhealth.com
- Lauder Enterprises @ www.voicestore.com

WebWhispers Webmaster

- FantumTwo@aol.com

Enhance the Taste Sensation

By Pat Wertz Sanders

Our sense of smell affects our taste. Since we laryngectomees have lost most of our sense of smell, we need to be looking out for things that will make food “taste” more like it used to. There are four acknowledged taste bud sensations — sour, sweet, salty and bitter. In addition, some authorities believe there is a fifth — savory (herbs, for instance), which reacts to aroma. The aroma moves up into the area behind the nose and thus allows a stronger “flavor”.

Experiment with herbs by putting a little bit of dried herb on your tongue and nibbling at it with your front teeth. You should get a strong flavor, sometimes too strong to be pleasant. Dried herbs taste a lot different and a lot better cooked with foods. Chewing a few leaves of a fresh herb, such as mint or basil, will taste good and fresh herbs can be added plentifully to raw salads and cooked dishes.

Here are some suggestions from other laryngectomees and from nutrition magazines to help make food a pleasure, even with for those of us with less sense of smell and perhaps less taste than we used to have.

- Cook freely with herbs and spices and use lots of onion and garlic. You may find that chicken is tasty again if cooked with tarragon or dill. Italian seasonings and salsa perk up flat dishes. Mashed potatoes with a dash of Cajun seasoning are delicious. Grits, rice or pasta dishes made with Jalapeno cheese are very flavorful but be careful of the hot pepper until you know it won't burn your mouth and throat.
- Vary the texture of your foods. Try a bowl of ice cream with a crisp cookie. Have an apple with your yogurt. Eat a salad with your meal instead of before it. Nibble on raw carrot sticks when you are having soft, cooked vegetables. The texture of food has been part of the enjoyment all along. We just don't think of that.
- Vary the temperature of your foods. Enjoy a sliced, cold tomato with hot vegetables. The contrast seems to add different flavors.
- Add a squeeze of lemon juice, a flavored vinegar or a mustard sauce to a baked potato or vegetables.
- Alternate your bites with a different flavors, temperatures or textures.
- Eat slowly, chew thoroughly, and savor each bite.
- Try something different. Instead of a bland salad dressing, try Caesar's or Italian or a make your-own vinegar and herb. You might like a strong salad dressing sprinkled lightly over vegetables.

You will find that you like things you would not eat before and that you have more taste left than you thought you did. Thanksgiving turkey time is coming up. Try pouring apple juice or wine over the turkey and topping with a lot of different herbs. You'll enjoy the aroma as it bakes. My family loves “blackened” turkey, made by coating the turkey with Cajun seasoning and cooking long and slow.

Have a Good Thanksgiving!

Pat Wertz Sanders lives in Birmingham, AL and can be reached at pat@choralmusic.com.

Thank You!

We greatly appreciate this important financial support and the thoughtfulness of our contributing members.

Patsy Armstrong	Wayne Baker
Mary Bergquis	Grady Bradshaw
Ellen Byrne	Walter Canney
Joe Casey	Scotty Chandler
Philip Clemmons	Carter Cooper
Jon Del Ben	Terry Duga
Bob Fitz	Paul Galioni
J.J. Gaston	Lorents Gran
Bob Hazell	Dutch Helms
Jack Henslee	Bob Hoover
Bob Hopkins	Max Hoyt

Contributions to:

Terry G. Duga

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Charlres Lamar	Ron Langseth
Len Librizzi	Scott Lowery
Ron Martin	Ken Morris
Darlene Parker	
Marianne Peereboom-Kooijman	
Janet Pounds	Bob Radlow
Red Rose Nu Voice Club	
Shirley Richardson	
Pauline Rohm	Diane Taliaferro
Mary Alice Renison	
Richard Scheele	
Joe Schell	Chon Tamez
Richard Tunnard	Al Weitzel

We Wish The Entire WebWhispers Group A Very Happy Thanksgiving!

1999 IAL Annual Meeting

The 1999 IAL Annual Meeting will be held in Reno, NV at the Peppermill Hotel Casino from Tuesday, July 13th through Saturday, July 17th. Tuesday will be devoted to Board Committee meetings. The actual sessions will start on Wednesday and end with the traditional Saturday night banquet.

Jack Henslee, Host Committee Chairman, has negotiated a very favorable hotel rate of \$68.00 (plus tax) per night.

Let's do another WebWhispers dinner in Reno!

Smoke Detectors...

One of the side effects of the laryngectomy is loss of a sense of smell, usually to a significant degree. A smoke detector is a must, especially for someone living alone or spending a lot of time alone.

And Air Conditioning

If you find yourself regularly in an air conditioned environment with very low humidity (such as at work), you can improve the situation by lightly moistening your stoma cover.

Airbag Issues

By Frank Morgan

My fellow laryngectomees,

I have seen several of us who keep their Servox in their shirt pocket when it is not in use. I wear my OptiVox on a string around my neck.

As I was cruising the Interstate a couple of days ago in my Red Cross car, I realised that laryngectomees are in a vulnerable position, and so I offer this.

My personal vehicle is a 1985 Monte Carlo. My Red Cross owned vehicle was a 1998 Ford Escort. What crossed my mind was that the Escort is fitted with an air bag while my personal car isn't.

If the air bag were to deploy for any reason, then anything hanging in front of my chest, including the OptiVox, would be thrust into my ribs and possibly my heart at an incredible speed.

This had never been pointed out to me before, so I pass it on case anyone else was unaware of the potential dangers of this life saving device.

God Bless
Frank

Frank Morgan lives in Newport News, VA and can be reached at SilntKnyt@aol.com.

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.

Multi-Lingual Servox

The first year after my laryngectomy, I was a "Servox-speaker." I spent a lot of time with my kids and their friends. At that time, my son was 13 and my daughter was 9.

"Children have a lovely way to accept... the voices we have."

Children have a lovely way to accept irregularities such as having a strange voice, like the voices we have.

One of the first times I was with my daughter's friends at school, this curious boy listened very closely to me and I could see that he wanted to try the Servox.

Of course, I let him do it. Soon he managed to speak quite well with it. Then he asked me: "But Tor, what is that other knob for?"

I waved my hands, making him understand that I needed the Servox to answer him. Then I said "As you can hear, I speak normal Norwegian, but if I use the other knob, it will change to English." As I changed knobs, I also changed languages.

For a short moment the faces of the kids were astonished, but when they found out that I fooled them we all broke out in good laughter!

Tor Wold lives in Trondheim, Norway. He can be reached at torw@online.no.

Report from CAL

By Ken Morris

I attended the 17th Annual Meeting of the California Association of Laryngectomees held in San Jose, CA in October.

This was an excellent conference and the program was first rate.

Workshops were conducted by the following Speech-Language Pathologists: Minnie Graham, Ph.D.; Jan Lewin, Ph.D.; Gail Monahan, MS, CCC; and Merle Irvin, MSPA, CCC.

Carla DeLassus Gress, D.Sc., participated in the Open Panel on Sunday, Oct. 4th.

"This was an excellent conference and the program was first rate."

A number of helpful tips were offered. Dr. Lewin suggested that a series of catheters from size 10 up to 22 be kept by everyone.

If a prosthesis cannot be inserted for some reason, the use of a smaller size will keep the puncture open and you can always build up to the proper size opening using the catheters.

If you use a 16 Fr., you would want, say, a 10, 12, 14, 16 and 18. Each TEP patient at M. D. Anderson Cancer Center gets this range when he/she leaves for home.

Another tip for dislodging food particles around the flapper in the LP prosthesis is to introduce a little vegetable oil into the valve, using a dropper or syringe.

A good suggestion for a cleaning tool to clear particles from the valve passage-way while in place is a brush made by Oral-B for cleaning between the teeth. It just happens to fit perfectly into the prosthesis. You have to be careful not to pull out the prosthesis as the brush fits snugly in a 16 Fr. opening..

Rita Kinney, Joe Mallon, Wayne Baker and Jack Henslee and the members of the Lost Chord Club of Santa Clara County and other volunteers are to be congratulated for their efforts.

As a visitor from Canada, I was made to feel welcome. American hospitality is indeed alive and well!

Ken Morris from Tononto, Canada can be reached at kenm@sympatico.ca.

On The Lighter Side

I was in the grocery store right after Christmas a couple of years back before having my TEP and was using the Servox to speak. A little boy heard me and asked, "Mister, did Santa bring you that for Christmas?"

Scotty Chandler lives in Anniston, AL and can be reached at chandler@nti.net.

Would you believe... A laryngectomee touring a large auto production plant was commenting on the high tech production methods using his electrolarynx.

Slowly, one of the production robots reached out and gave him a big friendly hug and a high five.

Joe Mallon lives in Santa Cruz, CA and can be reached at jmallon@slip.net
