The IAL News

- The International Association of Laryngectomees Vol. 57 No. 4 November 2012

Kansas Study trying to determine effort, fatigue associated with alaryngeal speech

By Charles C. Moore
Editor, IAL News

Out in Kansas City, Jeff Searl, Ph.D., CCC-SLP, and two graduate students are trying to determine the extent which laryngectomees experience fatigue associated with talking.

To this end, the team is making an appeal to laryngectomees to undergo a short test to see how widespread this is.

“Right now we have 190 surveys completed. Out of these, 120 are from people with a larynx and 70 are from people with a laryngectomy,” said Searl.

“We are happy with the return so far but we clearly need more people in both groups - particularly the laryngectomy group.”

The University of Kansas Medical Center is where this data is being gathered and all it asks is for a laryngectomee to go to a website set up for the study and fill out a short questionnaire.

Please see study on Page 11

Questions are asked about your medical background, the type of speech you use and so forth.
You also will be asked to rate some aspects of your speech and voice. It has taken from 5 to 15 minutes to complete the form.
Some of you may have done a paper version of this at the IAL meeting in Kansas City in 2011. It is okay to repeat it here electronically.
The link is:

Inside the News

Our Valued Advertisers
Griffin Laboratories...Pages 2 and 20
InHealth Technologies........Page 5
Romet......................Pages 7 and 14
Bruce Medical Supply........Page 9
Luminaud........................Page 14
Cermeda.....................Page 17
Atos.............................Page 19

Contents
UKMC Study........................Pages 1 and 11
IAL Information......................Page 3
Editors’ Column......................Page 4
Kathy’s Story.......................Pages 6, 8, 10
Club Dues Notice....................Page 10
Photos.............................Pages 12, 16, 18
Writers Needed.....................Page 13
Holiday “Thank You”..............Page 17
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A physician or other qualified healthcare provider should always be consulted for any health problem or medical condition. The IAL does not endorse any treatment or product that may be mentioned in this publication. Please consult your physician and/or speech language pathologist (SLP) before using any treatment or product.

The opinions expressed in the IAL News are those of the authors and may not represent the policies of the International Association of Laryngectomees.

As a U.S. charitable organization, as described in IRS 501 (c) (3), the International Association is eligible to receive tax-deductible contributions in accordance with IRS 170.

Newsletter Postage Must Be Guaranteed By Subscribers

Outside North America
IAL News Staff Reports

Costs have forced the IAL to stop mailing The IAL News to non-North American countries unless postage payment is guaranteed beforehand.

Canada is exempted from this Board of Directors action. Canadian clubs paying regular dues will continue receiving The News.

Foreign clubs who want to continue receiving The News, please contact the IAL at the telephone number or email address listed below.

Items Available From The IAL

- IAL Brochures
- Postcards to order copies of The IAL News (Or Change Address)
- Orange Emergency Cards (English)
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- “Laryngectomees Loving Life” DVD (35 minutes) ($10 donation requested)
- “First Steps”…Only available to download from the IAL website
Charlie’s Voice

“Pay it forward” is a term still used frequently in the United Kingdom and Canada. Basically, it simply means to respond to a person’s kindness to oneself by being kind to someone else. That is what we laryngectomees do. It is what is expected of us if we are able.

I have tried to do what was asked of me. I had three excellent teachers: the U.S. Navy where I spent eight years as a hospital corpsman; the late founder of WebWhispers, Dutch Helms; and my speech language pathologist, Caryn Melvin, Ph.D.

I have probably done 20-25 counseling sessions since my surgery in March 2005. All of them, though, were on the phone or in person. It wasn’t until a few weeks back I was asked to help on the internet. (The story is on pages 6, 8 and 10.)

First, the newbie, Kathy Turbucz Poirier, was terrified, and she is very bright, meaning in the beginning I had to choose every word carefully. For this I called on mainly what I had picked up from Dr. Melvin. Listen/read carefully before responding. Jumping in with a bunch of mind-numbing advice can exacerbate a serious problem. Better the counselor just send the patient back to his/her SLP or physician than to be the least bit dogmatic.

Now the Navy training. Never advise or speculate if a problem is the least bit over your head. In fact, I once sent Kathy back to her SLP. And I had her make up a list of questions for her physician.

Surgeons are busy people. Write your questions and have them ready.

Finally, the time comes when the newbie/patient has to be told by his/her peer that some things are a given for a laryngectomee. You are going to cough, so learn to do it as unobtrusively as possible. In the beginning, for most of us, we must be careful what we take out to eat.

I remember when I really wanted to go see “Walk The Line.” But I hesitated because of coughing. “You better get rid of that attitude,” said Dutch, “unless you want to sit at home the rest of your life.” I went, coughed like I had been taught and nobody paid any attention. And I very much enjoyed the movie.

Kathy was really easy because she listened and sincerely wanted her life back. And it seemed as if every day she would make a stride of some sort.

First she began to get over her imagined fears. I certainly don’t take credit for this. Her doctor, SLP and counselor were mostly responsible. But after every visit we would talk about what she had been told and how she had put it into practice. All of us have many similarities.

I remember the first day she walked outside and had courage to leave her yard. If I am not mistaken, it was about one-half mile. This she forced herself to do. That was the first and it abated most of her fear.

Then it was the grocery, then driving. She just bubbled. She was getting on with her life. Things began rushing out in a flood. Having her hair done. Visiting her co-workers at the bank. And, with me, she began talking about going to work. Now she and her husband, Claude, have all kinds of trips and the like planned.

And two weeks ago, she began “paying it forward.”

Charlie “Buck” Moore is editor of The IAL News.
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One woman’s journey from shock and fear to acceptance and joy

By Kathy Turbucz Poirier & Charles Buck Moore IAL News Editor

(Editor’s note: This was originally supposed to be my column for this issue. But I thought the original so good and decided to let Kathy tell her story. My only contribution is a little editing and not letting her give me too much credit. Kathy is my friend and a wonderful, courageous woman.)

March 30, 2012

My first visit to the cancer centre in London, Ontario, I already know I have a tumor but I’m feeling good, they will just take the tumor out, give me some radiation and life goes on. WRONG! This is the day I found out that I would be having a full laryngectomy with a possible removal of my esophagus and a stomach pull up. I sat in the office and I was numb. I felt nothing. I had been diagnosed with Adenoid Cystic Carcinoma, a rare form of cancer with no known cause. I also have 10-15 undetermined spots on my lungs that will have to be monitored. Surgery date is set for April 20, 2012 and we (she and her husband, Claude) go home.

It wasn’t until later that night that reality hit me, I was going to lose my voice forever, I cried like I have never cried in my life. What was I going to do? Was my husband still going to love me, find me attractive? So many doubts played in my mind.

The next morning I was determined to be positive that everything was going to be ok. I went to the store and bought recordable story books, 9 in total, and recorded 3 for each of my kids.

I also recorded a personal message to each of them, just so they would always have my voice, everything was going to be fine.

Kathy stands outside her home in Dresden, Ontario, Canada. She is already doing and planning how to get her life back to normal as much as possible.

Poirier family photograph

April 20, 2012

Surgery starts at 8 am, we get to the hospital at 6, our daughters meet us there. We hug and start the longest but shortest walk of my life in silence. No one speaks, we are lost in our own thoughts I suppose, I don’t know to this day what they were thinking, but I was thinking it was the last time I was going to see them. I was terrified, I wasn’t sure if I was going to make it and if I did, did I want to. We said our good byes and I was whisked away to the operating room. I remember lying down on the table, having my iv started and not much else.

Guess what? I woke up! I wasn’t sure if I was happy about that or not at first, I was so sick. Great news!

Kathy’s story continues on Page 8
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Kathy’s Story continued from Page 6

They were able to repair my esophagus so it didn’t have to be removed. The cancer hadn’t spread as far as they thought so my stoma is in the regular spot rather than halfway down my chest and I have a TEP puncture, which they said I would never have. I was elated, I would speak again. Downside, because my thyroid was removed, my parathyroid is in shock and is no longer regulating the calcium in my body. Low calcium makes every muscle in your body spasm, including your heart, not good. Terrifying actually, you can’t move. This happened to me 4 times in hospital, I thought once again that I was going to die.

After about day six I started to feel better, I felt safe, I could take care of my stoma, I had nurses to help me, I was smiling again. My husband spent every day at the hospital with me, morning till night, things were looking up. My husband got permission to take me down to the gift shop so we went. I got into the elevator smiling, I got off the elevator in terror. I was panicked, my nurses weren’t with me, what was I thinking, I was no longer safe. That was my first panic attack, I had to sit down while my husband found a wheelchair, I could no longer walk. For some reason once in the wheelchair I felt safe again and we continued. We made many trips to the gift shop, but I never walked, I always took the chair. Little did I know this panic would follow me home.

I had a lot of ups and downs in the hospital and my nurses were wonderful. I remember one particular night though that I felt so very sad, I missed my husband, I missed talking and felt nothing was ever going to get better. My nurse was so compassionate, she called my husband and even though I couldn’t speak he talked to me for a while and reassured me that everything was going to be ok while I laid in my bed and cried. He must have talked for a half hour straight while I just laid there and listened to his voice, I finally calmed down and was ok to go to sleep. I will never forget that nurse for doing that for me.

May 5, 2012

Day 15, time to go home. I am feeling great, can’t believe I am the same person as I was a week ago, I am ready to go home. I am eating, radiation starts May 30, I am going to do this. Everything has happened so quickly I don’t think I have really faced what has happened to me yet. I am just going along, in a daze really, running on auto pilot.

May 30, 2012

Radiation starts, they give me all the warnings and I am going along without a care in the world until treatment number 15. WHAM! I hit a brick wall. All of a sudden I was SICK, and so depressed I could hardly get myself out of bed. The realization hit me that I still have spots on my lungs. The fear set in, it was paralyzing. I was afraid I was going to die. I went to treatment and then I went home to bed.

I cried more tears than I ever thought a person could make. I wandered around my house looking at my life and thinking, I can’t do this, I needed help. I started looking online for people to reach out to and I found Buck. Now Buck and I have never met, but he spent hours with me on the computer, talking and listening and helping me work through my fears. You see I could not even leave my house by myself. I was certain tragedy would strike if I walked out the door. Every day I would find solace in chatting online with my new friend. Every day I would look for him and get my pep talk. I went to my doctor and got anti depressants and I also asked for a counsellor. I knew I could not do this alone and that is ok.

Aug 10, 2012

Radiation is done, time for a CT scan on my lungs to see if my spots have changed. My nerves are ready to break, the stress level inside of me is at its max. I can’t think, I can’t do anything but imagine the worst, I am so afraid.

Aug 14, 2012

I got the results of my scan, no change in my spots, the best news I could have heard. Something clicks in my brain, that I have just spent what I thought was the last 3 months of my life waiting to die. What was wrong with me. We all have to die someday and was I going to live or was I going to wait. Since that day, I am still talking to my friend Buck, but the conversations are much different, they are happier. I walk every day (by myself) and guess what? I haven’t died. I started driving again, at first just up to the store but now just about anywhere.

Kathy’s Story Continues on Page 10
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9
Kathy’s Story continued from Page 8

I stopped covering my neck, why do I have to hide? I had cancer, not my fault, this is me now, if I can’t accept it then no one else will either. I am getting ready to go back to work, part time to start but wow, back to work. All of this in a short 5 months, there are no boundaries to what we can accomplish.

(Editor’s Note: Kathy has continued to progress and grow since this was written several weeks back. She has bought a puppy. She and Claude have planned an April trip to Florida. It will include April 20, the anniversary of her surgery. She tells me she now has fun even when she goes to the grocery store. She has kept her little grandson and enjoyed it thoroughly. She is walking, driving, gardening and exercising. Best of all, to use a British expression, she is “paying it forward” by trying to help others.)

Hotel rates released for 2013 IAL Annual Meeting

IAL News Staff Reports

Rates for Spokane, Washington’s, Red Lion Hotel in the Park are $99 plus tax.

There have been inquiries about costs of attending the 2013 IAL Annual Meeting and the Voice Institute during June 5-9 for the Voice Institute and June 6-9 for the IAL meeting.

Obviously, there is no way the IAL can give any costs projections for travel, depending on what type booking and mode of transportation is used.

For example, a round trip ticket from Charlotte, N.C., is selling for $586 right now. But it is too early to book.

There will be lots of information in the February and April issues, detailing the Red Lion and its amenities.

For more hotel information please call the Red Lion at the Park’s Reservations Department at (509) 326-8000.

Clubs Urged To Pay IAL Dues In Timely Fashion

IAL News Staff Reports

Dues invoices for 2013 are being mailed.

Member clubs’ timely payments will be appreciated and recognized when received.

“ Their continued support provides the foundation for the membership to have representation in the IAL,” said IAL vice president Wade Hampton.

Dues range from $25 for the smallest clubs—one to 10 members—to $175 for the two largest categories.

The address for mailing is:

The IAL
925B Peachtree St. NE
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The IAL’s Sponsorship Program

The IAL Board of Directors has established a sponsorship program to support continuation of the organization’s work.

Individuals, clubs, organizations, foundations and non-laryngectomee product businesses are invited to contribute in any amount.

Donations are tax deductible under U.S. laws.

Contributions are cumulative over time with the category increasing by the total amount given.

An example is that an individual could begin with a $5 gift. When donations from that person reach $50, he or she would be designated as a “Bronze”-level donor.

Please join those who are committed to the continued existence of our nearly 60-year-old organization by sending a check today to: The IAL, 925B Peachtree Street N.E., Suite 316, Atlanta, Ga. 30309-3918
Study continued from Page 1

In reply to a question, Searl emphasized there was plenty of room for more volunteers.

“Absolutely, he said. “We need more people with a laryngectomy to respond in order to get meaningful data to talk about. We also are encouraging folks with a laryngectomy to send the survey link to their friends and family, both those with and without a laryngectomy so we can get the participant numbers up as high as possible.”

He said two observations and information from their clinical caseload over many years prompted them to look at the issue of effort and fatigue associated with talking after total laryngectomy.

“First, we had a group of folks who reported that when giving talks (such as to schools or other groups, or at work) or when using their voice for extended periods of time, that their alaryngeal voice (these were TE and esophageal speakers primarily) changed and in some instances became strained or difficult to produce. It sounded to us like vocal fatigue that a person with a larynx might experience. Not many folks reported this, but we’ve heard it on and off over the years. The second observation prompting our interest in the top of effort and fatigue was our own observation that some folks sound like they are using excess effort - sometimes this showed up in the quality of the voice (as strained), for others it appears that they are pushing hard with the respiratory system, and for others there appeared to be overly exaggerated articulatory movements (we realize that we typically want more precise articulation but some seem to take it too far and visually at least it comes across as “a lot of work”).”

Searl said the team wanted to first find out from laryngectomizes whether they have a sense of elevated effort when they talk and whether they experience change or fatigue associated with talking.

“If folks did report increased effort then we wanted to know where in there body they felt the effort was happening. If they experienced fatigue we wanted to learn some details about that - for example, how much talking does it take before you feel fatigue, how long does it take to recover, can or do you do anything specific to help the recovery.

“We have parallels to all of this in folks with a larynx. Some people have a voice that wears out on them with extended or extreme use; others push too hard with their larynx or their lungs thereby all the time when talking and they experience changes to their voice. So we are gathering data from our survey from folks with a laryngectomy and those without. And we are looking at the three main forms of alaryngeal speech - so all are invited whether they use an AL, TEP or esophageal speech.”

Searl said the study will allow us to get a sense of whether effort and fatigue are really an issue deserving of further attention in our clinics and in research.

“It may be that only a very small proportion of folks with a laryngectomy experience issues in this regard and these might simply need to be dealt with on an individual basis,” he said.

“However, if there is a more widespread increase in effort or fatigue then we will have to go the next steps that might include: determining if effort and fatigue are the same for all three methods of alaryngeal communication, exploring where the greatest effort is focused in the body, figuring out how to limit that effort, assessing whether there are things about the person, the surgery they had or the follow-up training they received that might predict level of speech effort or fatigue. So at the moment this is really exploratory in nature. Once we see if there is a real issue to deal with we can begin to envision future studies that get at ways to limit effort and fatigue in alaryngeal communication - and it would be in these studies where clinical practice could be impacted in a way that could help patients.”

Asked how long he thought it would take to complete the study, Searl said it would depend on participation by laryngectomizes.

“Because we have so many people that we can access who still have a larynx, it is relatively easy to get our non-laryngectomized participant numbers up. The laryngectomizee crowd is, of course, much smaller. But for us to be able to get at all the issues we estimate needing about 150 responses from people with a laryngectomy. I hope we can get that within about 1 year.”

Again, the link to the survey is: https://survey.kumc.edu/se.ashx?s=5A1E27D279A1087F
An auction is always fun

IAL Annual Meeting auctions are always fun. 2012 was no exception and money was raised for the IAL.

Photographs by IAL News Editor Charles “Buck” Moore
IAL News Needs Writers

The IAL News needs about six writers to form a team to improve coverage of the laryngectomee community. “What we want are people with an interest in writing and who have either demonstrated their ability or have completed at least college freshman English,” said Charles Moore, editor of the IAL News.

Moore said he wants to see the newsletter containing more stories about active laryngectomees, particularly those who are still working or have unusual hobbies. “I personally would like to see stories about athletes, truck drivers, motorcyclists, musicians, etc.,” he said. Also, Moore said he would like at least two regular contributors from the professional medical fields, physicians, SLPs, or researchers.

“We want to make an effort to make the newsletter totally about the world of the laryngectomee,” he said. “We want crisp, modern stories that will inspire and inform our fellow laryngectomees.”

Applicants must own or have access to a camera that will yield at least a 300 dpi photo that is required by our printer. Stories must have quality photos.

Finally, applicants must understand this is a voluntary, unpaid, untitled position, except for story bylines. And they must be willing to meet a deadline. Anyone interested please email Moore at:

swampfox95@hotmail.com

Spokane In 2013...
Members Mark Your Calendars

** Voice Institute Wednesday, June 5, 2013—Sunday June 9 **
IAL Meeting, Thursday, June 6, 2013—Sunday, June 9

Education * Fun * Activities * Vendors’ Latest

Left: The Red Lion Hotel—where we will be staying. It is located on the banks of the Spokane River.
Right: The hotel’s patio on the river.
(Hotel Photographs)

** The IAL Annual Meeting **
Michael Douglas to promote Oral Cancer Foundation

Actor and producer Michael Douglas has donated his time to help create a television public service announcement (PSA) on behalf of the Oral Cancer Foundation (OCF).

OCF, a non-profit organization dedicated to helping those affected by the disease. The PSA will support the Foundation's efforts to educate the public about the need for annual screenings to detect oral cancers in their early, most survivable stages. The public service announcement began airing in June, and will continue to air nationwide through summer and autumn.

Approximately 40,000 people in the US will be newly diagnosed with oral cancer in 2012. It is simply not just a smoker’s disease any longer.

Douglas' cancer is now in remission.

He first sought medical help in 2010 after experiencing a sore throat that persisted for a protracted period of time. After several visits to doctors, a tumor on the base of his tongue was discovered. With further analysis, it was determined that Mr. Douglas had stage IV squamous cell carcinoma oral cancer.

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**IAL’s Sponsorship Program**

A full explanation of how the IAL Sponsorship Program works can be found on Page 10.

The IAL thanks each and every sponsor for their donations.

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Laryngectomees Having Fun

The Durham Bulls vs. the Scranton Yankees baseball game was highly attended by laryngectomees at June's IAL Annual Meeting in Raleigh, N.C., including Pat Sanders, WebWhispers President (top right), IAL VP Wade Hampton (lower left) and IAL Board of Directors member Sapp Funderburk (bottom right) A great time was had by everyone, though, the home team lost.

Photographs by IAL News Editor Charles “Buck” Moore.
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Aquatic Laryngectomees

These photographs were taken in June at the IAL meeting in Durham, N.C. Top is IAL Board of Directors member, Elizabeth Finchem, with William Schmaiz, Whitesboro, NY, and his son, Rick. Bottom, Tony Talmich shows his skills, while IAL President Bob Herbst watches. There were many more swimmers but a page just allows for so many. The crowds who were attracted outnumbered the swimmers.

Photographs by IAL News Editor Charles “Buck” Moore.
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