



Whispers on the Web

A Monthly Online Newsletter for WebWhispers

March 2022



From The Editor's Desk

Hello again! It is starting to seem real, that we are moving beyond pandemic, at least for now. The closer we get to June, the more excited I get about seeing so many of you, (yes!) IN PERSON. As promised last month, in "No Better Place to Be", I provide some information about the upcoming IAL Voice Institute, and why you should attend if you possibly can. Links are provided on how to register for the event and to the application for WebWhispers members to apply for V. I. scholarships.

Aaron Wayne shares a touching story from his friend Billy Mark Robinson about a close encounter of the lary kind. We never know the effect we can have on other people. In moving on, we often inspire others.

In Voice Points' "Choosing to Go Big", Stacey Brill, M.S., CCC-SLP tells us how her effort to raise awareness and funds for us in Southwest Florida is blossoming into a program of national significance. More than a clinician, she has become a dedicated advocate for us.

In "NOW WHAT!", Tom Olsavicky takes us from pre-diagnosis to where he is today as a laryngectomee and an inspiring leader in our community. If you've ever thought about starting your own lary club, Tom is a good one to talk to. His local group now hosts two online meetings per week, available to just about everyone.

Whispers On the Web welcomes your suggestions and ideas for our newsletter and we encourage new writers to share your thoughts with our readers. We welcome your input and your comments at editor@webwhispers.org.

The articles in this issue have a common theme, moving on with a smile.

Tom Whitworth
WebWhispers President

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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

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No Better Place To Be

(Revised from May 2018)

While considering other suitable topics I could write about here, one topic continued to stick its head in the door and holler “what about me?” This happens every year. It is called the International Association of Laryngectomees Annual Meeting and Voice Institute and it just won’t stop calling my name. This is a topic I’ve written and spoken so much about that some may be sick of hearing from me about it. Sorry, I can’t help you with that and I won’t even try. It excites me and I can’t apologize for that, either. I’m a Lary nerd-what can I say?

I will never forget the effect my first Voice Institute had on me as a new laryngectomee, because the benefits were truly that profound. The short story? Without what I learned there and the overall experience, I know that my life as a laryngectomee would not have turned out as well as it has. Things now would be sadly different and I can’t even let my mind go there. I might not even still be here, and I don’t say that lightly.

I learned about the event only a month or so in advance and thought I didn’t have enough time to pull it off. To say that I arrived on a shoestring would be less than truthful. My shoestring had three repair knots and was reinforced with duct tape! With knowledge of a little financial assistance and hard-core determination, I did make it to Buffalo for the event.

I have not missed one since and the upcoming IAL Annual Meeting and Voice Institute in Charlotte, NC June 15-18, 2022 will be no exception. Many of us, have been yearning for the gathering even more than usual with it being postponed and canceled due to COVID.

If you are a laryngectomee or caregiver, there simply is no better place to be in the third week of June than the IAL Voice Institute. Director, Caryn Melvin, Ph. D, has recruited an exceptional faculty as always, and I can promise you an education you won’t find anywhere else. SLP grad students will benefit and practicing SLPs can earn more CEUs in the amount of time than any other place I am aware of. Suppliers of the products made especially for us will be there, too. Whether you’re a newbie or an “Old Salt”, this is the place to learn about new products that enhance our quality of life.



I truly hope to see or meet you there, especially those of you who think you can’t make it happen! If you haven’t already planned to attend, do so now. Click the link here to register: <https://www.theial.com/annual-meeting-registration52866b93>

Need help getting there? WebWhispers has scholarship funds available for WW members who are recent laryngectomees and other members who have not previously attended a Voice Institute. Additional applicants are considered based on other criteria, but only after newbies and Voice Institute first-timers have been assisted with attending the event.

Note: applicants must first register for the Voice Institute before applying and all awards are distributed at the WebWhispers Dinner on Thursday night, June 16, in Charlotte. Click here to complete and submit the WebWhispers Scholarship Application: https://webwhispersinc.formstack.com/forms/webwhispers_scholarship

For scholarship questions or information on ways to reduce your cost, email us at scholarship@webwhispers.org

The WebWhispers annual awards dinner is our only face-to-face event of the year. Details are still being worked out. Information on the dinner and how to register for it will be posted on our mail list and Facebook page just as soon as those details are finalized.

See you in Charlotte!

Enjoy, Laugh, and Learn,

*Tom Whitworth
WebWhispers President*



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 Kalmand@uthsc.edu or Erin.Guidera@moffitt.org

Choosing To Go Big

One can do their job, and do it well, or one can decide to go beyond the job description and try to change the world. Your change can start small, and stay that way while still making a difference, or you can try to go big. This is my journey of going beyond my job description to make a difference. It is also my story of going big.

As a speech language pathologist who specializes in working with head and neck cancer patients, I had spent many years listening to my patients discuss the limitations of their insurance plans. It was disturbing how many services were not covered, no matter how good the insurance. My heart told me I had to do something more to help not only my patients but all head and neck cancer patients in my community. My official job is as a therapist, but I have always felt my role should be as an advocate and a voice when nobody else would listen. I decided MY change would be to help patients afford services insurance didn't cover. The question was how?

After considering various options, ten years ago I approached a small but national Oncology Foundation and pitched my idea of hosting a 5k run and 2 mile walk to raise awareness and funds for local head/neck cancer patients in Southwest Florida. They agreed to assist me in my goal and a change movement was born. What started, that first year, as a small local event, has blossomed into a yearly well attended tradition. April 2022 will be the 10th anniversary with over \$250,000

raised, all of which has stayed in the immediate community to help patients in need.

I wanted my change to meet the needs of all patients. Thus, the financial assistance program created is unique in that anyone with a head/neck cancer diagnosis can apply. Differing from other programs, financial assistance is not based solely on income. Recipients can have a job, own a home, and have health insurance. The program was designed specifically to deal with what I was witnessing, including patients with health insurance going without services and supplies because there were high copays or supplies were not within their budgets. Consequently, with the financial assistance program, any patient, regardless of income, who applies and is approved has been given funds. These funds have covered PT/OT/Speech therapy co-pays; dental assistance for dentures, extractions, and obturators; feeding tube supplies/formula; laryngectomy supplies; nutritional supplements such as Ensure; compression garments for lymphedema; trismus devices and other needs related to their diagnosis.

Now the "Go Big" part... It has always been my dream and vision to expand my change to a national movement to raise awareness and funds for head/neck cancer. I'm excited and proud to say that 2022, I will see my dream come true. In April 2022, 5k runs/2-mile walks will be hosted in Cape Coral, FL; Broward County, FL; Asheville,

NC; and the Tri-City area in WA state. The current plan is to add five new locations each year starting in 2023. Funds raised at each venue will stay locally to provide financial assistance for patients in those areas. Thus, the small but ever-growing change in my community will now be a change in multiple communities around the country.

If you would like to join the movement, please check out our website www.yourpartnersincare.org. You can register there to walk or run at one of our race locations or to participate virtually. We are also always looking for volunteers for race day. If you know anyone interested in volunteering, please contact us on the website ... for students, we are set up to school volunteer hours. Donations can also be made on the website. There are many

ways you can get involved; just reach out to us at info@yourpartnersincare.org. We would love to hear from you and let you know how you can get involved and, in 2023, perhaps host your own run/walk event.

Going big has finally started! 2022 is going to be a great year and, with this expansion, I am excited to have begun my national change movement. More importantly, I am thrilled that the movement will change the world for other therapists and supporters as they help their patients in need across the country.

Stacey Brill M.S., CCC-SLP
Speech-Language Pathologist
Lee Health, Ft. Myers, FL
Event Founder and Chairperson





The Author, Billy Mark Robinson, posted this story of an encounter he and his wife Rhonna had on a lary support group page last January. I sent him an e-mail to ask if he would give me permission to use it in the book that I am currently working on. He replied that it would be fine. I am quoting it here word for word. Sadly, he passed away just before his birthday. He will be missed.

OK peeps. I've got a Doozie of a story for ya. The wife and I was shopping at Sam's club and we was next to the frozen section discussing Thanksgiving dinner. While I was talking to my wife with my EL this young girl was fixing to pass by us when she froze in her tracks.

She stared at me, her eyes got really huge and her face started turning red and she started sobbing at me. She apologized and said she hadn't seen or heard anyone using an EL since her grandpa passed away in 2010.

She said he used one and he and I even looked a lot alike. White hair, beard and resembling Santa.

I told her she was fine as I wasn't annoyed at all and I told her grandpa wanted a hug. She wept in my arms and just started sobbing more when she finally managed to pull away from me all the while she kept apologizing to me and said it was out of character for her.

I told her she was fine and it could have been her grandpa having us to meet like that and for her to know he's watching down on us right

then. I gave her another hug as she was trying to get her composure back and I told her that he would be proud of her and her son that she said he never got to meet.

I told her that he sure sees him now and I ended up telling her to have a Merry Christmas and a Happy New Year and she started to cry again but she managed to keep her composure long enough to wish me the same and for me to have a great day and thanked me again for the kindness.

I told her that it's how I was raised and she was welcome. I don't know how many trips like that I can stand. It felt good though. She acted like she really needed it and I think it has affected me too.

Its funny how something like an EL can trigger a total stranger into a meltdown but it sure happened today. I need a drink now...

(Rest in peace, my warrior brother.)



Now What!?

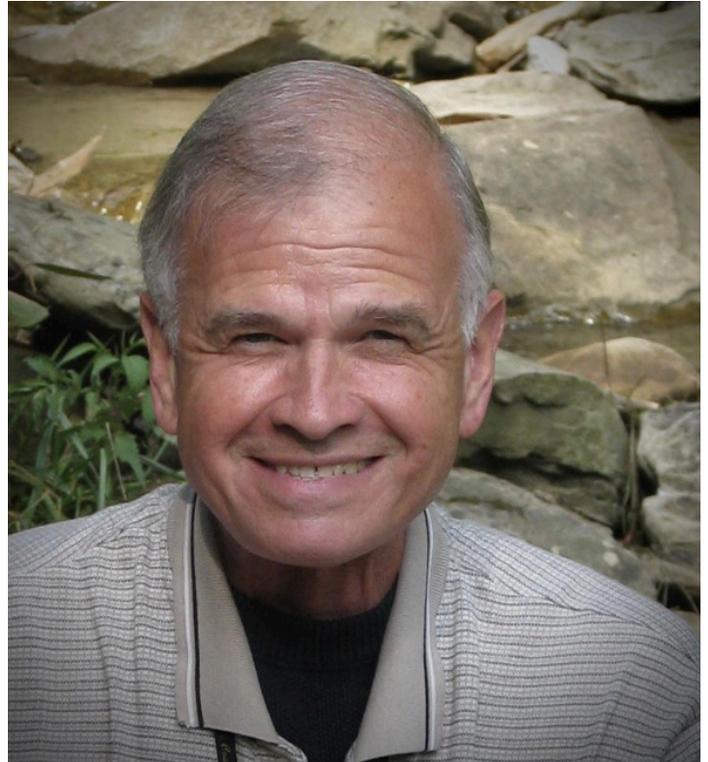
by Tom Olsavicky

In May of 2006 I was 64 years old, had been retired for 2 years and was looking forward to seeing a couple of places that were on my bucket list. However, one morning I woke up with a very hoarse voice. No pain, no reason, just hoarse.

After a couple of weeks without signs of any change, I went to my primary care physician who assured me that since I was not a smoker or drinker that this condition would pass. In the coming 5 months, I enjoyed a trip to Alaska and still had no signs of improvement so I was referred to a Speech Therapist to see if she could correct my voice.

Over the next six months, she gave me words to try to say, exercises to do, and yet there was no improvement. So in May of 2007, I was referred to an ENT who scheduled me for a biopsy of my right vocal fold which was dormant. This biopsy was Negative so he recommended that I have 3 days of Allergy Testing done, only to find out that I was mildly allergic to coffee, tea, lettuce and bananas. So I immediately refused to consume any of those and still there was no improvement.

In August 2007 a Voice Specialist did a second biopsy, but went deeper, and this time found Squamous Cell Carcinoma under my right vocal cord. So in September of 2007 I started 37 Radiation treatments that were expected to give me a 92% chance of eradicating the cancer.



Of course, I had to try it since the thought of losing my voice was devastating. In Oct 2007, I completed the Radiation which made it hard to swallow and turned my neck red; I was told to give my body a chance to heal and then see the Voice Specialist again.

My voice was still hoarse, so in Feb 2008, a third biopsy showed that the cancer was now Stage 3 and growing. I was advised to go to a Support Group and see folks who had been through this same situation and see how they were doing. That was a real eye opener, and I realized that I could do this.

I talked to a recommended surgeon and asked

him to schedule my total Laryngectomy which he performed on April 1, 2008. Although this was April Fool's Day, it definitely was no joke.

The ride to the hospital that morning was not something I wanted to happen but was necessary if I wanted to have a future. I couldn't imagine what life would be like without a voice but I had no choice. What would or could I do?

Fortunately, my wife was a retired Registered Nurse and she assured me that WE would get through this and find a way to cope. I spent the next nine days in the hospital, experienced no pain, but had to write anything I had to say or ask.

Then my Electro Larynx arrived, and I was given the okay to use it. The next few weeks included a lot of experimenting to find a good "sweet spot" where I could be understood. Once I found the spot, I was elated. Now what was I going to do with my new found voice? Once I was permitted to drive again, once people could understand me, now what?

My Speech Language Pathologist (SLP) suggested that I start a Support Group in my area since the closest one was 40 miles away and I was not seeing any of the 60 Larys that were within a 50 miles radius of me, at those meetings. I didn't think I would be able to hold a group together but was willing to give it a try.

After all, we didn't have one close, but I had seen, first hand, what a benefit it was, so I figured it was worth the effort and if it didn't work, we would not be any worse off. So my SLP found a suitable place to meet at no charge; the American Cancer Society was kind enough to send out letters to locally known Laryngectomees, Surgeons and SLPs informing them of the formation of the Peninsula Lost Chord Club and my meetings began in July 2009 with me, my wife, my SLP and one other Lary.

Once the word spread, we started to grow in numbers of Larys and their caregivers. We now have twenty regular members but I'm still trying to get all sixty of us together at one meeting.

Since Covid, I have been conducting two virtual Zoom Meetings a week which has helped me branch out to new Larys across the United States who wish to participate. Everyone is welcome so if you would like to join us regularly or occasionally just contact me at tolsavicky@cox.net and I will gladly add you to my invitees.

I believe that all things happen for a reason and I really didn't know why I was chosen but I can say that I feel that I now have a purpose and being able to help so many is a blessing for me and them.

