

Boston Cured Cancer Club for Laryngectomees

243 Charles Street, Boston, Massachusetts 02114

www.bostoncuredcancerclubforlaryngectomees.org

Newsletter for November and December 2018

Hello Folks! It took a while for authentic New England fall weather to kick in, but we are finally enjoying cooler temps. Brrr! Quite a change, just in this past week! Each day nature records the ever unfolding colorful changes of autumnal glory in the world around us... Let us savor these moments!

As the sun seems to sink a bit lower in the sky each day, our attention turns to our heating thermostats. With the dryness of that heat comes the need for enhanced humidity. It's a good idea to check that your humidifier is ready for you. It is so very important for "larys" to moisten the air which is delivered directly to the trachea and lungs.

While we are on the topic of humidity, many laryngectomees are finding great comfort in the use of their HMEs. For those of you who are not familiar with this term, a Heat and Moisture Exchanger (HME) is a button-like attachment to the tracheostoma which filters, humidifies and warms inhaled air. If you do not wear one you may want to talk with your doctor or speech pathologist about the benefits of doing so.

Now as we continue on the topic of heat and moisture and its effects on a laryngectomee's breathing we are happy to share the following information. We were delighted to welcome Ann-Jean Beck to our meeting in October. Ann-Jean is a medical doctor and PhD student doing research on optimizing access to medical devices for laryngectomy patients, with special focus on device reimbursement. Under the supervision of Dr. Daniel Deschler and Glenn Bunting, CCC-SLP, she will investigate the cost-effectiveness of heat and moisture exchanger (HME) use after total laryngectomy, with the aim to support reimbursement decision-making of the HME and accessories (e.g. the baseplate). The results obtained from this study can potentially be valuable evidence of the importance of using the HME to insurers worldwide. To evaluate the cost-effectiveness of the HME, she needs input from laryngectomy patients by means of filling out a questionnaire regarding using/not using a device and its impact on quality of life. This will take approximately 10 to 15 minutes to complete and can be done either online or on paper. All patients who have undergone a laryngectomy at least 6 months ago and visit the Mass. Eye and Ear for follow-up care *or* prosthesis replacements, whether or not they currently use an HME, are eligible to participate in this study. The study will start soon, and if you are interested in participating or would like to receive more information, please contact Ann-Jean Beck at:

617-573-6323 or AnnJean_Beck@meei.harvard.edu Please note "underscore" after Jean.

On a personal note, Andre finds great comfort in wearing an HME and he will be participating in this very worthwhile research study. He finds that it definitely decreases the annoying mucus production that so many laryngectomees must deal with. The filtering action of the HME is beneficial in all seasons but adds an extra comfort level during cold weather as it warms his inhaled air. Andre did eventually get his HMEs covered by his insurance, but it took too many phone calls over a far too long a period of time to get these prescription items covered. Whether you wear an HME or not, we encourage you to participate in this very worthwhile study. As our much loved and dearly missed member, George D'Auteuil shared at the last meeting he attended before his passing, "We are all mentors. Don't ever give

up. We may have lost our natural voice, but we will always be heard.” Please, let your voice be heard and contact Dr. Beck!

Our upcoming meetings are scheduled for Sunday, November 4, 2018 and December 2, 2018 in the 7th floor cafeteria at MEEI in Boston. “Meet and Greet” begins at 1:00PM with our formal meeting starting at 1:30PM. Please join us for some delicious refreshments and good conversation. Free validated parking in the MEEI lots is available to attendees.

Our September and October meetings involved lively, informal conversation regarding adjustments to life as a laryngectomee as well as strategies to deal with ongoing after effects of radiation and surgery. Member Walter Olsick shared his positive experience on the benefits of working with a lymphatic massage therapist in dealing with post-surgical swelling. Member George Chadwick, after having spoken with an EMT, shared the importance of posting your medical information on the top side of your refrigerator should an emergency arise. First responders look there for any information which would be helpful in your treatment. We thank these great guys for their helpful insight!

Please join us on November 4th and again on December 2nd. We draw strength from one another’s presence. We are not only living, but thriving, as cancer survivors and their loved ones. It is very affirming to be in the presence of fellow larys who have each endured tremendous challenges, and each have their own story of trial and triumph....inspiring all who attend.

We also want to remind you that after the December 2nd meeting we recess until March 3, 2019. Due to weather concerns, we do not meet in January or February. Newsletters are published four times a year.

In closing we would like to once again share our favorite acronym that we came across early in Andre’s recovery. It was a source of inspiration and comfort back then and continues to be applicable to daily highs and lows.

HOPE = Hold **O**nto **P**ositive **E**xpectations

'Hope to see you on November 4th!
Enjoy these cool, crisp, crunchy, autumn days!

Andre and Ginny Charpentier
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There is no medicine like hope, no incentive so great, and no tonic so powerful as the expectation of something tomorrow.

Orison Swett Marden