Laryngectomee Support: BCL January 2025 Meeting Follow-Up (Part 1 of 2)

Hello Folks,

As always, it was wonderful to meet with those who joined us online this past Tuesday. We're sending along some of the evening's topics in this email. Please note this is Part 1 of 2. In a separate email (Part 2 of 2) we will forward helpful links to resources which we have shared in the past. These will be of particular interest to folks who are new to our group.

Topic #1

ATOS Events:

Staying Active after Laryngectomy

What does "staying active" mean to you? Whether you enjoy time in the garden, short walks, long runs or just getting out to visit friends and family, movement can energize your mind and your body. The discussion touches on possibilities of getting back to some of the activities you enjoyed before surgery. The discussion may include:

- Tips to help you add movement to your day
- How can HMEs help to support lung health and the activities you enjoy
- Explore ways to stay socially connected
- Fun activities to improve mental wellness

MyLife events are a chance for laryngectomy patients and caregivers to interact with each other, learn valuable tips, share experiences, spend time with your local rep and enjoy meeting and learning from others in the laryngectomy community. You are always welcome to bring a guest!

Hosted by: Megan Stegman

Thursday, January 16, 2025 Yes...This Thursday! 5:00 pm - 6:00 pm CT

Event code: vcev25dc-001

Click on the Link below or copy to a browser to sign up for the event and to see the event description.

https://events.atosmedical.com/ereg/newreg.php?eventid=826236&language=eng

If you need Help Contact:

Dan Chojnacki Marketing Events Coordinator 1.414.626.1734

dan.chojnacki@atosmedical.com

Topic #2

David, who had his laryngectomy 27 years ago, shared some great information. Many years ago, in conjunction with the International Association of Laryngectomees, (the IAL), David co-authored a guide for those new to living as a laryngectomee. *First Steps* is available as a free download by clicking this link.

https://drive.google.com/file/d/1acYQWml3GzS9ixJpXjxviYluqRnz8Klc/view

David also recommended a book entitled **Self Help for the Laryngectomee** by Edmund Lauder which is available for purchase and/or download from the Lauder Electrolarynx website. Scroll down on the home page to find the book information. This company also provides a number of other helpful resources.

https://www.electrolarynx.com/#/

Topic #3

Tony has been a total laryngectomee since 1990 and uses an electrolarynx and esophageal speech to communicate. He is happy to talk with anyone with regard to suggestions to support communication and maximize voice quality.

Tony has worked successfully with many people in person and in online formats. He can be reached through his cell phone or through his email. Tony **prefers** folks reach out to him through his **cell phone**, by either texting or calling him.

To Contact Tony send me an email at : acharpen@umich.edu

Topic #4

Itzhak Brook MD, a total laryngectomee, recently announced the publication of his **6th Edition of his Laryngectomee Guide.** He recently shared the following information with those on his email list.

I am happy to announce the publication of the 6 th edition of the Expanded Laryngectomee Guide, now spanning 379 pages. This updated and revised edition offers valuable information to assist laryngectomees and their caregivers with a wide range of concerns, including medical, dental, and psychological issues.

The guide includes comprehensive details on head and neck cancer and its surgical treatments, side effects of radiation and chemotherapy, various speaking methods, and care for the airway, stoma, and voice prosthesis. It also addresses eating and swallowing challenges, and provides guidance on respiration, preventive medicine, urgent care, anesthesia, and traveling. Additionally, the guide offers helpful resources specifically for laryngectomees and head and neck cancer patients.

The E Book is free for download https://bit.lv/3xvA49f

Itzhak Brook MD has also written **My Voice, A Physician's Personal Experience with Throat Cancer** which addresses many of the social emotional aspects of surviving and thriving in the aftermath of having a total laryngectomy. This book is available on Amazon. Links can be found in our 'December Meeting Follow-Up, Part 2' which you receive in a separate email.

Topic #5

Len shared the very sad news of the recent passing of **Itzhak Brook MD.** We had the pleasure and the honor of meeting Dr.
Brook in person when he was a guest speaker at one of our meetings at MEEI. He also was our guest speaker at one of our first online Zoom meetings in the spring of 2020. To say he was an extraordinary man is an understatement. Dr. Brook made immense contributions to the laryngectomee community. He will be greatly missed. May he rest in peace.

We are including the message Len received from the Head and Neck Cancer Alliance as well as a link to Dr. Brook's obituary.

Dear Alliance Ambassadors,

It is with profound sadness that I share the passing of Alliance Board Member and Ambassador Itzhak Brook, M.D.

For decades, Dr. Brook served as a dedicated advocate and key opinion leader, traveling both nationally and internationally to attend meetings, provide guidance, and champion the head and neck cancer community. His wisdom and leadership were instrumental in shaping the Alliance's mission and programs, leaving an enduring legacy. Dr. Brook took immense pride in his work and was honored to have positively impacted so many lives.

His contributions extended far beyond his role with the Alliance. Dr. Brook was the author of two invaluable resources for the head and neck cancer community: *My Voice: A Physician's Personal Experience with Throat Cancer* and *The Laryngectomee Guide*. The latter, translated into 29 languages, has become a vital tool for patients, caregivers, and medical professionals worldwide. These works reflect his unwavering commitment to improving lives and empowering those affected by cancer.

You can read more about Dr. Brook's remarkable life and accomplishments in this heartfelt
obituary prepared by his family. Additional details about his contributions to the Alliance and the head and neck cancer community can be found here.

On a personal note, I had the privilege of working closely with Dr. Brook for the past eight years. As one of the inaugural Ambassadors, he was always available to provide advice and support, particularly when it came to addressing patient concerns. His generosity, compassion, and dedication will be deeply missed.

Warm regards,

Eileen

Eileen Sexton

Program Director Head and Neck Cancer Alliance PO Box 21688 Charleston, SC 29413 eileen@headandneck.org

Here is the direct link to Dr. Brook's obituary.

https://docs.google.com/document/d/13WLwTiM1hR8wQQ3LFbRMePj9cUMFss8AwJ1YCmDQ34s/edit?tab=t.0

Closing thoughts from Tuesday evening....

Keep your eye out for our 'Part 2 of 2: January Meeting Follow-Up'. This second installment, so to speak, is information which we have already shared but would like to keep available to new folks as well as anyone who may have missed it the first time around.

It is available on the **resource page** on this website.

Andre and I continue to be humbled and inspired by the strength and resilience of you, the wonderful folks we meet along the way. Your courage and determination are truly inspirational. While it is great to be present to those with whom we can virtually meet, we are also cognizant of those who are not able to attend...and we miss them and wish them well.

As we courageously go forward into this new year, may we look to each day as a step towards brighter tomorrows. Let us remember to focus only on the step in front of us, the staircase awaits!

We shall look forward to gathering again online in February.

With our very best wishes,

Andre and Ginny Charpentier

"Faith is taking the first step even when you don't see the whole staircase." Martin Luther King Jr.

"Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says, 'I'll try again tomorrow'." Mary Anne Radmacher