Just the other day, while speaking to a lady who was facing a laryngectomy, I was asked, “How long did it take for you to feel normal?” It has been many years since I was asked that question or had even considered it. The first time the same question was posed to me was by my speech/language pathologist, Alma Owens. Alma asked me the same question about 11 months after my surgery. At that time I told her that it had taken almost a year. For several days I asked the same question of other laryngectomees I knew, and the most common answer was, “About one year.”

After being asked the same question nine years later, a totally different answer came to mind. Although I gave the questioner the same answer we all came up with years ago, “About a year,” the answer I heard in my head was, “I never felt normal after my surgery, but I do feel very special.”

I didn’t go into all of the gory details about mucus plugs, fistulas, feeding tubes, radiation, chemotherapy or all of the leery stares I witnessed while talking with my Cooper-Rand. I didn’t tell her about the embarrassment I felt every time I had to cough or sneeze, especially while out in public. I felt it unnecessary to share with her the many, many times I’ve been given a cure or remedy for my hoarse throat from friends; most of which included whiskey of some sort. I just politely explained that for most of us it’s one day at a time, and she will need to be honest with all of her emotions and allow herself to mourn the loss of something very valuable.

So naturally I’ve reviewed this question off and on for the last few days, and I am so delighted and pleased with my new way of thinking. For the past nine years I’ve been able to call any of my friends or relatives, and even without caller ID, they knew exactly who was calling! I must say I was shocked at first when I called any of our vendors and had to give them my name. I finally realized, unlike any other businesses, my voice sounded very similar to most of their clients.

I was, once, zipped through security at the airport because of my voice and not for the fact that I had a broken toe. Then I was allowed to keep my cuticle and small scissors, which I stupidly packed in my carry-on bag, because I told her (as I lifted my necklace and showed her my covered stoma), “I use both scissors for this.”

I’ve realized that my friends and family have accepted my laryngectomy since they now talk louder to be heard over my coughing. Or when no one in my orchestra even looks my way when I start coughing, even during a “rest,” when we are all silent. Isn’t that the way it always goes? When I don’t want anyone to hear what I say, it ends up I’m heard across the room, and when I want to get someone’s attention across the room, no one can hear or understand me.

My friend Janice told me that she felt back to normal when she started dreaming about herself as a laryngectomee and only considered it “more of an inconvenience.”

continued on page 3
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*Specifications Subject to Change Without Notice
Now I’m comfortable to joke about my voice or the fact that I have no vocal cords. One day I was shopping and a lady said, “Oh my, you’ve lost your voice.” I said, “No, actually I lost my vocal cords.” She didn’t find my answer as amusing as I did. I also get a huge kick watching non-laryngectomees put an imaginary electric larynx under their neck, or a finger on their throat, and talk like we do. My friend’s little girl likes to imitate my voice, and when she does, we end up laughing and giggling.

Two people have actually told me they don’t worry about throat cancer as much as other cancers because I make it look simple and easy. What a strange and bizarre compliment.

There are those times when I feel like a laryngectomee: when the automated response on the telephone cannot understand my tone of voice. Or when the young girl at our grocery store follows me around until I tell her, “Yes, I would love a cup of water.” When the paramedics didn’t look for my emergency bracelet and tried to give me oxygen through my nose. When people who are hard of hearing call me and then can’t hear what I’m saying. It’s really irritating when they get mad at me because they can’t hear me. Then all those times when people can’t understand what I’ve said, and instead of asking me to repeat myself, they just shake their heads and agree, no matter what I’ve said.

I’m not saying that it’s been easy for me or my family, but I’m very proud of all the accomplishments we’ve made together and our ability to retain our sense of humor.

You bet I feel very special! I’ve survived cancer, and what I was left with after the battle. There are days or weeks that I don’t even think about being a laryngectomee. Best of all, I can get out of most anything by saying, “Oh, I better not do that because of the dust, fumes, it might take too much exertion, or when I eat that it _____.”

—Tina Long
IAL milestone on accepting all forms of speech remembered

In the November 1993 issue of the *IAL News* there appeared a brief but important notice from the IAL Board of Directors that stated the organization does not discriminate on the basis of the kind of speech a laryngectomee uses.

It may be hard for some to believe today just how many battles had to be fought and won to get official recognition by the IAL that all forms of speech following laryngectomy surgery were appropriate. And it may further surprise some that remnants of this long-running debate still resonate among at least some laryngectomees and others.

For decades following its creation in 1952, the IAL took the position that only traditional esophageal speech was desirable, despite a statement in 1957 that included the goal for laryngectomees to learn to speak by “natural or artificial means.” At that same time the position was that anything other than traditional esophageal speech should be a “last resort.” Indeed, the use of the electronic artificial larynx was often referred to as a “crutch” since it was believed that the ease of its use would discourage laryngectomees from taking the time needed to learn esophageal speech. People who were not successful at learning traditional esophageal speech were often thought of as lazy and looking for the easy way out.

Even for those who were successful in learning traditional esophageal speech, the length of time it took is reflected in the Laryngectomy Prayer (see page 8), which was first printed in the *IAL News* in 1958. It expresses thanks for God’s “help through so many others during my recent and terrible silence. Never let me forget the anguish nor the despair suffered by me while speechless . . . .”

It would seem that the “terrible silence” and suffering while “speechless” might have been lessened if the other available methods of speaking had been viewed as at least a stopgap measure with which to communicate while learning traditional esophageal speech. It is not unusual now for laryngectomees still in the hospital to begin to use an electronic artificial larynx with an oral adapter.

Additionally, the *IAL News* reported a number of surveys taken during the 1950s and 1960s that indicated that as many as 50 percent of laryngectomees never became proficient traditional esophageal speakers. And in 1970 SLP Marshall Duguay listed 18 medical conditions that could completely prevent the learning of traditional esophageal speech by some laryngectomees.

One of the real heroes who helped further broaden the thinking of the IAL on the issue was SLP Dr. Shirley Salmon. Dr. Salmon had published *The Artificial Larynx Handbook* and stated that 40-60 percent of laryngectomees were not able to acquire good esophageal speech; of this number, a full two-thirds could not learn it at all, with the remaining third not able to use it effectively. “Thus the artificial device is a substitute and, if it is used well, it’s a better communicative tool than poor or no esophageal speech,” she concluded. Dr. Salmon had considerable credibility with the IAL and laryngectomees, and her position on using the electronic artificial larynx helped to force individuals within the organization to take another look at the issue.

So powerful was the resistance of many to abandon the primary place of traditional esophageal speech that when the TEP prosthesis was invented and then marketed in the early 1980s, it was advertised as an option for those laryngectomees who were UNABLE to learn traditional esophageal speech, instead of a new way to produce esophageal speech with a greater success rate and a number of distinct advantages over traditional esophageal speech. And it was only in 1983 that the IAL elected its first president who used an electronic artificial larynx.

IAL Board Sets Policy

It has long been understood that the IAL promotes total rehabilitation of all laryngectomees. The IAL has also understood that every laryngectomee has the right to select his/her own method of alaryngeal communication.

During the Annual Meeting of the IAL Board of Directors in Rochester, MN, the Board was asked by its Rehabilitation and Public Affairs Committee to adopt a resolution stating that the IAL "will not discriminate against any laryngectomee, nor will they condone discrimination by others, for using any form of alaryngeal communication and will support all laryngectomees in the development of alaryngeal communication—methods of their choice."

The Board approved this policy unanimously and asked its staff representative to make sure that a copy of it is provided to each member club. IAL President Jerry Hough had this to say, “We want everyone to understand that no laryngectomee should ever be looked down upon or discriminated against by anyone for using one form of alaryngeal speech over another.

The recent IAL club survey revealed that some IAL clubs were concerned about laryngectomees being discriminated against for using an artificial larynx instrument. It is hoped that this action by the IAL Board of Directors will discourage such discrimination. Joanne Penn, MS, Rehabilitation & Public Affairs Committee Vice Chairman and a speech pathologist in Seattle, Washington, added, “Communication is the important thing. It doesn’t matter how you do it.”

(November, 1993 IAL News)
larynx, Mabel Disinger, who was also the first female IAL President.

There are some laryngectomees who, because of the nature of their surgery, are unable to orally speak by any method. And there are many others who may only have one option instead of being able to choose among two or more. As a laryngectomee (who became one at age three) and working SLP, Joanne Fenn put it, “Communication is the important thing. It doesn’t matter how you do it.”

As we objectively look at the ways of speaking after a laryngectomy, we can see that each method has both advantages and disadvantages. Laryngectomees who can and do make a choice among them do so by weighing the benefits versus the trade-offs. The IALs making its position on this issue officially and finally clear in 1993 was a long time in coming, but a welcome statement that recognizes the reality of our individual differences and consequent different communication capabilities as well as needs.

—David Blevins

**One-year anniversary noted in e-mail**

(Note: The following e-mail appeared on the WebWhispers Internet-based laryngectomee support group Web site in July 2007. Terry Gaffney’s story is a reminder of how important support from a number of sources can be for someone facing a laryngectomy.)

Hi all,

July 14 is my one-year anniversary and it’s gone by so fast. When I first learned in the doctor’s office that I had to have my lary done, I started to walk out and said I do not want to have it done. I had seen what a friend of mine was going through as he had his done several years before. I would rather suffer the consequences and not go through the surgery.

My doctor asked me to stop and sit down and have a talk together over me not having the surgery. He told me what would happen if I did not have the surgery—the tumor getting larger in my throat and not being able to breathe or eat at a certain stage of growth of the tumor. That didn’t sound like what I wanted to happen to me either. He said I was in the very early stages of cancer, and he was right as it was in situ stages (note: the cancer had not spread) as the biopsy confirmed after the surgery. So I agreed to have the lary done. I went to support groups and was educated on what was to happen next and in my future recovery expectations. I also used WebWhispers for much information to help me get ready and to recover afterwards.

Now it’s my one-year anniversary, and it’s not as bad as I thought it would be to be a lary. I have met many people in the support groups I go to and have made many new friends there.

The night before I had my lary done I was at peace with myself, and I never used any medications to sleep that night, but I had Zanax from the doctor to help me through the night. I was glad to be getting the procedure done and over with to start my road to recovery. I am using esophageal speech now and an electrolarynx, which I never use anymore.

The point of my story I was scared to death of having the lary done at first, and I went through it with the help of support groups and friends I met and WebWhispers. I’m glad it’s done, and I can proceed with my life now with some new restrictions. I was not alone through this venture, as I was helped by many, including my family. This is much better than the route I wanted to take at first. We just have to be strong and not let our minds take over our bodies. We can overcome anything that confronts us no matter what it is. One year after my surgery, I’m much better then I ever thought I would be.

I just wanted to share my story with everyone else who had their lary done and those who will have theirs done soon. It’s not the end of the world for us; we are just a little different than we were before.

—Terence Gaffney
Almost immediately after the delegates’ meeting in Burlington, Vt., Charlie Blair, President of the Florida Laryngectomee Association, invited me to speak at the Florida Conference. Of course I accepted right away.

When Janice Hayes found out I was going to the Florida Conference, she decided to go with me so she and Pat Sanders could have a chance to discuss a project Janice is working on. Janice was happy to pay her own way as a donation to the IAL.

We flew into Orlando on Thursday, Sept. 13, and stayed until Saturday, Sept. 15. While I was taking care of my hotel registration, in walked Laura and Tony from Griffin Medical. Laura had a new shorter hairstyle and was stunning as usual. Tony has a beautiful singing voice. Who knew?

The opening ceremonies started Friday afternoon. Charlie welcomed everyone and gave the itinerary for the weekend. I’m not sure if it was at that point or during another time that Charlie was addressing the group that he explained how important our speech-language pathologists are. He finished his statement by saying, “I should know, I met my wife, Nancy, at a convention and she is an SLP.”

Pat Sanders was the first speaker of the afternoon. I read in the program that she was going to talk about communication. I figured she would discuss all the technical stuff about computers and the Internet, but instead she shared a little bit of her own personal
story. Everyone got a peek of Pat in real life: she didn’t know how to type or even own a computer until after her laryngectomy! I always thought Pat was born with a mouse in one hand and a keyboard in the other. She also told us how she found Dutch Helms (founder of WebWhispers), and how her son, Dutch and she put WebWhispers “on the air.”

Pat and I had the privilege to speak to a group of very kind and welcoming people. I told my husband, David, and Butch, that I was afraid I would put people to sleep, but at least no one would snore. Butch gave me the “OK” sign and a big smile after my talk.

Before Charlie announced that the meet and greet would be set up by the pool, he looked out the window and said, “It’s not raining, so we will be able to meet by the pool.” Well of course within 30 minutes it was raining. Frankly it was a lot cooler mingling and talking to everyone inside.

Many of the vendors were there except Janet Breski from Eagle Medical and her husband, Gene, from Mountain Precision; they were attending their grandson’s graduation. Soon after we checked in, we caught Jim Lauder heading toward the pool. Let me tell you, this guy has great legs; I bet he was on the track team.

I had the opportunity to talk to Dorothy Lennox, and she gave me a lot of good advice and suggestions. That’s what so great about Dorothy and Tom from Luminoid is that they try to talk to everyone and will help any of us, even if it means sending someone to another vendor.

I always enjoy seeing Richard Crum, with InHealth Technologies; he is such a gentleman and a celebrity. Before several of us went to our first convention in Reno, Jane Del Vecchio told us we might even meet a few celebrities. When I first saw Richard Crum, I felt like a fan seeing her favorite star. (Right after my surgery I watched his educational video on hands-free speech.) I’m sure I made Richard a little nervous that first convention, but I’m happy to say after nine years, Richard is used to my zealous persona.

The real star of the conference was little Kinney Brooks. Many of us were delighted with Scott Brooks (with ATOS) and Corina’s courtship, and we all felt like aunts and uncles when Kinney Brooks was born. I’m not being biased, but Kinney is the cutest and smartest little guy I’ve seen in awhile. Many may not know that Scott has a teenage son, also very smart, who also keeps Corina and Scott busy.

A conference, convention or party wouldn’t be the same without Karen and Cliff Griffin. They always seem happy to see everyone and are so compassionate and fun. I thought they only spoiled me, but I found out they spoil everyone.

While we were listening to one of the speakers, someone tapped me on the shoulder, and when I turned around I saw one of our former members of the Greater Atlanta Voice Masters, who had moved. He didn’t know we were going to be there and we had no idea he would be attending the conference. Peter Zecher brought his wife, Karen, also a former club member, to the hotel on Saturday so we could have breakfast together and catch up on all the news. What a great dividend to a perfect trip.

One thing I noticed was I had a chance to talk with everyone there since it was a smaller group than the IAL Annual Meeting. I met a few new laryngectomees, families and students who were attending the Voice Institute and enjoyed talking to my good friends I only have the chance to see once a year.

The Florida Association members did a great job! And getting to “cut up” with Butch McMahan and Robert Smiley is always fun. Earl Mogk, Maggie Geehan and Charlie Mail were very busy being hosts to the attendees, students and VI staff. Carl Kilmer and his wife are always smiling and busy, but they always have time to welcome everyone and answer questions and give directions.

Thank you, Charlie and Nancy Blair, for inviting me to come and letting me share the camaraderie and fun.

—Tina Long
The Society of Otorhinolaryngology Head-Neck Nurses (SOHN) held its 31st annual meeting in Washington, D.C., on Sept. 14-18, 2007. The society was kind enough to give the International Association of Laryngectomees a booth in the vendor area, and I had the honor of representing the IAL to this fine group of nurses. A decision was made to include material from WebWhispers and The Foundation for Voice Restoration at our table. Due to the generosity of some Board members and Herb and Sally Simon of the Montgomery County, Md., club, the cost of travel and a place to sleep were handled at no cost to the IAL other than the materials we have in stock.

It is one heck of a frightening thought to follow that pair who represented us at the SOHN in Toronto, Ontario, Canada. In 2006 Dr. Carla Gress and Philip Clemmons represented us to this fine organization. At least I did not have to speak to the whole group as they did. On Sunday, Sept. 16, we had seven hours of being able to talk with individual members, and on Monday, Sept. 17, there were another six hours of contact. Luckily, Herb Simon spent several hours at the booth helping me talk with the nurses.

I feel like we talked to almost all of the 300-plus nurses. I was surprised at how few of our brochures were left to send back to Interim Executive Director Gary Miner when it was over. The majority of the nurses worked in operating rooms and ENT clinics. I was able to talk to nurses from all over the U.S., Canada, England and even Israel.

I was glad I had materials from several sources. It seemed like each one would take an interest in something else. One nurse from one of the western states was very impressed with WebWhispers because so many of her patients live in rural areas far from an ENT or SLP. One of the nurses from Israel is interested in trying to set up a laryngectomee club there. Most of the nurses I spoke with had ideas such as these.

It was interesting how many of these nurses were unaware of us. They are the nurses who primarily work for the hospital, surgeon or the ENT (both pre-op and post-op) but not normally in the recovery of the new laryngectomee. Most of them said that they wanted to talk more with the SLPs to whom their doctors refer their patients. The value to them would be to better help the caregivers as well as the laryngectomees get through the first few days of their new lives.

My biggest surprise was how often the nurses said “thank you,” not just to me, but to all of us who are involved in the recovery of laryngectomees. I did not go to Washington for any reason other than to help spread the word of the IAL. What I got there was an education—an education in just how important it is for us to help others. Those of us who have walked through the jungle of surgery, no voice, radiation, chemo and the other impediments to our having “normal” lives can make the lives of those that follow so much easier. Cancer put us all in the same place, and now we can lead others through the same problems by helping them so that they don’t have to reinvent the wheel.

—Sapp Funderburk

Laryngectomee Prayer

Oh, Heavenly Father, I thank you for Your sweet gift of speech, the second such gift to me during my lifetime; and for Your help through so many others during my recent and terrible silence. Never let me forget the anguish nor the despair suffered by me while speechless, for only in remembering can I tenderly assist those who unfortunately come after me. Teach me to do so with a clear understanding, a gentle compassion, a deep humility, and with much patience.
Free Head and Neck Cancer Screenings

National Head and Neck Cancer Awareness Week for 2008 is not scheduled until April 21-27, 2008. But some local communities have free head and neck cancer screenings that are conducted by medical interns, ENT M.D.s, and head and neck nurses at different times of the year, or more than once per year. Such is the case with the Yul Brenner Head and Neck Cancer Foundation and its Georgia chapter.

These screenings are helpful for the general public since cancers caught early are easier to treat successfully. But laryngectomees can also benefit from these screenings, as they check for any possible recurrences or new cancers in the head and neck area.

Be on the lookout for events in your community. You can find out if there is a screening scheduled for April in your area at this location on the Internet:

http://www.yulbrynnerfoundation.org/screenings
The International Association of Laryngectomees is pleased to announce the availability of the Prohaska Medical Financial Assistance Fund to be awarded to laryngectomees in need of medical assistance. This fund was created for the sole purpose of helping some of our disadvantaged laryngectomees. We are accepting applications. Our committee will carefully review all applications, and vote on which candidates will be appropriate recipients for the amounts to be awarded.

The criteria used for the Prohaska Fund, and application forms to be filled out by the laryngectomee and ENT/SLP, can be downloaded and printed from the IAL Web site: www.larynxlink.com

The application can be mailed, faxed or e-mailed to anyone interested in applying. Please submit completed forms to:
Prohaska Medical Financial Assistance Fund
c/o International Association of Laryngectomees 1203 Wolf Swamp Road
Jacksonville, NC 28546
E-mail: ialhq@larynxlink.com
Fax: 910-455-1855
Phone: 866-425-3678

Attention: All applications may be faxed or mailed, but they must be postmarked no later than July 30, 2008. The Prohaska Medical Financial Assessment Committee will review all applications. Candidates will be selected by July 30, 2008.

If you are aware of someone who could possibly use some assistance, please let him or her know about this opportunity.

Prohaska Fund Assessment Committee
Elizabeth Finchem, Chair
Terrie Hall
Philip Doyle
Tina Long, Ex-Officio
The National Institutes of Health announced in September 2007 that a blood test is being developed that may detect the presence of proteins produced by a growing cancer. The test could one day become an important tool for monitoring throat cancer, particularly advanced throat cancers.

One potential use would be to monitor the effectiveness of chemotherapy and radiation treatments. The researchers found that throat cancer patients who showed a decline in several cancer-related proteins in their blood following chemotherapy and radiation were more likely to remain in remission (cancer no longer growing), while those who experienced a large rise in those proteins over time frequently had a return of the cancer. These findings could lead to the development of a blood test that helps doctors to detect the recurrence of throat cancer early when there is still time to pursue another form of treatment such as surgery.

As one of the researchers put it, “Cancers of the head and neck are insidious because surgical removal of the tumor can severely impair a person’s ability to talk and to swallow. A blood test that enables doctors to closely monitor a patient’s rehabilitation while sparing the patient’s voice, speech and swallowing ability is an excellent example of the predictive, preemptive and personalized approach to medicine that the NIH strives for.”

According to the NIH report, “It is estimated that more than 34,000 Americans will be diagnosed with cancer of the oral cavity and pharynx (the middle part of the throat that includes the soft palate, tonsils and tongue) in 2007, and that 7,550 Americans will die from it. Alcohol and tobacco use are the most important risk factors for head and neck cancers, with tobacco use accounting for 85 percent of the cases. Just last month, other NIH-supported doctors reported that sexual transmission of human papillomavirus (HPV) is strongly associated with throat cancer, especially in cancers arising from the tonsils and base of the tongue.
Evaluating the Annual Meeting

Workshop and Breakout Sessions

In the last issue of the IAL News I discussed the importance of evaluations and the role they play in assisting the IAL Board of Directors, the Voice Institute director and the host club in determining what you, the attendees, felt were the high and low spots of the Annual Meeting.

In this issue we'll examine the feedback we received from the individual breakout sessions from the 2007 Annual Meeting in Burlington, Vt. I cannot stress enough the importance of the participation of attendees in this process. Your feedback is important. Without it we have no objective method to determine what needs to stay and what needs to go.

I have been in contact with the chairman of the Annual Meeting Committee and have tossed some ideas his way for consideration. The presenter can pass out all the forms they want to as many folks as they want, BUT the key is getting them collected at the end of the session when everyone is ready to move on. The end responsibility is on you, the attendee, to fill out the form.

In reviewing each of the workshop session evaluation forms, a clear theme emerged. Topics that revolved around life after becoming a laryngectomee scored the highest. The session on improving relationships and sexuality was the big winner. One commented that it “lacked visual aids.” I’m not exactly sure where that was headed, but it does show that even though we have lost our voices we haven’t lost our senses of humor.

The next winner, if you are keeping score, was titled “Getting Back to Work.” As I mentioned in a previous article, just because we have lost our ability to speak “normally” doesn’t mean we have lost the rest of our skills and abilities.

Each session was well received by those who attended. The average “score” on each category for which we requested feedback was “Completely Satisfied.”

Scores like that can be attributed to the material that was presented and to those doing the presentations. Each presenter should be proud of his or her work. Some have been dealing with the same subject for some time while for others it was their first time.

As a result of your feedback, the Annual Meeting Committee will now have some concrete evidence as to the type of programs to be presented in Little Rock, Ark.

Remember, when you attend next year’s Annual Meeting and the breakout sessions, fill out those all-important evaluation forms. It’s the only way the board and the Annual Meeting Committee will know exactly how they did, and these forms provide a basis for determining whether to repeat or drop the topic in the future.

—Mike Dreishbach

Volunteers sought for research

Laryngectomee and newsletter editor Jim Sansing is interested in locating laryngectomees who would be willing to participate in a survey. The survey will cover questions such as:

- What type of speech do you use and why?
- Did you develop fistulas (or hard-to-heal wounds) following surgery?
- What kinds of support did you receive before and following your surgery?
- Did you have voice training? If so, who provided it?
- Others

Volunteers will be asked to fill out questionnaires. Confidentiality will be maintained, and no names or other personal information will be used in reporting the results.

If you are interested in participating, contact:

Jim Sansing • Sansing@juno.com
or write

Jim Sansing, 4782 Oakland Drive, Pensacola, FL 32526
Beattitudes for the Differently Abled Person

A reading was included in the service at a Norfolk, Va., church not long ago:

Blessed are you who take time to listen to defective speech, for you help us to know that if we persevere, we can be understood.

Blessed are you who walk with us in public places and ignore the stares of strangers, for in your companionship we find havens of relaxation.

Blessed are you who never bid us “hurry up” and more blessed are you who do not snatch our tasks from our hands to do them for us, for often we need time rather than help.

Blessed are you who stand beside us as we enter new ventures, for our failures will be outweighed by the times we surprise ourselves and you.

Blessed are you who ask for our help, for our greatest need is to be needed.

Blessed are you, when by all these things, you assure us that the thing that makes us individuals is not our peculiar muscles, nor our wounded nervous system, but is the God-given self that no infirmity can confine.

Written by Marjorie Chappel


EMS offers a wide variety of superior tracheostomy and laryngectomy supplies and accessories to enhance the laryngectomee’s quality of life. Our prices are affordable and competitive, and we are dedicated to providing excellent customer service. We are a Medicare approved provider.

We are a proud distributor of Kapitex products, such as Laryngofoam filters, Trachi-Naze and Trachi-Naze Plus Heat and Moisture Exchangers (HMEs), Buchanan Protectors, and many others.

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• ask about our FREE samples •
Whether you call it an artificial larynx (AL), electronic larynx (EL), artificial laryngeal device (ALD) or perhaps refer to it by a brand name (such as Servox, Tru Tone or Cooper-Rand), most users of these devices can make significant improvements in communicating with them through correct practice, improved technique and proper instrument adjustment. Most ALs also require fine tuning, and many benefit from adjustment on a weekly basis. While some of the suggestions may apply to any type of AL, the emphasis here is on the devices that are used by holding them against the neck or cheek.

If you have spent much time with other laryngectomees, you have certainly noticed differences in the quality of speech produced by AL users. We notice that some are louder, clearer and easier to understand than others. Part of the problem is that many AL users appear to be self-taught and would have benefited from good instruction at the beginning from a speech-language pathologist (SLP) or other qualified therapist. Of course some of the differences we hear are the consequence of radiation, scar tissue, wearing of dentures and physical or other problems that interfere with speech. In some cases these circumstances may not be correctable, or significantly improvable. Nevertheless, most laryngectomees can improve their AL use through proper initial instruction, experimentation and practicing good technique.

Most ALs are made to be used by holding them against the outside of the neck or cheek, such as the Servox, Tru Tone, Romet, OptiVox, Nu-Vois, Sola Tone, Xtra-Vois, etc.) Some important tips on using them well include:

1. Find that “Sweet Spot”! A sweet spot is a location where sound and vibration is most efficiently transmitted into the esophagus and mouth for speech. There may be more than one sweet spot, and it can change over time, with additional ones coming into existence as the healing process moves forward. There will occasionally be two, three or even more places on the neck that produce a loud and clear sound. A simple way to find the sweet spot is to open your mouth and keep it in one position and say the “ahhhhhh” sound as you place the AL in different locations on your neck. Some SLPs prefer a combination of sounds such as “mama” or “no” as this will produce more resonance.

It is important that you maintain a uniform pressure of the AL head against your neck at each location you try. If you have not experimented with looking for new sweet spots, you may discover that you have developed a better one, or additional ones you can use as alternates to the primary spot. In addition to experimenting with different locations, try different amounts of pressure to get a good compromise between too tight, which can be painful (and muffle the sound in some ALs), and too loose, which will produce the loud buzzing sound that interferes with intelligible speech.

The individual needs to find a sweet spot but also find a natural posture for his head/neck and arm/wrist. A sweet spot does not really qualify as a good one if the user has to maintain an awkward posture to use that location.

The laryngectomy operation can produce scar tissue and swelling from the accumulation of lymph fluid in the neck area (edema). This can muffle the sound when using the AL against the neck right after the operation, and for weeks and even months afterward. This problem and post-operative pain can cause many laryngectomees to initially use an AL intra-orally with the “straw” adapter, which puts the sound into the mouth instead of through the neck. Knowledgeable doctors and SLPs recommend using an intra-oral device at least until the staples/stitches have been removed and the wound sufficiently healed, and some doctors insist on its use until they clear the use of the device against the neck.

Neck tissue that has been treated with radiation can also become thickened, tender and more resistant to the use of the device held against the neck. Those who have had to use an AL intra-orally because of these problems should remain open to trying an AL against the neck as healing progresses since quality of sound is often superior to the device used intra-orally.

The location of one or more good “sweet spots” is essential. And once you have found one, continue to experiment over time as a better or additional one or more may develop.

2. If you are able to do so, learn to hold and operate the AL with your nondominant hand (ex. if you are right-handed, try and use it with your left hand). Doing so frees your dominant hand to write, shake hands, etc. Experiment with using the thumb and finger to operate the device since many people have better muscle control with one or the other. The use of the finger might be especially important for
a device like the TruTone, where varying the pressure in small steps causes the change in pitch. The first and second fingers work well together in operating the dual tone change buttons of the Servox and similar instruments.

3. Coordinate pressing the button on and off with your phrases and sentences. Certainly let go of the button at the end of a sentence. But you may discover that letting go of the button between phrases within a sentence is also helpful to your listener, although pushing the button off and on with each word should definitely be avoided. Work toward being fluid with your phrasing. These pauses will also make it easier for people to understand you. They help to accent words, which will help convey the intended message. Pauses are important.

4. Vary your speech rate (how fast you talk). A variety in your rate along with pauses can help substitute for the pitch variations in your pre-laryngectomy voice.

5. Over-articulate and slightly exaggerate your mouth movements. Open your mouth wider and give more emphasis to the final consonant sounds in words (such as the “d” sound in the word “cold,” the “t” sound in “pleasant,” the “ch” sound in “speech,” the “p” sound in “tape,” etc.).

6. Talking too fast is a problem for many laryngectomees. Try and speak more slowly than you did with your pre-laryngectomy voice. Some people have a more difficult time separating the buzzing sound the AL makes from the words you are saying. Many speech-language pathologists consider the speech rate as affecting intelligibility more than any other single speech factor. Combined with #4 above, it is possible to vary the speed of your speech to provide variety and emphasis, but also not speak so fast that it becomes a problem for your listener.

7. The “h” sound is virtually impossible for laryngectomees to say. But an approximation can be made by prolonging the vowel sound that follows the “h.” An example is “heat” and “eat.” Prolong the “e” sound in front of the word “eat,” and it is more likely to be perceived as the “h” sound. Other pairs of words you can practice are at/hat, it/hit, am/ham, all/hall, eye/high, ill/hill, is/his, as/has, add/had. Another solution for the missing “h” sound is to begin to substitute the “k” sound. But stop short of fully inserting the “k” sound where the “hi” should be.

8. Avoid expelling air out of your stoma as you speak, or making noise as you breathe, if you can. It calls attention to us in undesirable ways. This is called, among other things, “stoma blast.” This noisiness is left over from your pre-laryngectomy speaking when you had to use exhaled breath to speak, or the result of unnecessary strain to force esophageal or TEP speech. Most of us initially produced some unwanted stoma sounds, but audible breathing and air expulsions while talking can become a habit. It is one we want to avoid, or break if we already have it.

9. If your AL has a pitch and/or volume control, practice using them to change the pitch to provide variety, and adjust the volume to different situations of background noise.

10. Maintaining eye contact and using facial expressions and gestures can also help your listener understand you. Facial expressions, appropriate distance from your conversational partner, using little clicks or other sounds that let your partner know that you are listening are helpful. Non-laryngectomees generally make sounds that indicate they are listening such as “uh huh,” “oh,” or a word or two such as “yes,” “I understand,” etc.

11. In using the telephone, a problem many users create is that they hold the microphone part of the phone too close to their stomas and the phone picks up breathing sounds. The easiest solution is to hold the microphone part of the phone close to your nose (up and away from the stoma). It is close enough to your mouth so that sounds from that source can be heard, but further from your stoma. Speakerphones can also help.

Most laryngectomees can make substantial improvement in their ability to use the AL. The name of the game is to be understood, and good practice and technique, along with a properly adjusted instrument, can make a big difference.

Thanks to Elizabeth Finchem, Pat Sanders, Herb Simon, Harriet Thurston and SLPs Carla Gress, Dan Kelly, Brian Shute, Kathy Webb and Tammy Wigginton who contributed ideas or editing suggestions.
Research finds link between HPV and types of throat cancer

HPV (human papilloma virus) is again in the news. An earlier issue was the controversial recommendation from the federal government's Centers for Disease Control that girls ages 11-12 receive a vaccine to prevent four strains of HPV that are linked to the development of genital warts and cervical cancer in females. The vaccine is only effective if it is received before being exposed to HPV through genital or oral sex. Many parents were opposed to their daughters receiving the vaccine when some states considered or passed laws requiring the vaccination.

The most recent HPV news is that the sexually transmitted virus also sharply increases the risk of developing certain types of throat cancer.

Earlier research indicated a possible link between HPV and the development of cancer of the vocal cords, although the strongest evidence still links tobacco use and heavy drinking of alcohol.

The current study appeared in a recent issue of *The New England Journal of Medicine*, and the major researcher stated, “It makes it absolutely clear that oral HPV infection is a risk factor” for oral cancer. Those in the study were shown to be 32 times more likely to develop one form of oral cancer than those free of the virus. Previous studies hinted at these results, but this was the first study to definitely link the two. According to the study, the number-one factor for the development of oropharyngeal cancer is HPV, ranking above both smoking and alcohol abuse.

These findings could help explain why oral cancer rates have been increasing in recent years, particularly among younger people and those who are not smokers or heavy drinkers. According to one writer on the findings of the study, “HPV-linked oral cancers have been on the rise since at least 1973,” Dr. Gillison commented, and she expects this trend to continue. At present, “about 60 percent of all oropharyngeal cancers and about one-third of all oral cavity and pharynx cancers in the United States (totaling more than 11,000 patients) are associated with the virus.”

HPV is commonly found in many Americans. The Centers for Disease Control estimate that 20 million people are currently infected, and at least half of all sexually active people acquire it at some point in their lives. By age 50, 80 percent of women will have acquired the infection.

These findings may help explain why people who do not have the known risk factors—smoking, heavy drinking, exposure to Agent Orange and other chemicals, and others—develop larynx cancer. And if individuals know they carry the virus, it may cause them to seek screening more often for the development of cancer, since early detection is the key to effective treatment and preserving the larynx. Additionally, knowing that contracting the virus can put people at risk for developing cancer may make them use safer sex practices designed to keep people from contracting the virus in the first place. Finally, knowing this connection means that vaccines currently under development for HPV may be effective in preventing HPV-related oral cancer.
The Provox LaryClip, in combination with the LaryButton, offers a durable, comfortable, and airtight stoma seal; especially important to HME and FreeHands users.
October 5, 2007—11:10PM
A Yuma man whose only means of communication depends on a $650 electronic speaking device has had one donated to him after his was confused for a bomb and dismantled by a bomb squad member about a month ago at Food City. Richard Currier, 59, had his voice box surgically removed for the treatment of throat cancer. He needs the electro-larynx, a battery-operated instrument that uses a humming sound, to help him speak.

It is Currier’s only means of communication because he lost his ability to read and write in a recent car accident, said Shanna Thomas, a family friend. He no longer has any family members to help him and is aided by Thomas.

Thomas said Currier was shopping at Food City, 16th Street and Avenue B, on Sept. 12 and left his electro-larynx device in the grocery basket after he placed his groceries in his vehicle. She said because of the car accident, he has no short-term memory and did not realize he left the instrument in the shopping cart.

She said the person collecting the carts thought the device was a pipe bomb.

YCSO Capt. Eben Bratcher said Food City employees called YPD because they thought the electro-larynx was a “strange object.”

He said YPD thought it looked suspicious and contacted YCSO, which sent a bomb expert to check it out.

“It doesn’t look like one they’ve seen before,” Bratcher said. “It looked like a flashlight with two nine-volt batteries duct-taped to it. A normal one

doesn’t have batteries taped to the outside.”

Bratcher said the bomb expert tried to dismantle the electro-larynx but broke a part of it in the process.

Currier did not have money for a new one, and Medicaid denied a replacement.

“It’s the first time I’ve heard of this,” said Jim Lauder of Lauder Enterprises, a Texas company that is the U.S. representative for a German company that manufactures electro-larynx devices.

Lauder is the donor of Currier’s new electro-larynx. His company was contacted by Yuma Rehabilitation Hospital speech pathologist Shanna Cale, who was contacted by Thomas.

He said families of electro-larynx users often give them to him after their family member dies, and he keeps them to donate to those who are in need.

“I had one available, and Mr. Currier was definitely in need, so we sent him one,” Lauder said.

Thomas said Currier received the device Oct. 4, and “he was like a kid in a candy shop.”

She said he had been very frustrated before, and since he received his new instrument, he had called her a dozen times to talk to her with the new device.

“I couldn’t be more grateful,” Thomas said.

—Nicole E. Squibbs, Sun staff writer

(Reprinted with permission of Nicole Squibbs and the Yuma [Arizona] Sun.)
IAL Board of Directors holds first e-mail-based meeting

The IAL Board of Directors held its first e-mail-based “meeting” on Oct. 24-25, 2007. This format for a meeting of the Board became possible and necessary as a result of the elimination of the IAL’s Executive Committee by the Delegates at the Annual Meeting in Burlington, Vt., this past July. An important objective for moving to make use of the Internet for the Board to make decisions was the need to cut back on the expenses involved in face-to-face meetings. An additional consideration was to design a method for any decisions that had to be made between regularly scheduled meetings of the Board to represent the viewpoints of the entire Board.

Under the previous meeting schedule established by the Bylaws, the IAL Board of Directors would meet twice per year—once at the Annual Meeting, and again mid-year at its Interim Meeting. The Interim Meeting is held at the hotel location of the upcoming Annual Meeting. For example, the IAL Board is scheduled to have its face-to-face Interim Meeting in Little Rock, Ark., this coming March.

In the past if any urgent business arose at any other time that could not wait until one of these two meetings, the group authorized to act for the entire Board was the Executive Committee. It was made up of the organization’s officers and two additional elected Board members. But one of the problems experienced with this system was the extraordinary expense of a face-to-face meeting of even this smaller group. The existence of the Executive Committee also dates back to a time when there were as many as 30 or even more members of the Board of Directors. So there was and still is one additional method provided in the Bylaws where emergency issues could be dealt with, and this is via a written document signed by two-thirds of the members of the Board.

The problem in conducting a meeting via e-mails sent through the Internet is that no one, including other organizations, has much experience in how to go about doing this. As IAL Bylaws Chairman Sapp Funderburk put it, “We are breaking new ground and reinventing the wheel of how to conduct a meeting which is democratic, but also efficient. And another big hurdle is how do you lay out the ground rules for the first such meeting ahead of time when any meeting of the Board is totally under the control of the Board which may accept or reject any guidelines provided prior to the meeting?” The challenge is to “marry” the characteristics of the Internet and e-mails with the standards of efficiency and fairness to meeting participants found in the guidelines that provide structure to most organizational meetings—Robert’s Rules of Order.

Organizations like the IAL conduct its business according to its Bylaws. But beyond the structure found in these usually not-very-detailed guidelines, organizations typically rely on Robert’s Rules of Order for assistance in the details of conducting a meeting. The guidelines provided by Robert’s evolved over centuries as procedures most likely to produce an orderly and productive meeting, but one that was also open and that provided full and fair discussion before the majority voted its will. But as Parliamentarians are fond of pointing out, Robert’s Rules of Order does not answer any and all issues that may come up but are guidelines where the intention of order and fairness must be taken into account.

The ideal format for a meeting that seeks agreement among a number of people is a face-to-face one. One involving exchanging e-mails is much less desirable. The Board is also looking into the possibility and costs associated with a video conference type of meeting, which can be held in the same amount of time a face-to-face meeting typically takes but can also be run in complete compliance with Robert’s Rules.

As this is being written the meeting has not taken place, but items on the agenda include replacing several members of the Board of Directors who have resigned since the Annual Meeting, attempting to solve the problem for a need for a permanent address for the IAL, a decision regarding the position of Executive Director, dealing with a petition from a former Board member, and anything else the Board wishes to take up. The results of this unprecedented meeting will be reported in the next issue of the IAL News.
Our 2008 Annual Meeting and Voice Institute will be held in Little Rock, Ark., and hosted by the Lost Chord Club of Central Arkansas. The dates chosen for the AM/VI are from Wednesday, Aug. 27, through Saturday, Aug. 30, 2008.

The University Of Arkansas Medical School has agreed to host the Voice Institute and the hotel that won the bid contract is the Peabody Hotel (four star), which is located in downtown Little Rock.

For those of you that shop till you drop, the River Market shops are within easy walking distance, as is the Clinton Presidential Library Center. Across the road from the library is the world headquarters for Heifer International, a leader in earth-friendly design. This “green” headquarters represents a commitment to promote sustainable solutions that protect water quality, natural resources and the environment.

If you do not feel like walking, you can choose the tracked trolley that will carry you throughout downtown and across the Arkansas River to the other side for more tourist-packed things like the new baseball stadium, which can be seen from the Peabody Hotel, and the WWII submarine that is docked on the riverfront to tour. Of course next to the Peabody is the Old State House Museum that is open to the public and is free. Other areas of interest: the Central High School Historic Site. This is the high school where in 1957 nine African-American students entered the school under federal troop protection. Another great attraction for veterans is the MacArthur Museum of Arkansas Military History. This museum interprets the state’s military heritage and honors the contributions of Arkansas servicemen and women, at home and abroad, who served in military conflicts from the state’s territorial period to the present.
If you go online to www.littlerock.com, you will see what the Convention & Visitors Bureau has on its Web site. Also, you can view the Peabody Hotel by going to www.peabodylittlerock.com.

We believe that our headquarters hotel is one of the very best we have ever used for an Annual Meeting.

The room rates are as follows:

- Single superior room $110 + tax
- Double rate $110 + tax
- Triple rate $120 + tax
- Quad rate is $130 + tax

More information will follow and will be posted on our Web site soon.
How I Came to Become a Drunk Tester

As we approach the holiday season I thought it would be a good time to remind everyone, laryngectomees and non-laryngectomees alike, not to drink and drive. Very seldom do we, as laryngectomees, go back to engaging in behaviors that are detrimental to our health. I would venture to say that 99.9 percent of us have laid down the cigarettes, cigars or any other type of tobacco product. Some of us, myself included, liked to partake of the “spirits” from time to time. It appears there is a well-established connection between tobacco, alcohol and cancer of the larynx.

This direct connect, when coupled with my pre-laryngectomee occupation of being an instructor, a 911 center supervisor, acid reflux, and a not-so-healthy diet, led to my larynx cancer. After all the radiation and chemo in an effort to salvage my voice, it returned and I had “the operation.” Whether you’re on the radio, even though it’s a small selective audience, or standing before a crowded classroom, you become known for your voice.

Following my laryngectomy I was out visiting some friends at the Garner Police Department. Garner is a suburb of Raleigh, N.C. I know most everyone in the department from my days as a 911 dispatcher. They wanted to know what I was doing and I told them “nothing.” I also told them that I wasn’t overly thrilled at doing nothing and inquired whether they had anything that I could do, perhaps as a volunteer. That was the wrong question to ask.

I soon became the unofficial administrative assistant to the investigation staff. They sent me back to school to again become certified as a Department of Criminal Information operator through the North Carolina State Bureau of Investigation. They had me running all sorts of inquiries on the state’s system once I was again certified. This volunteer position soon became a 35- to 40-hour a week job. No real money, except for an occasional lunch or cup of Dunkin’ Donuts coffee. This relatively cheap labor garnered me their Outstanding Volunteer Award for 2002.

While running errands at the magistrate’s office, I stopped in to visit my friend at the Raleigh/Wake County–City-County Bureau of Investigation. These guys are the CSI Raleigh types. I also knew them from my 911 days. They gave me the grand tour, which included one large room whose sole purpose was conducting Intoxilyzer examinations. I inquired as to what the job requirements were for an ID technician. I also inquired if there were any openings, and they said I should keep my eye on the county Web site, which I did. I felt that I had the qualifications to become an ID tech so I applied. I was interviewed and accepted a position in May of 2003.

These ID tech positions require one to interview prisoners, enter their information into the countywide database, take their fingerprints, and verify their identity by comparing the prints they give us with those that are on file. I also give suspected impaired drivers Intoxilyzer examinations to determine their blood alcohol content.

Performing Intoxilyzer examinations is rather interesting. I was required to attend a week-long school to learn not only about the instrument but also the laws surrounding the driving while impaired statutes. We were also required to drink and take the examination. I didn’t partake of this opportunity as at that time I had not developed my little gizmo that would allow me to take the exam. At the end of the week-long class, I had to pass a state-required test to become a certified Intoxilyzer operator. I kept thinking that when I go to court and testify in these cases, some defense lawyer is going to question me on how I, as a laryngectomee, can give this exam yet not be able to take the exam myself.

At the time I was using a Cooper-Rand as my “voice of choice.” Occasionally one of the arrestees will state that they are unable to understand me or say that I sound like Peter Frampton. Some state they can understand me and then halfway through reading them their Intoxilyzer rights they say they can’t. They also try to use this as a defense when cases come to court. I had one lawyer state, and I found this amusing, that “What we have here is a failure to communicate.” So far none of the judges, DAs, or for that matter most of the defense attorneys have had or have made an issue out of me utilizing a Cooper-Rand to communicate.
After my trip to the Voice Institute in Boston, I switched my “voice of choice” to a Nu-Vois III. I haven’t experienced any further difficulties being understood. Every once in a while one of the intoxicated folks will still call me “robo-cop.”

When I had my laryngectomy I also had my puncture for a TEP. Due to some issues concerning large stoma and small thumb I have let it close naturally. One of the last things I had tried was a baby bottle nipple to cover my stoma and voice while it was in place. This worked well but was awkward to say the least. I then thought that if I used the baby bottle nipple, stuck a catheter in the nipple end and attached one of the mouthpieces we use at the other end of the catheter, I might be able to take the exam. Well after some failed attempts to get all the plumbing right, I was successful.

Another ID tech and I tried it out one night when things were slow. I attached the mouthpiece into the tube of the Intoxilyzer just like I would if I were giving the examination to a suspected impaired driver. I then took a deep breath, occluded my stoma with the nipple and “blew” into my contraption for about 5-7 seconds. This is the same period of time required of those with normal plumbing. I took the exam twice, the same as required of “normal” folks. I obtained the desired results. I was able to take the examination and pass.

Now when I am called upon to testify in court about giving the examination, I can truthfully say that I can also take the test. In North Carolina if one refuses to take the examination, they automatically lose their licenses for 30 days plus get a 12-month revocation by the Division of Motor Vehicles. This is a total of 13 months without the chance of obtaining limited driving privileges, etc.

Some of the people refuse to take the examination for medical reasons. Some say they have asthma, they smoke, they have dentures, to name a few. Should this be the case, I again inform them of their 13-month suspension, and if they refuse it’s logged as a willful refusal. Normally this type of case doesn’t make it to court. If it does and the person’s lawyer attempts to claim that his client was unable to blow for the required length of time because of the client’s medical condition, it quickly becomes evident to everyone present—judge, lawyers, jury, etc.—that if I, as a laryngectomee, can take the exam, and I do not “blow” through normal methods, then the client should be able to blow as well. Most of the time it gets no further that the district attorney inquiring if I can take the examination. My response of “yes I can, and here is my own test ticket” is enough evidence that the defense gives up without much of a fight.

Even though I have used both the Cooper-Rand and the Nu-Vois III as my primary method of voicing, I have encountered only a handful of people who absolutely refuse to listen and understand. Another benefit of my utilizing either the Cooper-Rand or Nu-Vois III is that it gives me a tool to actually demonstrate what it is I want the arrestee to do when taking the exam. The mouthpiece that the Intoxilyzer uses is about the same diameter of the “straw” for the Cooper-Rand. I just hold up the mouthpiece and the straw and state that I want them to wrap their lips around the mouthpiece like this. I then demonstrate how they should place their lips on the mouthpiece by placing mine on my end of the Cooper-Rand’s straw. The Cooper-Rand and Nu-Vois III also provide a great sound-effect device when I have to explain that the instrument will make a tone or noise when one is taking the examination properly. I give them a 5-second buzz of the Cooper-Rand or the Nu-Vois III and there can be no question as to whether or not an adequate demonstration was provided.

Being a laryngectomee has required me to re-evaluate many things in my life. It has also made me make numerous adjustments as to what I can and cannot do or must now do differently. I have been fortunate enough to find a position with an organization that does not view me as having a disability.

Today I am a supervisor in the processing unit. I have a crew of 5 ID techs. I don’t get the opportunity to give as many exams as I did previously. I always keep my little contraption handy just in case another laryngectomee is brought in to be tested. Should you decided to visit our fair state, don’t drink and drive. You may end up with me as your Intoxilyzer examiner or one of my crew, who have been trained on how to give a laryngectomee an Intoxilyzer exam. We have ways of making you blow.

—Mike Dreisbach
Burlington 2007

56th Annual Meeting & 47th Voice Institute

Kitchen tour at the New England Culinary Institute

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International Association of Laryngectomees

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The IAL News
A newsletter that is published four times annual. A $5 a year donation is requested but not necessary.

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