

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

October 2023



Contents

From The Editor's Desk

VoicePoints

**Starting a Laryngectomy
Support Group**

Linda Stachowiak
MS/CCCSLP BCS-S

Call for Contributors

Member Contributions

Being Myself

Brooke Elkan-Moore

Cancer Can Be Positive

David Kinhead

Greetings, friends!

It is good to be back. We welcome our new members and those who have been with us for a while. Here in the southeast portion of the US, autumn is returning and we are back after having taken an extended summer break. We begin this new season with a treat for you. This issue is all about new beginnings and rediscovering who we are within this community. As this month's columnists will attest, you may not need look further than your own home and immediate circumstances to rediscover who you are and who needs you within our community.

In Member Contributions, many of you might be able to relate to Brooke's recent encounter with Val that has boosted her confidence. I can almost guarantee that we will hear more about this in the future as she embarks on this new adventure. If you have ever contemplated attending a support group meeting (or starting one), VoicePoints may offer just the inspiration you are looking for. Linda Stachowiak, SLP gives a behind the scenes account of what it is like to start up and coordinate a group. If you have ever met Linda, you know what a joy it is to be with her. Her positive spirit is contagious and her dedication to the laryngectomy community has endured for more than 40 years. She is a true inspiration! David, another long-term member, also relates his personal experiences with support groups and various activities that have effected a positive change in him and in his community for the last 10 years since becoming a laryngectomee.

As our newsletter grows with our expanding community, the structure and content of our newsletter likewise is evolving. Currently, we are seeking new contributors to add to our pool of writers for the Whispers on the Web newsletter. We are looking for individuals to help highlight the positive aspects of rehabilitation and life as a laryngectomee. If writing is not your cup of tea, but you wish to assist our WebWhispers team in some other way, please reach out to the editors at www.editor@webwhispers.org. We have many ways to help make your voice heard.

See you again around the holidays!

WebWhispers is an Internet based support group. Please check our home page for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to editor@webwhispers.org

Kim Almand, Managing Editor

Tom Whitworth, Editor

Disclaimer: The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.



Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S, CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at Kalmmand@uthsc.edu or Erin.Guidera@moffitt.org

Starting a Laryngectomy Support Group

Over my career as a speech pathologist, I have always worked with laryngectomy patients. One thing I know for sure is that losing your ability to speak as you once knew it is a big change! Since laryngectomy surgery is not commonplace, folks often feel like they are alone, and no one can really understand how they feel. That is what has prompted me over the years to be actively involved in laryngectomy support groups. I felt that people needed a place to go where they themselves and their loved ones could be among others who have gone through what they have gone through. Although I had been a speech pathologist for many years, I myself was not one. I found that having routine support groups gave people an opportunity to learn from others, be accepted with an alternate means of communication and give hope for their future.

In the early years of my career, I was involved in three support groups that were mainly run by laryngectomees themselves in a traditional role. Namely there was a president, vice-president, secretary and treasurer. Most meetings were held in a church basement, social hall or hospital conference room. Most often, funds were raised by having a split club with half the proceeds going to the group treasury. Over the years, I also recall having some fun social events outside of

the meetings. A summer picnic with a singing contest or a bubble gum blowing contest, a catered holiday party or a dinner out at a local restaurant.

Unfortunately, over the years I also saw a lot of clubs fizzle when no one wanted to volunteer for a position in the group and the ones holding the positions were feeling like they no longer could do it. It seemed that the spirit of "volunteerism" was dwindling. This of course may not be the situation where you are living. I know of a few groups that still run in this traditional way and have many volunteers willing to take an active role in keeping the groups going. That was not my situation when I moved to Orlando and began working at the then named MD Anderson Cancer Center in Orlando (which is now named the Orlando Health Cancer Institute). I decided to try to start a laryngectomy support group at our hospital. My goal was to have an educational component and a social component. I decided that I wouldn't develop it with traditional roles such as president, vice-president, secretary and treasurer. We would have a meeting with a guest speaker and then time for socialization. I discussed it with my boss, and she supported it, which meant I would be given the time once a month to organize/attend and she would support me reserving a conference room at the hospital

for the meetings. Of course, I had no budget, which meant that if we wanted to have coffee and snacks, folks would need to volunteer to bring them to the meetings! I felt that I could live with that, so I pursued it. That was 14 years ago and I'm happy to say that to date, the meetings are still going. They have looked a little different over the past three years since Covid, but they are still going, virtually. We are hoping to go back in person soon!

My role as the coordinator of the group is to be sure that any laryngectomee in the community is invited to attend with any family or friend that wishes to accompany them. What does this mean? Getting in touch with speech pathologists in the community who work with the laryngectomy population as well as knowing the doctors who do these surgeries so they can spread the word. I do a monthly email blitz to any laryngectomee who is interested in learning more about our meetings and speech pathologists and physicians who can refer additional interested folks. At the beginning of each year, I try to ask the members what topics might interest them and then contact folks who I think might be good speakers on the topic. I ask the presenters to speak for 45 minutes, leave 15 minutes for questions and answers, which leaves us 30 minutes or more for socialization. Our meetings are 1 ½ hrs. I must admit, coming up with topics and speakers can be a challenge! What I have learned is that it's really necessary to repeat topics every so often as the meetings are constantly adding new folks and losing others... over the years some of my often repeated talks have been on CPR for the Laryngectomee/Emergency Preparedness, Dental Care for the Head and Neck Oncology Patient, Swallowing and Swallowing Disorders after Laryngectomy, Nutrition, and Tricks of the Trade (whereby laryngectomy patients can share things they have found helpful with others). We routinely had Atos Medical and

InHealth Technologies give us presentations on updates on new technology/supplies etc. Most recently during Covid, we joined forces with all the laryngectomy support groups in Florida and called ourselves the Sunshine State Laryngectomy Support Group. This of course was because we were all unable to meet in person and thought that joining forces was a prudent decision. It was a great option when we were all feeling so disconnected; however, I have heard from many that they are missing the in-person meetings. I'll admit that I'm feeling the same way!

In the end, if you're thinking about starting a laryngectomy support club in your community, you can develop and organize it any way that you might think will meet the needs of the group. One thing that I know for sure is that the dates and times will not meet everyone's needs. If you have it Monday-Friday during typical working hours you will have limited attendance from the younger laryngectomee who returns to work, as taking time off for the surgery and post-op recovery often means significant time away and an eagerness to return to gainful employment. In my case, my meetings are from 4-5:30. Several folks don't want to drive home in rush hour, others don't want to drive in the dark during the winter months, yet many others attend!

Support groups are a great way to help folks feel supported through their journey after surgery. I would encourage you to start one or build the one you are in...it's well worth the effort and appreciated by all!

Linda Stachowiak MS/CCC-SLP BCS-S has 41 years of clinical experience specializing in the areas of head and neck cancer, voice disorders, swallowing disorders and trach/vents. She is presently working as a Speech Pathology Clinical Specialist at the Orlando Health Cancer Institute, Orlando, FL. She has been an adjunct instructor at the University of Central Florida, University of South Florida and the State University of Buffalo teaching courses in dysphagia and upper-airways disorders. She participates in multi-institutional research and she has presented at the local, state and national levels.



Call for Contributors

Do you like to write? Have a gift for encouragement? Want to offer wisdom or support?

The editors of Whispers on the Web are currently looking for member contributors for the monthly newsletter!

Who: Persons with a laryngectomy, spouses, or caregiver members of WebWhispers

What: 3-4 articles over the course of a year.

How/When: Please submit a sample of your writing and ideas for future newsletter topics to the editors at: editor@webwhispers.org by November 15, 2023

Questions? Please contact the editors at editor@webwhispers.org

Being Myself

Brooke Elkan-Moore

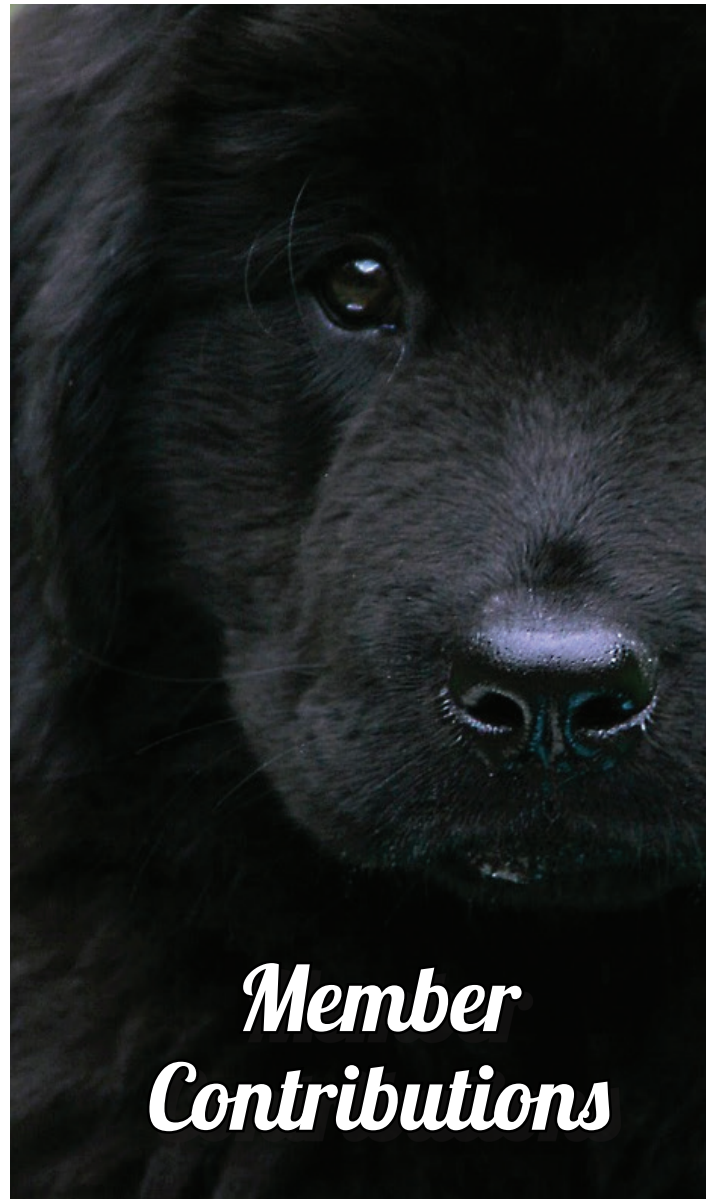
When I had my surgery, I think I spent more time worrying about what others would think of me and less of what I thought of myself. Would I be ignored? Would I be able to do things I loved? Would I be considered “sick” all the time? Would others deny me what I wanted to do because of their perception of me? Could I try new things? Go new places? Meet new people?

Well, this past weekend I decided to finally put my fears to rest and go on a road trip by myself to not only meet new people who knew nothing about me but also to find a new companion to fill some of the lonely spots in my home. After a long search, a long wait, and a lot of excitement I set off for upstate New York to meet Val, a 6-month-old Newfoundland female who needed a second chance at a good life.

Newfs have been a part of my life for over 35 years, introduced to me by my late husband Larry who was totally in love with the breed. I had always wanted a dog of my own after living with family dogs: a Dalmatian and Cocker Spaniels, but my early adult life entailed a lot of travel for work, and I lived in a small city apartment. Moving to Hudson Valley and meeting Larry finally gave me a chance to own dogs. Little did I know how much dogs would be a part of our lives.

I threw myself headlong into the world of Newfs, joining regional and national Newfoundland clubs, serving on boards, as committee chair and writing columns for newsletters and digital magazines. Over the years, we have owned dogs from local breeders, from the UK, and from rescue. A few months ago, the last of our shared dogs, Smokey, succumbed to a stroke and my heart and home were missing the shared routines of living with a dog.

Yes, I had a bit more freedom to head off to the IAL (International Association of Laryngectomees) meeting without worrying about a dog sitter. A



trip to the west coast to see family was likewise simple, but oh! the joy of waking up and finding a magnificent beast ready to share the day was missing.

When I applied to That Newfoundland Place for a rescue dog, I was sure I would be rejected for having what most people consider to be a disability. Surely, they might think the fact that I can't shout or speak at times would be a liability. Would my years of experience count for or against me? Amazingly, no one said one word about me being a laryngectomee other than to ask if I was doing well after I brought it up. My perception of my being a lary as a forward or defining aspect of my life was not what others thought. 35 years of dog life was way more compelling.

In the virtual home visit, I spoke clearly even when nervous and showed them around the fenced yard including a tempting koi pond that all our dogs have waded into with much glee. I talked about my use of hand signals and series of clapping clues that supplement my voice as needed. We talked about what I wanted in my next dog.

For me it was a smaller dog, probably a female after a long time of larger males, and a personality suited to going into schools, libraries, hospitals, senior centers and other community locations to share the joy of dogs and provide emotional support to others.

One day on Facebook, a photo popped up of Val right after she and her sister were pulled from a hoarding situation. She had such joy in her eyes and her head tilted to the side showing her sweetness and energy. She was a mess of mats

and clearly not in perfect shape, but she spoke to my heart. I called and asked, "Can she be mine?"

And so the process of matching us led to my road trip. I set off after teaching a class in cement leaf casting at my local cooperative extension 4-H site, and soon found myself with Val leaning on my leg looking up into my eyes. Clearly, I was bringing her home with me!

After a night at a local hotel and dinner at the Bowling Alley Bistro, we made the short drive back to her foster home the next morning to leave an apple cake as a thank you and set off to begin our new life together. Keep an eye out for updates as she continues to settle in, grow out her coat, and find her perfect spots inside and out. As for me, I am getting more and more confident in just being ME.

Brooke Elkan-Moore, Lary since January 2021

Cancer Can Be Positive

David Kinkead

I had a total laryngectomy ten years ago. While it took me a year to heal because of esophageal issues and a fistula, I eventually got back to what we larys call the new normal. While of course, having a stoma and using an electrolarynx was a big change in my life, the positives of the last ten years outweigh the negatives.

Because of my laryngectomy and the immediate aftermath, I am retired and now have the time to devote to volunteer activities involving cancer groups and laryngectomy groups.

I give many hours of my time to the Cancer Support Community of Arizona whose motto is "No One Faces Cancer Alone." I participate in many family and group activities there including art, family game night and bingo. I also spend several hours a week helping plan fundraising activities, leading art classes, manning the grill, and working events such as



kids' art when needed. Without my laryngectomy I would never have found this place and had the opportunity to meet and help so many people. I have made many lifelong friends and really enjoy my time spent there.

I am also very much involved in a laryngectomee support group at Mayo Clinic in Phoenix. While the pandemic hurt this group when we went virtual,

we still get together about every other month. The SLP who ran the group retired and a lot of people have left the group. I was instrumental in planning meetings and securing guest speakers for the group meetings. The virtual meetings are no replacement for in person meetings and I am aware of several groups that are going strong.

Many local club meetings have given way to internet groups where laryngectomees now log on to get support and answers to questions.

I have attended six of the IAL (International Association of Laryngectomees) Voice Institutes (VI) and Annual Meetings (AM). The first few meetings taught me so much about what was happening in my life and how to cope with the "new normal." After attending my third meeting I decided I could do more and became a member of the board of directors for a few years. I was very much involved in planning the VI and AM in Phoenix in 2019 and enjoyed so much being involved. However, the best thing about the Annual Meeting and other conferences I have attended such as the Texas Laryngectomy Association and the Swallows in England is the people I have met. Through these meetings, along with learning new things and helping the "newbies," I now have what I consider good friends all over the world. I correspond with these friends on an ongoing basis and even after ten years still learn from these people.

The group that has given me the most help and where I consider my best lary friends to be is WebWhispers. I have volunteered with them since 2015. The members I have met are down to earth people who want to be a big help to the new and "old" larys.

These people (and I won't name names in fear of leaving someone out) have had a very big influence on my life as a lary. I have done everything for the group from moderating messages to enrolling new members. I have served as their delegate at several Annual Meetings at the IAL and take great pride in being a member of their group.

I titled this piece "Cancer Can Be Positive" because having cancer and then a total laryngectomy,

has made me a more positive person. Rather than worrying about my career, I now have more time to spend with my family and four grandkids, all of whom only know me as a laryngectomee. I have time to spend with my new friends from all the organizations I am involved in. While I do travel a lot, the Annual Meeting is the highlight of my travels every year. I always make it a priority to see something special in each city we travel to, such as a baseball game, museum, or a tour. I also try to get some of the iconic food the city is famous for such as crab cakes in Baltimore, Disney Springs Restaurants in Orlando, Mexican food in Phoenix, and fried ravioli in St Louis.

While having a laryngectomy is a big change in your life, you can make it a positive thing if you work at it. I feel I have done this and you can too.

