

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

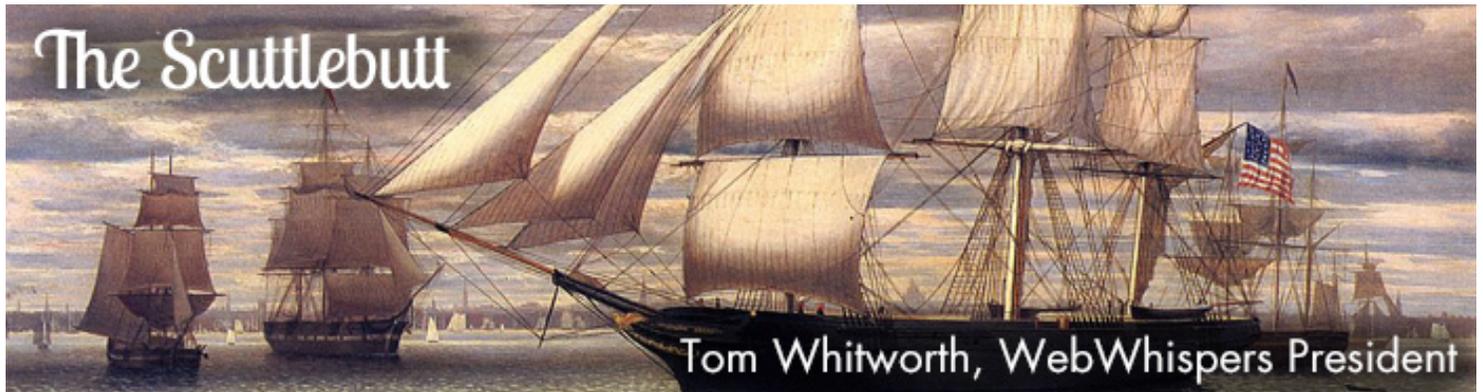


August 2017

Name Of Column	Author	Title	Article Type
The Scuttlebutt	Tom Whitworth	We've Come a Long Way!	Commentary
VoicePoints	Sarah S. Persia, M.S., CCC-SLP, BCS-S	Patient-Maintained Voice Prosthesis: FAQ	Education-Med
Between Friends	Donna McGary	Tech Talk	Commentary
Speaking Out	Members	"When did you get your first computer?"	Opinion
Dear Lary	Noirin Sheahan	Computers vs Real Life	Commentary
Travel With Larys	Janine Mattoon	My Trip to the IAL	Experiences
The Speechless Poet	Len A Hynds	Send to...God.com	Prose & Poetry
Bits, Bytes & No Butts!	Frank Klett	Amazon: One Big Mother	Computers

INDEX AND LINKS TO EACH ISSUE MAY BE FOUND AT: <http://webwhispers.org/news/WotWIndex.asp>

COMMENT HERE
FEEDBACK



We've Come a Long Way!

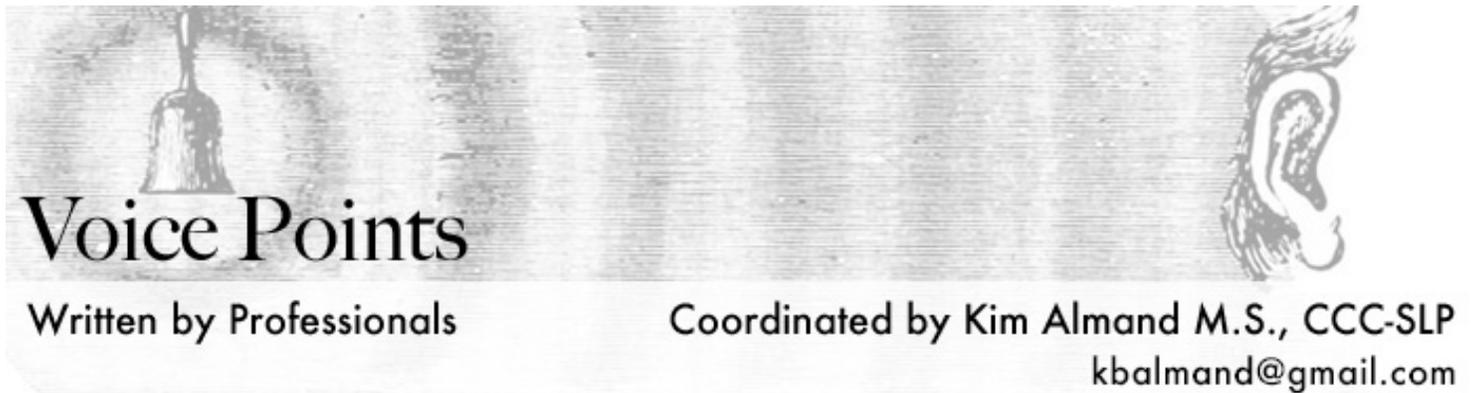
This issue calls attention to matters of technology, including the Speaking Out question "When did you get your first computer?". I've thought about it and actually pondered what constituted a computer in today's terms. I do know that my first at home desktop computer was way before the inception of the internet. It was a DOS based machine with the green screen, connected to a dot matrix printer. I had been allowed to take an extra one home from work in order to keep up my reputation as a workaholic. As far as I can remember this machine could run Lotus 123, and Word Perfect and I don't think much else worth mentioning. It's hard to forget the day our four- year- old daughter (circa late 1980's) showed her amazed parents the letter to Great- grandma she had typed. It was still on the screen and she wanted me to print it so she could drop it in the mail to her great-grandmother, with whom she was very close. Yes, the letter was short and quite elementary, yet far more than we realized she was capable of and it was on the computer!

As I considered the topic for this month, I also caught myself again remembering the sleepless nights following my surgery, when I basically lived in a recliner. Healing slowly and often in pain, I spent a good bit of awake time, day and night, on my laptop communicating on the web, researching and learning all I could. In particular, the one or two nights that will always stand out in my mind, are the nights I found my first support as a laryngectomee. I'm not quite sure about the order as I was still on pain meds, I think, and maybe still somewhat in shock. I do remember the most important things here. Among that first online support, from googling "laryngectomee" and searching similarly on Facebook, I found Lary's Speakeasy, where I "met" not only Louis Trammel but also my good friend Jim Lauder. They responded to me on the same night. I had heard of WebWhispers but, given my state of mind, could not remember the name. Searching led me to the webpage for the International Association of Laryngectomees (IAL), which showed me a link to WEBWHISPERS, where I met Pat Sanders and then many others. All on the computer, I began to receive support and realize I could do this laryngectomy recovery thing. My mind is not capable of completing a thought as to where I might be without this online support. When Mary Beth showed me her letter to Great-grandma nearly thirty years ago, I could not have fathomed where the computer would have led me today. Who would have believed it?

As far as I know, our website remains the most active source of support worldwide, for laryngectomees and caregivers. We are visited by the clinical professionals who work with us as well as students of the Speech-Language Pathology profession. The graduate student age group

sometimes comprises the largest group of visitors (exam time). Uses of the website average more than 10,000 monthly, and we've grown beyond the computer, along with most everything else. The number of our viewers on mobile devices increases each month and is over 48% during the past six months. What began at a time when not everyone had a computer, grew to 10 members at the end of 1996. In the past year, our net growth in membership was 288 and we could easily surpass 4,000 by the end of this year. It all began when Dutch Helms sought to bring laryngectomees together, using his computer and the internet, then known as the "World Wide Web". Again, who knew?

*Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President*



Patient-Maintained Voice Prosthesis: FAQ

The topic of patient-maintained voice prostheses (non-indwelling devices) is one that comes up frequently in our clinic, not only from patients and caregivers but from other clinical professionals as well. Here I will offer a brief review of some of our most frequently asked questions.

Is it right for me? This is the question I hear most frequently from patients. Within our laryngectomy community there are many members who live a great distance from the clinic, with limited access to care near their homes. The patient-maintained device often times makes sense from a logistical standpoint. But is it for everyone? There are many factors to consider for both clinicians and patients. Our first consideration is always the patient's wishes and we must also look closely at other clinical factors such as: Is the TEP visually and physically accessible for the patient to change it independently? Is the tissue at a stable point where frequent size/tissue changes are less likely? Is the patient or caregiver comfortable with the removal and placement process? The answer to these questions, as well as overall cost, helps guide our recommendations.

For further reference, a more in-depth discussion of device expenses, insurance coverage and obtaining specific supplies may be found in another recent VoicePoints article: Navigating the World of Laryngectomy Supplies (Donocoff, McCarroll, and Ebersole, WotWeb November, 2016):
<http://webwhispers.org/news/nov2016.asp>

Will it last as long as a clinician-placed device? A traditional school of thought seemed to be that a patient-maintained device may not last as long as a clinician-placed TEP. However, in our clinic we have seen this is not always the case; in sum, it is unique to each patient. The state of the esophagus may sometimes

contribute to premature valve failure, due to such issues as, among other things, postsurgical reconstruction changes, stricture, cricopharyngeal spasm, and the presence of reflux. In addition, variations in anatomy and the physical characteristics of the tracheoesophageal tract and stoma may impact the life of the device. One recent study showed that the device life of patient-maintained prostheses did not differ significantly from the life of other clinician-placed devices (Lewin et al, 2014). There are many variables unique to each patient, and a certain device life cannot be guaranteed. However, hopefully more research will continue to come to light to help guide us in determining what may work best for each person.

Do I still need to see my SLP? In our clinic, after first placing a patient-maintained device we typically follow up within a few months to ensure that things are working well, and then can stretch the follow up interval longer as stability is established. We do continue to see most patient-maintained device users at least on a yearly basis (more often if needed) to ensure continued correct sizing, monitor for tissue changes, or address any stomal issues. Many patients are extremely proficient at managing their own prostheses and do not need my assistance. However, it's always a good idea to maintain an ongoing connection with a clinical professional, in the event that issues do arise.

Challenges are not unusual when attempting to transition to a patient-maintained device. I appreciate the words of Brian Kanapkey, an SLP of many years' experience with TEPs, when he says, "In the age of flaps and salvage surgeries, it is a bit more tricky than it once was." But regardless of which type of TEP provides the best outcome, we work hard to respect each patient's goals, and to do our very best in finding the highest level of independence and best quality of life possible after total laryngectomy surgery.

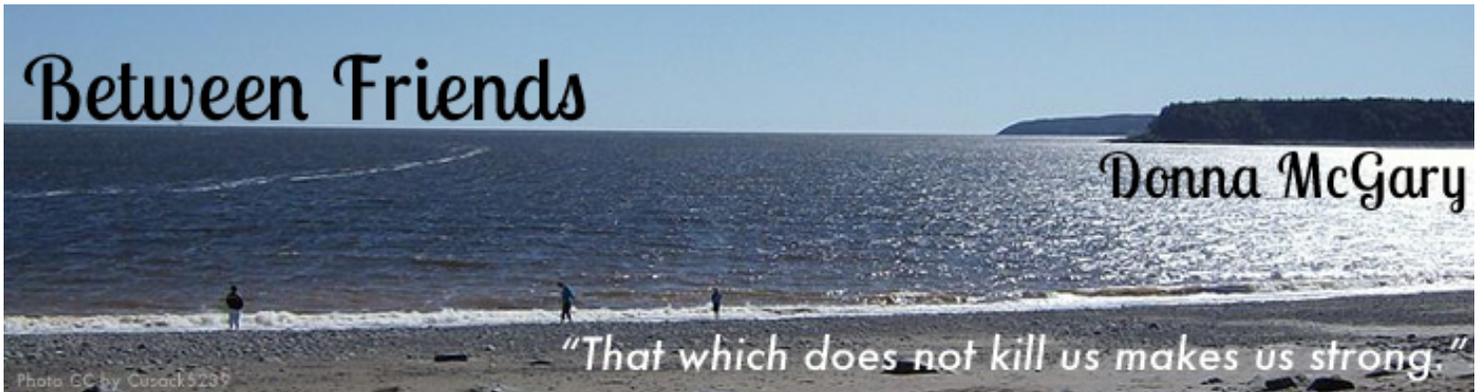
Sarah S. Persia, M.S., CCC-SLP, BCS-S
Wake Forest Baptist Health
Winston-Salem, NC

Sarah received her Master's Degree in Speech-Language Pathology at The University of North Carolina at Chapel Hill. She then completed training at Wake Forest Baptist Medical Center and in Otolaryngology at UNC Hospital. Post-fellowship, she gained additional experience at The University of Arizona Medical Center before returning to Wake Forest Baptist, where she works primarily with Head/Neck Cancer, Laryngectomee patients, and in the Center for Voice and Swallowing Disorders.

References:

Lewin JS, Portwood MA, Wang Y, Hutcheson KA. Clinical Application of the Provox® NiDTM Voice Prosthesis: A Longitudinal Study. *The Laryngoscope*. 2014;124(7):1585-1591. doi:10.1002/lary.24488.

For additional information regarding talking again using a TEP and various voice prosthesis options, the WebWhispers Library is an excellent resource: <http://webwhispers.org/library/TEPProsthesis.asp>



Tech Talk

From time to time Frank Klett has written about his experience using Alexa – one of the voice activated “personal assistants” now on the market. Siri and most recently Google Play all offer pretty much the same options. I was surprised to learn he could use Alexa since my experience with voice activated systems on the telephone has been dismal. Turns out he also uses an EL (a TruTone) and has no problem communicating with Alexa providing he uses the handheld speaker option.

Despite his success I was not convinced it would work for me. My son and his family have Alexa and it seemed more like a gimmicky toy than anything else. And even though I have an apartment attached to their house I was never compelled to give Alexa a chance.

However, a while back my son came upstairs with Alexa’s “baby sister” the EchoDot and wanted to show me how it could be used as an intercom. And lo and behold, Alexa/Dot understood me right from the get-go! We sent the girls to the far side of the house and I tried calling them. No problem- they could hear me plain as day and I, them. Then we played some music and I asked her a few basic questions, no problem. I was impressed enough that when Amazon had their Black Friday sale in July I bought one. Scroll down and read Frank’s column Bits, Bytes and No Butts this month for my first impression and more details as well as a link to buy the mic.

My initial experience had mixed reviews. Good for basic stuff but the music was a no go. Dot couldn’t find the song I wanted and then played something entirely different. She couldn’t hear me say stop (ambient/background noise is a problem especially with an EL (I use a Servox) and as of now am not using the handheld mic. But it is a fun “toy” and I continue to experiment with it.

This week I am house/dog sitting and they have the original Alexa so I tried talking to her. She was OK with a few basic questions w/in 10 feet but got confused when I asked her a more complex question like what time was high tide or “how do you freeze cooked salmon?” That stumped her.

She practically apologized for not understanding me saying something like her vocal recognition will get better over time and then added salmon to my shopping list!! I tried to get her to delete it but she said I needed the app and figured since it was their leftover salmon in the fridge they wouldn’t mind it being on the list when they come home in 10 days LOL!!! I did discover that Alexa was fine with music. I had no problem getting her to play Lyle Lovett and even to stop and play a different song. Alexa has better speakers so maybe that helps or maybe Dot just didn’t recognize Lone Bellow. In the meantime, I’ll work on helping this Alexa recognize me.

My son also just bought the remote stand for his dot and loves it. Said he used it the other day by the pool and it worked great. When I mentioned to him that I thought it was fun and cool but not sure it would be all that useful he said he and his wife had thought the same thing when they first got Alexa but over time they have found it very useful, particularly with the reminders, shopping lists, news bursts in the morning, basic questions that you would otherwise have to look up and music. Moving forward they'll be using her a lot more with home automation systems.

It is cool as a house intercom system too- he called the girls downstairs the other night for dinner. So I can see possibilities. The kids used it to set a timer for the youngest's eye patch which she had to wear for two hours every day. I think it could work equally well to remind folks to take their meds or check their blood sugar for example. One thing I wanted to explore was whether it can be used to call 911 for example (assuming I have my EL with me and I am w/in range) or dial any number and connect to my smart phone. As it turns out none of these devices can call 911 because of regulations requiring a call back number when you dial 911 and they cannot accept incoming calls at this time, although I expect that to change in the future. For now, there is a free app that works for Alexa, Google Play and Siri called "Ask My Buddy" which allows you to alert someone in your network that you need help. I'll check it out and let you know what I think but if anyone has used it I'd love to hear your opinion.

I am particularly curious to find out just how much Alexa or any of the latest voice recognition programs could learn/be taught to understand our distinctive voices. The technology doesn't just have problems with lary voices. I have a friend who is losing her sight and she relies on Siri for email etc and says her distinctive Southern accent results in some very funny texts.

I'm kind of surprised at how much fun I'm having with this – I think I might be turning into a bit of a techie in my dotage!



“When did you get your first computer?”

Upon returning to the classroom in the late 80's as a substitute teacher, I was required to keep my teaching

certificate active by taking grad level courses. Many of the courses I chose were introductions to computers; but with no computer at home, it was difficult to practice what I had learned. The computer courses offered for credit were taught using Apple/MAC's, yet the school system switched to PC's in the late 90's. This was more than confusing to a tech novice.

Meanwhile, I signed a full-time contract in 1995 to teach art at the middle school level and became the school Yearbook Editor, as well. At that time, I purchased a used, cheap word processor (basically a typewriter with memory) from my neighbor, so that I could easily alphabetize student names, edit spelling, save them on a floppy disk for printing at school, and paste them on the yearbook layout pages. Now they have yearbook software! Within 2 years, I bought my brother's used, not so cheap MAC, just to keep up with the rapidly changing technology and to become acquainted with Photoshop for some of my lessons. At that time, email was available to me only on the school library's computer and was limited to those few (mostly school employees) who had an email address. Times have certainly changed.

Barb Gehring - Akron, OH 2013

I had my laryngectomy almost five years ago and do only esophageal speech if any at all. Six months later my niece Brenda gave me her old tablet thinking perhaps I would use it for communication which I did and have ever since. Also along with it she allowed me to ask her two questions a day re emails. I live out in the middle of the desert here in Nevada so even with all the brain spinning and problems it has been an extremely helpful aid for the most part. I use only a very few apps...music! YouTube movies! Las Vegas Sun for news and google for other stuff. Keeps this 86 yr. old gal moving right along! Ha! Ha!

Virginia Johnson, Beatty, NV

Oct 2012

In 1977 I was assigned to the Utilities Department of a large chemical/pharmaceutical manufacturing and research facility as one of the engineers. One of my duties became budgeting and monthly accounting. This was a major duty because the operation budget was seven plus million dollars a year. Just as a small example, we produced 1.2 million pounds an hour of high pressure steam and pumped 80,000 gallons of salt water a minute.

The budgeting and accounting was done on an IBM main frame computer using punched card input and COBOL programming. I had to acquire at least a basic familiarity with COBOL to be able to read and decode the thousands of lines of code.

Several years later, we moved the accounting to a DEC computer system where we could plug a phone into a modem and do data entry directly. The system used BASIC programming, and though punch cards were eliminated, reams of printout still had to be read and decoded.

Fast forward a few more years and we acquired our own DEC-20 where we could do the work right in the office.

All this lead me to become interested in the use of a computer for home. My first was a Commodore bought in the mid to late 1980's. I'm not sure we did anything remotely useful with that. The evolution from that period through the '90s to the 21st century has been so rapid that my memory really cannot develop a timeline.

By the time I retired, the utilities budget which took weeks to complete had evolved, primarily through my

efforts, to an interactive, multi-page spreadsheet workbook that could run a budget in a few hours.

Meanwhile at home, the Internet had become a reality with CompuServe and Netscape becoming our dial-up partners. I progressed from the Commodore to several home assembled computers and finally to a few Dell computers. Today, I have a home assembled server, a Dell desktop and a Dell laptop as well as an Android smartphone.

Considering what we do today with social media, online banking and transactions, email, broadband connectivity and all, the computer has become a wonderful tool, a dangerous vulnerability and a miserable time-waster (if we let it).

Being an eighty-year-old fossil, I still prefer sitting down with a good book for a few hours each evening.

Carl Strand, Mystic CT
Laryngectomy 1993

We first bought a BBC computer for our children (family) approx. 30 years ago because we believed the hype about children needing these skills and of course we wanted our kids to have a head start. I remember switching on and it must have asked me to input our name early on in the set up but the screen suddenly changed color and showed a blinking message "welcome Trevor Hutson!" I was blown away that this computer knew my name (I had forgotten I must have put it in earlier in the process), The floppy disks, the tape players that had to be calibrated, the general difficulty in getting it all together and of course having to learn Martian to input info meant I gave up within weeks. My kids gave up within months and altogether it was not a good experience! These days are a lot easier while everything goes right but when a problem occurs!!!

Yes I have used them but I really still don't like or trust them.

Trevor Hutson – Keynes, UK

I got my first computer in 1988. The reason I got it is I wanted to teach myself to use a computer and see what I could learn on the internet. I knew it was going to be the thing of the future. I was 37 in 1988.

Karol Beaufore – Apena, MI

In 1993 Sears ran a half page ad in the Seattle Times ... Mackintosh computer, printer, all the latest software, no money down and six months to make the your fist payment. \$2500. I told my wife that I am 64 years old and it's about time I got in to the coming Internet technology.

I went to Sears and purchased the desktop Mac, and when I asked the salesman where do I go for lessons he said ... This is a Mac you don't need lessons. Just take it home and you will see just how easy it is to operate. If after thirty days you haven't figured it out come back, and I will discuss it further with you. I never went back. I have had four Macs and currently a 21.5 inch iMac. In all of these years I have never had a breakdown, or problem that wasn't of my own doing.

Also, being legally blind I can high light everything and have the computer read it back to me. I do all of my banking, pay my bills, and never have to buy any stamps. When I have to talk to someone on the phone I type out all the important facts I think they might want to know, and my computer read it to them. It really works well for me.

Johnnie Dontos - Woodway, WA
Class of 11/30/2015

Got my first computer in the early 80's, one of the very first Texas Instruments. It had a total memory I believe of 64MB.

Dave Ross – Edgewater, FL

I received my first computer from my daughter right after I came home from hospital, because I couldn't speak, so I could text and stay in touch. It was frustrating at first, as I wasn't much of a tech literate, but with grandkids help, I managed to adapt, great teachers. Best gift I could have received, that was how I found WebWhispers.

Joe Hilsabeck - Edelstein, IL
2009

It was in 1994 that really started me on the path to computerism. It was then I had open heart surgery, with metallic valves installed, a bypass and a pacemaker, and the net result strangely enough was to write in a very shaky hand. Not my normal strong hand, which I had from my schooldays. I thought it could be my advancing age, but I was only 64 then and considered myself youngish.

I had a secretary who could type all my letters, but I missed writing and bought myself a typewriter that kept a record on tape of everything I had written. A forerunner of the computer I guess. Ten years later I went down with the cancer of the throat, and at the same time I discovered that my typewriter tape was no longer being made. I could no longer use it That first six months without a voice, was therefore made doubly hard, as I could barely read my attempt at writing, neither could the person trying to read my comment.

My youngest son came to my rescue however, by buying me my first computer, in 2005, plus I was talking again. It was four years later when I discovered Whispers On The Web, and my life changed completely. I have friends all around the world. It is truly a family.

Len, The Speechless Poet, of Ashford, Kent, England
2004.

In early June of 2009 my brother and I met with my surgeon and on that day it was decided that my surgery would be done on 9/8/09 The surgeon told me about the WebWhispers site and that is where I should do my research. Little did she know I never owned a computer before although I did some data entry at work I never been on the Internet before.

Well my brother was a computer geek and he explained I would need some way to communicate with family and professionals so he ordered me my first Dell that night. Now he lived 60 miles away so when he dropped it off he said you're on your own. So there I was trolling WebWhispers nightly while learning to use email because of all the new friends I made. The emailing came in handy after the surgery because the surgeon didn't trust me as I lived alone so had to email her every morning by 9 am. That was great also because we solved a couple problems without me going to the hospital. Anyway learning the computer made my surgery a piece of cake and I'll always thank WebWhispers for that.

**Lou – Chicago, IL
2009**

April, 2006. I bought a printer but needed a computer to use the printer. I was very naïve. For about a year or two I was afraid to even connect to the internet. I made a lot of mistakes. I finally crashed it about three years ago. I never backed it up, didn't know. Now I have my second computer, still a wired desktop. Still learning. Baby steps.

**John Grundusky – Hawk Run, PA
01/12/2012.**

I got my first computer in 1987. I was a student at UC, Riverside, CA. I was doing a class at the photography museum. I was, and still are, researching Harry Pidgeon, who had built a 30' yawl in 1925 and sailed around the world alone. He taken many photographs that eventually were donated to the museum. My task was to catalog the images and write a research paper. I did all the research. I needed to type my paper.

We purchased a Gateway computer from Costco. I knew nothing about computers, so I cut my teeth on this one. I figured out how to write the paper and slowly was working my way to finishing. I was working on the bibliography and somehow underlined the entire document, all 25 pages. I could not figure out how to remove the underlining, so I had to type the entire paper over. A good lesson!!!

**Marilou Percival – Ontario, CA
8/2013**

I worked for Northeast Utilities in CT, I think it was about 1978 we went to computers somewhere around there. We had a computer at our house really early, when the screen was green and we had to do c/ prompt and type in a bunch of stuff to get on. I remember we only had so much time we could be on, and we had to dial on. If we were on the computer we could not use our phone. Then there was the internet, love it.

We always had a computer and my son was a computer technician, I remember him saying "try it, it can't blow up". I remember when I used the 1st word processor. How it was so easy to make corrections and add and delete. Wow, I loved it. No carbon paper!

Linda Palucci - Kissimmee, FL

Got my first computer just after surgery for laryngectomy in 1986 while recuperating.

**George Myron – Ocala, FL
1986**

I became interested in computers in the spring of 1998 when I purchased my first mobile home. A neighbor and I purchased a huge pile of scrap computers and as a pastime and hobby we learned how to build Frankenstein computers from this pile of parts. Those days you needed to install separate cards on the motherboards for monochrome or color display, sound, printing, dial up modems etc. USB did not yet exist so there were extreme limits on the peripherals and accessories one could add. These predecessors of today's computers are in comparison quite archaic.

I remember building my own PC and always got excited when I upgraded like from monochrome to VGA color and then again ultimately to SVGA graphics and color monitor. Sound on computer was the next big thing and then ultimately connecting to the internet through the America On Line platform. I am still amazed that my relationship with Lisa lasted through this phase because between a full time job with 20 or more hours overtime a week, computer building workshop (and playing on the computer) and sleep there was little if any time left to devote to her. Now I devote my life to her. Just I wish I still had that energy, enthusiasm and ambition!

I initially became involved because I was amazed at potential activities which could be done on a computer. I enjoyed video games and connecting with people throughout the world. We built computers and sold them cheap to many of the elderly residents at the Mobile Home Park and we even offered setup and a couple of hours of instruction on how to use them along with a full 30 day warranty on parts and labor. We never made much money but it was fun and very rewarding on a human relations level. The challenge of making a pile of garbage breathe new life was very appealing to me. It was more fun than my day job which was auto mechanic and shop manager.

**Michael Csapo - 29 Palms, CA
Class of 2000**

**Next month's question is "Tell us a little about yourself.
What was your primary occupation? Your favorite job? Special skills?"**

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.

Staff of Speaking Out



Computers vs Real Life

My first 'computer' was an Epson programmable calculator that I used during my first job in the late 1970s. I was working in a lung-function lab in a London hospital, and after every patient had blown their lungful of air into our various instruments, we would multiply and divide the results to relate these to the 'normal value'. For example, a 65-year-old woman, 5ft tall, who could blow into a tube at a peak-flow-rate of 350 litres per minute scored a good 97% of the 'normal value' and would have no reason to worry, whereas a 60 year old man, 5ft 9 inches tall who achieved the same flow-rate would only have scored 62% of his expected value, which might indicate a problem with his airways.

There was probably a good five minutes of calculations after each patient. I managed to program the calculator so that all we had to do was to key in the person's results along with their age and height and instantly all the normal values would get printed out. Magic! Everyone was astounded. Needless to say, I was delighted with myself!

Somehow that led on to printing out full booklets of 'normal-values' for lung volume, peak flow etc. that all of my colleagues could use, and we could share with other lung function labs in the region. It seemed like such a simple idea and in my youthful innocence I said it would be no bother at all and would easily have it done before I went on holidays. Ideas might be easy, but life has a way of resisting them! Mistakes were made, printers broke down, paper ran out, time and patience ran out even faster. Would I admit defeat? Postpone the delivery date? Not a chance! My youthful self-esteem could not envisage such a set-back. Come hell or high water, those booklets would be done.

My boyfriend arrived from Dublin, expecting to see the sights of London for a day or two before we got the ferry to France. Instead all he saw was a lung function lab with piles of pink and blue sheets (pink for ladies, blue for gents) needing to be sorted into booklets and bound. Lucky for me that he was happy to row in, and somehow we got it all done before we stumbled out into the dawn to catch the train to Dover.

In fact this is a good illustration of how computers have affected my life. What starts off as a simple time-saving application always seems to mushroom into a huge project that, ironically, consumes all my spare time! If only I had reflected on this first lesson and learned not to make rash promises, I might have saved myself a lot of heartache!

I heard an interview yesterday with Tim Harford who has just written a book "Fifty Things that Made the

Modern Economy". One of the things he didn't list was the washing machine, and when he was asked why not, he said that it hadn't actually made a significant impact on how we live. Everyone thinks that the washing machine saved women loads of time on laundry, and therefore made a great contribution to women's liberation. But when he looked into the research he found that what actually happened was that women started doing more laundry! I know this from stories of my mum's childhood where Monday was washing day, and on Tuesdays her mother and sisters would be running in and out taking the clothes on and off the line depending on the weather, and then Wednesday was for ironing and folding away. The washing machine only simplified the first step. But because it seemed like such an advance, women started washing clothes every day and expectations for clean clothes increased with the invention. Overall women spent as much if not more time on laundry once they got a washing machine. The more things change, the more they stay the same!

Is it the same with computers? Those five minutes we used to spend doing multiplication and division to find out whether a patient's lung function was within the normal range – were these minutes 'liberated' for more useful work after I got all the booklets printed out? I wonder. Hopefully some of the time got devoted to improving patient services. For myself, I got more and more drawn towards computing and electronics – the technical side of patient care, and less involved in direct patient interactions. Looking back, I can see the negative sides of that. I lost touch with what had inspired me to go into the medical world in the first place and became more and more bogged down in research and QC and maintenance contracts and machine specifications. All very important for high-tech medical care, but I lost touch with the core value of kindness that was my original inspiration for the career. In the long run, I got burned out long before cancer showed up.

Maybe that would also have happened even if I had shied away from the programmable calculator and continued with long-hand multiplication and division. It's easy to lose touch with our youthful ideals as adult life teaches some of its ugly lessons. Luckily I started meditating in my early thirties and as I got disillusioned with my chosen career, I was getting in touch with that within us that doesn't compute or fuss or intervene or desperately strive to cure all the ills of the world. That has been my real saviour – especially in learning the sometimes ugly lessons that laryngectomy teaches. Like how to recognise and believe in myself when each word I say sounds like a harsh squawk. How to go out and meet with people when I dread the sound of my own voice.

I still battle with that, and at first placed all my faith in the promise that the world of computers and technology might develop a more pleasant, feminine-tone-electrolarynx. It doesn't seem like too much to ask of the medical technology world that gives us Proton Therapy and CT-scans and MRI images. A few dollars will buy you a synthesiser to give you a melodic note around middle-C – which is roughly the pitch for a female voice. How difficult could it be to feed that melodic note into an electrolarynx? For a year or so post-laryngectomy I teamed up with some of my old colleagues and we started looking into this possibility. But, like many simple ideas, it has stubbornly resisted our attempts to translate it into reality.

I've not yet thrown in the towel, but am very grateful that, as my expectations for a pleasant-tone-electrolarynx recede, resistance to the sound of my current voice is also softening. I still don't like it, but I can live with it. For that, I have to thank meditation practice, as well as all the friends and family who encourage me to keep involved and join in conversations.

Technology and computers have played a very positive role in my life (WebWhispers is computer-based after all), but ultimately I've learned more from learning to let them go than from whatever magic they promised. Like the washing machine that tricked us into doing more laundry, these lure us into big ideas that can have little connection with real life. The words on this screen tell a story, while the fingertips that type them sense only the hardness and the clicking of the keys. Although the words are enticing, the fleeting sensations have

their own allure. They don't tell a story. At times, they even seem to come from another world. A world where calculations and computers have no role.

It's that world that draws me more and more. Does life begin where words and calculations cease?



My Trip to the IAL

Janine Mattoon



Going to the IAL this year was a trip of a lifetime for me. I had really wanted to go to the IAL annual meeting, especially since I missed going last year. Ron mentioned that if we flew into Richmond, Virginia, we would only be a 5 hour drive from Harman, West Virginia and a few hours drive to Newport News, Virginia.

Harman, WV is a town of 200+ people. It is also the town where my Great Grandfather was born. I grew up in a small town in Idaho hearing stories of this place where the other half of our Snyder clan lived. We all dreamed of going there someday. This was my chance to fill that part of my bucket list. It was so beautiful driving over the Blue Ridge Mountains and seeing the Shenandoah River Valley. We drove into Harman not knowing a soul and not even knowing if there were any of my family still living in the area. We stopped for a soda at the local restaurant and I told the young lady at the counter that I was the Great-Great Granddaughter of Captain Sampson Snyder (one of the founding fathers of Harman, WV) and asked her if she knew anyone related to him. She said, "Yes, the owner of this restaurant. Would you like me to call her for you?" I said, "Yes!"



And so started a day of meeting one cousin after another. Another cousin took me to see the Snyder Cemetery where my Great-Great Grandfather Captain Sampson Snyder, his wife Elizabeth Bonner-Snyder, and many of my ancestors were buried. I also got to see the 3-story house he built. I entered Harman knowing no one. I left there knowing several cousins and got phone calls from more when we returned home. I also received several large packages in the mail of family information for my genealogy book. My trip to Harman was more than I dreamed it could be.

The next day we took a nine hour train trip through the mountains of northern West Virginia. There we saw rushing rivers and beautiful cascading waterfalls. We even met the owner of the train.

Then we headed for Newport News, Virginia and the IAL. We stopped along the way to see Yorktown and the battlefields of the Revolutionary War. We ate dinner on the waterfront of the James River and Chesapeake Bay. I could imagine the battleships coming into the bay. IAL was a fun and active week of meeting many old friends and making many new ones.

Since I had just got out of the hospital 2 days before starting on this trip, everyone was very wonderful to me. One day we went with friends, Jack and Jeanette, to Monticello, which is the home of Thomas Jefferson. Afterwards we had lunch at an old Tavern from the 1800s called Mickey's Tavern. They served yummy old

fashioned southern food. Another day we went on a bus trip with the IAL to the Maritime Museum and saw many of the old ships used in the Civil War. I had heard of the iron ships but did not know what they looked like. I wonder how they ever floated!

IAL was at a very handy location at City Center. There were many different restaurants in the area surrounding a beautiful fountain. The hotel also had a nice restaurant with a great variety of foods. There were many things to see and do in the area including Williamsburg, Jamestown, Yorktown, and of course the beach.

I enjoyed visiting with the vendors and seeing all of their new products. They too have become my friends over the years. I enjoyed meeting Tom, the new President of WebWhisper and I enjoyed visiting with all of my friends I have met previously at IAL and on WebWhispers Cruises. I miss the Ladies Axillary where you really got to meet and know the other ladies in the group but I enjoyed the Caregivers Meetings.

If you have never been to an IAL annual meeting, please go! They are wonderful. You can learn a lot and make a lot of new friends. This was certainly a trip of a lifetime for me.



Send to...God.com

Every single evening,
as I'm lying in my bed,
this simple little prayer,
keeps running through my head.
God bless all my family,
where ever they may be,
keep them warm and safe from harm,
for they're so close to me.
And god, there is just one more thing
I wish that you might do.
Hope you don't mind me asking,
please bless my computer too.
You see. This little metal box,
holds more than odds and ends.
Inside those small compartments
rest so many of my friends.
So when you update your heavenly list,
on your own great CD-ROM,
please bless everyone, who sends a prayer,
straight up to, <GOD.COM>



Bits, Bytes and No Butts!



Frank Klett

This Amazon is one big Mother!!

Amazon Echo or Alexa?

As a lary I was very curious about the Amazon Echo when it first came out since I have not had much luck with "voice command" features on phones. I am a EL user and that further added to the obstacles of using voice commands.

As it turned out I ordered the Amazon Echo based upon a questions asked return policy. As it arrived with a hand held remote microphone thingy I had no problem issuing voice commands, however I had to use the hand held microphone to be heard. I have had no luck at all trying to use the Echo without the voice remote.

I asked the Webwhispers community for inputs on their experiences with the Echo and I received a great review from our very knowledgeable and esteemed Donna McGary. The following excerpt is Donna's review of the Amazon Dot...(for those not familiar with the Amazon Echo and Dot they are pretty much the same in functionality...the biggest difference is that the Echo has a more powerful speaker).

So I have Echo Dot and although I haven't played with it that much so far I have discovered a couple things. First, I use a Servox EL so similar to you that way and am generally well understood even on the phone altho I am seriously phone-averse but that's my problem – everyone says I need to get over it HAH! I can ask Alexa basic questions fine from 6-15 ft away as long as there is no background noise like a fan or A/C. Certain words cause a problem- but it's promising. She was fine with the calories in an avocado but peach sent her off on a tutorial about sweet wines!!! I understand "she will learn" to recognize my voice better over time so I guess I need to practice. I also discovered that while I can get her to play music I can't get her to stop no matter how close I get and how loud I "yell". Same ambient noise issue. I actually had to manually turn it off – doubly annoying since she hadn't even gotten the name of the band I requested right so I never heard the song I wanted. LOL! Not sure how useful she will be but for \$35 it's a fun toy. It does work as an intercom for the house and that might be helpful or at least fun for the kids and annoying for their parents. Since the SO question this month is about computers I will write about my new techie toy and if you want to explore it further that would be a nice tie-in. I am curious about the hand-held mic you mentioned. Nothing like that comes with it so both my son & I were wondering what you used.

The voice remote can be found at: [Alexa Voice Remote for Amazon Echo and Echo Dot by Amazon](#)

So the answer to the question I asked was " Is the Amazon Echo ready for Lary Prime-Time and I do believe the answer is yes! (Your mileage may vary) Just in case you are wondering I am not affiliated with Amazon or any other company, it just so happens that their product is the one we are reviewing this month.

I also now have what many others out there have...a God Box! Yup. All the crap I can't figure out or find an answer for goes right in there for safe keeping. Sooner or later the answer will come out or I'll die and then I can take it to the Man and get a straight answer from His very own mouth.

Right on top of all my other trivial questions is just how Amazon manages all those orders...and what do you think I found in my email today? The very answer I have been seeking:

<https://youtu.be/-d3DKy-ahdg>

Google has also begun to market their own version of the Echo and it is called the Google Home. I'll need to find someone who has one to write up a review for us...any takers??

I found an article from Ask Bob of Bob Rankin fame on how to avoid Automated Voice Mazes. If there is ever a useful bit of advice his must be the number one for the year or maybe decade! Bob has a brief article to help us navigate the maze the ad men would love to snare us in. One hot one is "Get Human.com."; another is jumping up and down on your "0" key that is a zero as in Operator, but not with the "o" for oh. Better yet read over his article at:

http://askbobrankin.com/howto_avoid_voice_menu_mazes.html?awt_l=CasIU&awt_m=JKafwCTY_eP6SL

Speaking of Bob he has also offered an excellent freebie for us in a free version of Kaspersky Anti Virus. For those of you unfamiliar with the Brand name Kaspersky it is considered to be one of the best if not the best

anti viruses available today.

Why is it free? Easy... they are anxious to sell you their fine line of products and offer you the opportunity to try it out with no cash needed and this is the real deal, full real time protection. If you like it they would love to sell you a "full version" which has a few more bells and whistles that many people may find essential while others may not find necessary.

Either way this is an excellent anti virus for just the right price (FREE) and for those of you considering a purchase or real time upgrade may want to give this a look. I have downloaded it and done the installation and it is very straight forward and never once asks for money. (I always verify any free offers that I write about ...to be certain they are as advertised).

http://askbobrankin.com/freebie_kaspersky_antivirus_is_now_free.html?awt_l=CasIU&awt_m=liGx8CII7eP6SL

On the "what's next side of Amazon" they are working on taking the top spot away from Microsoft in the on-line health records arena. For those of you unfamiliar with the Microsoft free product it is called the Microsoft Health Vault. What does it do, you ask? Not really a lot. It is an on-line database of all your health conditions, medications, doctor's info, etc. But while the Vault provides the vehicle you must input the data, for the most part. There is a provision for drug companies, hospitals, larger medical groups to automatically download your information as it is generated and updated. It would certainly be a boon if all information were kept current and complete. Therein lies the catch, since it relies on our human interaction to maintain our records, we are the weak link in the chain. So now we will have Amazon (who has a very, very substantial technical group) coming in to try and set things right. No word yet on the name of the service or any more technical details so you can keep an eye out for more information from Amazon. If you would like more info on the Microsoft Health Vault you can follow the link below:

www.healthvault.com

Speaking of Health Vaults don't forget to visit our library for more info on your Lary condition from those who know it best. Us, the Larys of Webwhispers and the vendors and member medical communities that work with us daily and strive to help us make sense of our new stuff! You can follow the below link to the library and a wealth of information at your finger tips: <http://www.webwhispers.org/library/library.asp>

While you are there spend some time perusing the various areas of interest designed for Larys by Larys.

From the for what it's worth department...

I had the pleasure (tongue in cheek) of going to the Department of Motor Vehicles yesterday in order to renew my driver's license. As with everything else our society has changed in so many ways since 9/11 I had to gather together all my proof of who I am and where I am from. Getting it all together every 4 years seems a bit of overkill, but things as they are I do it (because I feel I need my license). You can note here that I have not driven in 5 years. The surgery on my neck has left me with serious loss of motion and it just plain friggin' hurts so I have opted to leave the driving to my wife ...which is a thrill in itself.

So we head over to the DMV and I planned it to hit them after lunch and when things should be slow. So far my plan went well. As I get in the ID line 20 -30 folks in it. I fumbled around for my paperwork when a very stern looking gent asked me if I was a US citizen. My full hands kept me from getting my TruTone in place so I spluttered out, Yup! He asked if I had my 6 points and again I tried to splutter out Yup! At this point he had

enough of me and told me to follow him, which I did as he took me down the row and said, "Stand here. You are next. This is the 'Special Needs' counter." I started to tell him to shove his Special Needs crap, but then I thought, what the hell! You want me to get "special", I'll take special!

Bottom-line I was in and out in less than 10 minutes. Learned from that a lesson, if they want to give me "special", I'll take "special".

So no need to ask for "special" but no reason to refuse it either!

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For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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