I Found My Voice in Phoenix, Arizona

Steve talks about his journey from surgery to the Internal Association of Larygectonmees conference in 2019.

My Laryngectomee surgery was on February 25th, 2019. I heard about the 2019 International Association of Larygectomees (IAL) conference and the Voice Institute (VI), from several Facebook groups, particularly WebWhispers. It was late March and I was only 1 month post-surgery, however was feeling great and started wondering if I could attend the conference which was only 6 weeks away.

After hearing how valuable the conference was from several other Laryngectomees that had attended in the past, I reached out to my surgeon. He said if I felt up to it, he would clear me to fly, "as long as I brought my suction machine…and make sure it's fully charged!" My plans were set in motion!

I flew to Phoenix on Tuesday May 14th, exactly 11 weeks after my surgery. Getting through TSA was my first concern. I had a carry-on suitcase full of medical supplies and my trusty suction pump. I looked at the TSA rules online in advance but still wondered if they would allow this? I still had not mastered the Electro Larynx (EL), did not have a voice prosthesis (TEP) yet so I was using able to communicate using a 'white board'. I did bring a note explaining that I was a Laryngectomee, could not speak and that I had the medical supplies in the carry-on bag. TSA was very appreciative that I had the note in hand and with a little extra screening of the medical supplies I was on my way!

Fortunately, on the plane was our territory manager from Atos, Kathryn Flynn, so the flight and getting to hotel was a breeze. The conference was held at a Doubletree by Hilton. As it turns out, Hilton has an app that allows you to check in from your phone and even get your room key on your smartphone. Since I was only able to communicate in writing I downloaded the app. I did stop at the front desk first however it took only seconds to present my ID and credit card. The hotel staff was so accommodating and fully prepared for our group. The hotel even used text messaging for any guests that wanted it so that was an added bonus for me. The entire process was easy and went off without a hitch. I checked into my room, plugged in my portable mini humidifier, (did I mention the Laryngectomee conference was in the desert where it was less than 20% humidity!) and proceeded directly to the registration desk for the IAL.

The first person I met at the conference was Helen Grathwohl, President of the IAL. She was at the registration table. Although I had my EL on a string around my neck, it was hard for anyone to understand me. I pulled out my whiteboard and started to write my name. Helen's heartfelt and warm greeting was, "PUT THAT DAMN THING AWAY AND START USING YOUR ELECTRO LARYNX!" As she shook her head and wagged her finger at me.

> **I knew from the first minute that I was in a place where others understood what we are going through and were not pre-judged by that odd hole in our necks!**

Needless to say, Helen and I bonded! I was given a name tag that said, "First Time Attendee AND Delegate." Both were very rewarding to me!

Immediately, I was reading name tags and meeting people that I had talked to on Facebook over the last several months. Many of them had helped me with advice as I was a 'newbie'. It was great finally being able to meet face! Additionally, several members of the Laryngectomee Club of Montgomery County (LCMC) were at the IAL as well; Kyd Deitrich, Karen White and Mark Reichenbacher, so I

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never felt like I was alone!

On Wednesday, the VI sessions began. There were experts, primarily Speech and Language Pathologists (SLPs) giving classes and informative on the most basic subjects for any Laryngectomee, caregiver or other SLPs. The sessions ranged from; anatomy changes, voice restoration options, EL usage, TEP and Esophageal speech techniques. There were group sessions where I was able to get additional help using the EL. Other classes included HME and stoma care clinics and travel tips.

The most beneficial part of the conference was picking up tips and advice from the SLPs and fellow Larys as well. There were several that were almost 40 years out! Also, there was a very interesting presentation my Dr Michael Hinni from the Mayo Clinic in Phoenix talking about ground breaking laser surgery on the Larynx. Based on the results he shared, hopefully it will become the norm, not an exception. It was truly fascinating. There was a swimming session for Laryngectomees however I thought it best to just stay on the sidelines for that one…perhaps next year!

I was encouraged to apply for a scholarship in advance that was offered by WebWhispers.org. The funds were provided by Atos Medical. I was a very lucky recipient and received the scholarship at a presentation at the WebWhispers banquet on Thursday night. With the tremendous expenses of the surgery, supplies and other items I needed, it helped to make my trip to the IAL possible.

One other event stood out at the conference: Bill Brummel, the maker of the documentary "Segue" gave a talk and played an un cut short version of his film. It's about a group of Laryngectomees in England that formed a choir. It takes you through their journey, and ends with their final musical production. It was truly inspiring and reinforced to me that there is a normal life ahead for Laryngectomees. Needless to say by the end of the film, there wasn't a dry eye in the audience!

On Saturday morning the IAL had its annual meeting. Although I was only a Laryngectomee for 11 weeks, I was asked by Herb Simon to be a voting delegate representing the LCMC. I considered it an honor. Contrary to my initial concerns, the meeting was very smooth; reports were presented, ballots were cast for open positions, no one got into any disagreements, and the meeting was adjourned early!

So why did I say I found my voice in Phoenix?

As I mentioned earlier, I was only 11 weeks into this journey and had been struggling to find my "sweet spot" Herb Simon, President on LCMC had lent me an Servox EL to try out and had worked with me on many occasions. My SLP at Johns Hopkins was working with me as well but I still couldn't get the hang of it. At the IAL, I met Jim Lauder who I had spoken to before my surgery and had kept in touch with ever since. I had the Servox (which Jim repaired on the spot) but he gave me another unit to try as well. Atos lent me a TrueTone Emote to try out and Tom Whitworth from WebWhispers gave me a basic TrueTone. At this point, I was walking around with 4 or 5 Electro Larynxes!

Then I met Tony Talmich. He said Steve, put everything away and let's find your sweet spot...viola we found it...it was right there, hiding under the lymphedema under my chin all the time! Of course Tony was partial to the TrueTone Emote however I was most comfortable with a 50 year old vintage Servox that Jim Lauder gave me to use! What a mensch! Several other people helped me to perfect my speech including Susan Reeves and Tom Lennox and several other SLPs during the breakout sessions. After one or 2 days, I could carry on a conversation. I was so relieved to finally be able to communicate verbally after almost 3 months. So...now I can say, "I found my voice in Phoenix Arizona!"

I want to thank everyone that encouraged me to go to the IAL. I also want to thank everyone at the IAL who worked tirelessly to hold such a wonderful event, Tom Whitworth from WebWhispers and the team from Atos Medical for their help and assistance, all of the SLPs and every single person that attended the conference that was there to provide unconditional support to me and all of the other fellow Laryngectomees and caregivers, and my wife Robin being by my side through every step in this journey and encouraging me to make the trip without any hesitation at all (and for being my driver to and from the airport!). The saying 'it takes a village' was not just a phrase we use, it was on full display at the IAL.

This was a trip that came at a very fragile stage in my journey and will stay with me for many years (and future IAL conferences) as well.

Steve Cooper

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