

Nu-Voices Club of Mt Sinai Hosp, Inc

Member of IAL

July 16th, 2017

Dear Members and Friends,

President Saul Silver called the meeting to order at 1:30 PM. In attendance were 11 members and friends as shown and named below.



**Standing L-R: Saul Silver, Cindy Fontanez, Clarissa Bushman, Harold Masters, Larry C. Powers, Frank Deppolder
Seated L-R: Joe Fontanez, Don McDonagh Leslie Getz McDonagh**



**Jay Hauben, who had to leave
before the group foto was taken**



**Gerry Silver
Ace Photographer**

We missed

- Cecilia Wennerstrom who is off at a trial with Sophia, but expects to be at the meeting in August.
- We had hoped to have a new attendee, Patrick Temple that Jay visited in the hospital. Unfortunately, he was still in the hospital as of Wednesday.
- Scott Goldman was taking his Mom fishing (his passion) on a party boat from Montauk. He hopes she will not get seasick and hopes to be with us at the August meeting.
- Larry Velez, but we were happy to see a recent Facebook post by Larry saying that it had been four years since his laryngectomy and that he was “a very happy person”. We are all happy for Larry.
- Leola Glover who wasn’t feeling well.

Frank Deppolder read the “Prayer for Laryngectomees” and Saul Silver led off the round table.

Nu-Voices Club of Mt Sinai Hosp, Inc

Member of IAL

July 16th, 2017

Inhealth Technologies publishes a monthly blog of news articles of interest to laryngectomees. Here is a link to the latest issue: http://www.inhealth.com/category_s/180.htm

No new developments in trying to arrange for Dr Brook's presentation at one of our meetings, still trying to get ATOS to approve expenses for Dr. Brook. Saul sent another email to ATOS rep Dave Barry, but we haven't received a response yet.

Don McDonagh had a bad fall, which turned out to be a broken elbow. He and Leslie had to make the rounds between the VA hospital, an urgent care facility, an orthopedist and an infectious disease specialist to get the right diagnosis. Don and Leslie finally found out that he had a broken elbow and did not have a recurrence of cellulitis. Don't any of their doctors get it right the first time?

Saul reports that he is now taking steroids by a nebulizer for his shortness of breath and is feeling much better. He is continuing his immunotherapy. Thanks to Gerry and the team at the NYU Cancer Center he has been able to deal with all the curve balls thrown to him.

Cindy Fontanez reported that she and Joe were not at the June meeting because she finally had her overdue surgery and is now doing very well. She returned to work two weeks after the surgery. She also said that she and Joe had come a long way since meeting us. Joe is much more confident with his care, especially suctioning. She commented that Joe used the suction machine as she was driving to the meeting. Preciously she would have pulled over when Joe did this. Cindy is off to Puerto Rico in August. She is not sure if she will make it to the August meeting. **We thank Joe and Cindy for the donuts they brought to the meeting.**

Joe told us about the trials he endured in hospitals, nursing homes and rehab facilities because of his inability to speak at that time. He is happy and thankful with his electrolarynx.

Larry Powers said he is due for a prosthesis change and he is planning to make an appointment with Tamar Kotz to do it. Gerry said that he is speaking much better and she easily understood him on the phone. Larry is now also carrying his backup electrolarynx at all times.

Frank Deppolder said he is due to see Dr. Caruana for his 6-month checkup. He is still suffering with his rheumatism and wishes it would go away. He will have company in August as his friend Lorraine Faustino will be visiting from Arizona.

Nu-Voices Club of Mt Sinai Hosp, Inc

Member of IAL

July 16th, 2017

Clarissa Bushman is still struggling with her meds but is not letting them get the best of her. Her friend Harold Masters joined her at the meeting. She said he is part of her support system and she is grateful to have him. Harold was happy to be at the meeting and to be part of her support system.

Jay came across an article written by an Operating Room nurse about her husband's care in a hospital after his laryngectomy. Reprinted as pages 4 and 5 of this newsletter. Jay printed it out and passed around some copies of it at the meeting. It is truly a cautionary tale about the need to make sure that any medical professional who touches a laryngectomee needs to understand the necessity for oxygen via the neck and not the nose or mouth. It is truly frightening how many of them are totally ignorant about laryngectomees and their needs. This article prompted a big discussion of the subject among the members present. Several of the members had encountered this medical ignorance themselves. It is understandable because laryngectomies are a very small percentage of the population and the majority of doctors, nurses and EMTs have never encountered one, so we and our caregivers have to educate them.

Jay also found an interesting post on Web Whispers about a long-time laryngectomee. It is reprinted on page 6 of this newsletter.

Jay was happy to tell us that his new prosthesis is working well. He also spoke about his sister and her treatments for cancer. She is in some pain and is continuing with her treatments in New Jersey although she may lose her eyesight. Time will tell.

Jay had to leave early because a previously scheduled commitment was rescheduled for 3 P.M. on July 16th.

We ended the meeting about 2:35 with our usual silent prayer and posing for Ace Photographer Gerry Silver.

The August meeting will be on the 2nd floor, Seminar Room B of 1470 Madison Avenue, between 101st and 102nd. We will meet on Sunday, August 20th at 1:30 P.M.

Saul Silver, President
390 First Avenue, #8F
New York, NY 10010
(212) 677-6392
argentum@nyc.rr.com

Leslie McDonagh, Treasurer
150 Claremont Avenue, #2C
New York, NY 10027
(212) 662-6515

Article by OR Nurse

Hi All!

I'll apologise now in case this gets a bit long. I originally posted this info on the Facebook group but was asked to post it here too for the many members here who aren't on Facebook. I'm not known for 1 line posts, so sorry! :D

As an OR nurse of 30 years, I'd looked after a few patients with existing trachs and also helped to create them, including one yesterday. However, I'd never in all my years ever encountered a lary. So when David became one, I realised that the differences extended to more than just him breathing through his neck. I spent the month before surgery and several months after trying to educate myself as best I could, because at that stage, I had no idea if there were any other larys in our area (have since found out there are 5 others) and also no idea if any medical people knew about them. Majority don't. Thankfully most are happy to be educated.

One of our fears, and I guess most larys is, what will happen if you need to go to hospital? Will they apply oxygen to your face? Will they try to intubate you via your mouth? There's a very high chance they will. What if you go in for surgery? Will you wake up in the recovery room with nasal prongs? There's a high chance you will. To be blunt, going to hospital could be the last thing you do if the people caring for you don't understand how you are different from everyone else.

Since I've been back at work after David's surgery, I have spoken to quite a few of the anaesthetists, and given they specialise in airways, it's disturbing how little they know. They can't get their head around the disconnected airway. They keep thinking trach. They keep calling it a trach, I keep correcting them. This week one of them asked what would they see with a laryngoscopy (that pleasant little scope up your nose, or when they look in your throat to intubate you when you still have a larynx). I said, he doesn't have a larynx, so a laryngoscopy is impossible. He corrected himself and said oro-pharynx. I said you'd see the top of his oesophagus. He said "oh, does he still have one of them?". I rolled my eyes and said no, he eats through his stoma. This is a man who sticks things in people's airways for a living!

This Monday coming, David is having a gastroscopy and colonoscopy. I opted to have it done at my hospital so I could make sure they understood exactly what he needed. I also knew the other hospital didn't have all the equipment they may need for his airway. As soon as I found out who was doing the anaesthetic, I baled him up and asked him if he'd had any experience with larys. He said yes, he had looked after a couple of the other locals. I still asked him some questions, which he scored 100%. I breathed a sigh of relief. He will only be having sedation, so should only need an oxygen mask, but they still need to be prepared to intubate because some people decide to stop breathing.

If you are going for surgery, ask to speak to the anaesthetist that will be looking after you, before your date of surgery. You have to assume that no-one knows what they are doing, so you need to sound like you do, by asking some questions. While the terminology may sound like double Dutch to you, the anaesthetist will know what you mean.

1. Do you understand what it means to be a laryngectomee, or a full neck breather? Ask them the difference between a trach and a stoma. Educate them to the difference if they don't know. Show them your stoma.
2. What type of mask will you pre oxygenate me with? The answer should be a round size 1 neonatal resus mask or a paediatric mask turned sideways.

3. Where will you hold the mask? Answer should obviously be your neck.

4. Where will you put the tube when you intubate me? Through my nose or mouth? If they say either of them, ask what the point of that would be.

5. What type of tube will you use? Answer should be a trach tube or a reinforced flexible ET tube. Normal ET tubes can be used, but they are stiff and don't fit the lower trachea like the flexi ones do.

6. If using an ET tube, how far will you insert it? Answer should be no further than the first black line (they all have them).

7. When I go to recovery, will I have a Hudson mask or nasal prongs? Answer should be neither, they both go on your face! You should have a trach mask. If they don't have them, take your own or tell them to get one from the ICU, they will have them.

8. Throw in a trick question. What will you do if I have a laryngeal spasm? I've heard they can be dangerous. If he goes through the procedure, ask for a new anaesthetist. You can't have a laryngeal spasm! By this stage, if he says the procedure, he hasn't listened to anything you've said.

If you have a TEP, remind them NOT to touch it. If they dislodge it, it will cost them their life!

I am in a position to do so, so I've set up an anaesthetic bag for David for Monday. In it contains a size 7 & 8 reinforced flexible ET tubes, a 14fr Y-suction catheter, a neck mask, a paediatric oxygen mask (because we don't have the tubing separate, so need to get it from there for his neck mask), a 14fr urinary catheter in case they do pull his TEP out (I've threatened them, so it should be safe!) and a size 1 round neonatal resus mask. I have also printed and laminated some posters that have been posted on the Facebook page that I'll stick all over his bed. Plus typed up certain protocols for them to read. I've also laminated CPR for neck breathers. I think I've covered it all! David thinks I'm going way over the top, but I think you need to because the knowledge amongst medical staff is limited. Mostly it's none.

Even if you are going to the hospital you had your surgery, don't assume they know. Never ever assume, EVER.

You have to keep reminding them right up to the point of you going to sleep. Keep reminding them, neck only, nothing on my face. Drum it into them.

I'm so sorry this got really long, but I think it's vitally important that people know about this stuff. Larys can die because they receive the wrong care in hospital. Don't let it be you!

Jane (wife of David, total laryngectomy, bilateral neck dissections 7/7/16, Australia, back at work, enjoying life, drinking bowel prep tomorrow, sucks to be him!)

Story of 13-year lary reprinted from Web Whispers

A laryngectomee reached 13 years cancer free. He sent this story to the WebWhispers mailing list:

Jay

=====

I'm not sure how much one can prepare yourself to wake up next morning with no voice or way to talk even knowing you do so in hopes of being cancer free?

The morning after the nurse asked if I wanted to go for a walk...I was ready to be off & running! The nurse needed some time as none of them had dealt with a Laryngectomee before, but soon we were off. The surgical unit had a square floor so as we reached the first corner the nurse asked "do you want to keep going?" but as soon as she asked she realized we had not brought anything to write on. After a chuckle & some reading lips we proceeded on. I was amazed after spending all day yesterday in surgery how well I felt. As we got to 2nd corner she chuckled "so no sense asking as it is same distance back both ways." We kept on going and as we rounded 3rd corner I could see nurse station & my room. I've always wondered how NFL players could cramp up and was about to get the answer. Froze in time I could not move...now nurse lost it thinking I was having heart attack or couldn't breathe. She called for help and after I got back to my room the head nurse asked her to step out as she was so upset. As she was leaving I heard her say "Just not what Randy needed."

I wrote on my notebook to the head nurse "please make sure she stops back later."

When she did come back I had already written her message out...

I HEARD YOU SAY "JUST WHAT RANDY DID NOT NEED?" BUT AS WE WALKED THE HALLS THIS MORNING I SAW PEOPLE IN BEDS, HOOKED UP TO MACHINES AND CONFINED. I REALIZED I'D RATHER BE ABLE TO WALK WITH NO VOICE THAN BE LIKE THEM! SO IN FACT IT WAS EXACTLY WHAT I NEEDED!!!

She got a tear in her eye, grabbed my hand and said "Young man I'm done worrying about you. With an attitude like that you are going to be just fine!"

As always Eternally optimistic
Randy Wienke, Brooklyn Wisc
Lary Class 2004