The IAL News

The International Association of Laryngectomees  Vol. 60 No. 1  February 2015

Speech Language Pathology Involvement in Laryngectomee Support Groups

By Candy Moltz, MS, CCC-SLP, IAL BOD Member-at-large

In the February 2014 issue of the IAL News, an article was offered concerning Laryngectomee support groups. Its content specifically addressed the importance of Lost Chord Clubs in the rehabilitation of laryngectomees and practical advice on starting a Lost Chord Club. It has been noted that the membership of laryngectomee support groups is on the decline and many existing clubs report dwindling attendance. The possible 'causes' for this decline are many and perhaps a sign of our times, but sometimes it is simply that new laryngectomees are unaware that the clubs exist. This article is the result of information gathered from laryngectomees who regularly participate in laryngectomee support groups and shared how their clubs integrate and utilize speech language pathologists (SLP) in the meetings. The goal is to encourage SLPS to volunteer and make themselves available to their local Lost Chord Clubs.

Barb Nitschneider, Secretary for the IAL, told about various support groups in which she participated. In her experience, the SLP arranged a room for them to meet and scheduled a variety of programs. The meetings were open to any head and neck cancer patients, whether or not they had a laryngectomy. The support group met monthly, but not during the winter months. The meetings informed members of cancer programs available through the local hospital, but also included other interesting topics, including laughter therapy, palm reading and vendor presentations of new technologies. Outside speakers, like a policeman talking about safety in the community were also offered. The opportunity to ask questions about their individual situations also led to great discussion and discovery. Every year they use a portion of their dues for a Christmas meeting at a local restaurant. Barb indicated that her favorite things the support group provided her included; fellowship, education, updates from visiting vendors, speech therapy and the feeling that she was not alone in her struggles as a laryngectomee and that her club was helping new laryngectomees begin their rehabilitation.

Pictured above: Lacy Martins do Nascimento, SLP coordinator; Sally North, president of Dallas Lost Chord Club; Milton Hassell, member of Dallas Lost Chord Club; and Candy Moltz, SLP and longtime member of Dallas Lost Chord Club

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Barb had the opportunity to be a part of more than one support group in her walk as a laryngectomee and felt it was very beneficial having a speech pathologist associated with the group to provide leadership, group speech therapy as needed, and bring in new laryngectomees to the group.

Chuck Rusky, Treasurer of the IAL, reported he has been a member of the Orange County Lost Chord Club in Santa Ana, CA for the past 19 years. They meet weekly for an hour at their local ACS office and have about 12 in attendance. Chuck hates to miss his meetings and feels they have helped countless other laryngectomees and their families through their trials and tribulations. He continues to attend today for the great advice he received and still finds something new to consider or some new individual who needs help. Irene Hennessy, an SLP, has been meeting with the Santa Ana Club for the past 20 years. She typically attends their meetings once a month for a two hour meeting and spends most of her time helping the new laryngectomees with their speech and speech aids. The Orange County Lost Chord Club was established by an SLP about 40 years ago. She teaches at Cal State Long Beach and she invites members of the club to come to her class to demonstrate to her students how laryngectomees talk with speech aids, TEPS and esophageal speech. The club has also volunteered to talk to the physician interns in the ENT department at University of California, Irvine, where the laryngectomee volunteers try to impress the young doctors about the importance of additional help and support after the laryngectomy surgery. The Orange County Lost Chord Club lends Cooper Rand intra-oral speech aids to patients before surgery to encourage immediate communication as soon as recovery would allow.

Club members speak to thousands of students every year about the hazards of tobacco use and they fulfill all requests coming in to ACS for speakers.

In summary, Chuck’s club supports one another, has speakers on medical and non-medical topics and arranges to volunteer in their community. Chuck has observed clubs that were completely organized and run by an SLP, and when that SLP had to move away, the club fell apart. He believes the success of his club comes from laryngectomee leadership and organization, with the support and input from a speech pathologist and a commitment to help new laryngectomees with their rehabilitation.

Jessie Hart, a mentor and laryngectomee speech teacher, former IAL Board of Director member and leader in laryngectomee support in Texas, has given many lectures at the TLA about forming local support groups and nurturing the relationship between laryngectomees and speech pathologists. She believed, and rightly so, the two groups had so much to offer and teach each other. There is not enough space in this article to enumerate the millions of ways she volunteered her skills.

Katrina Jensen is an SLP who works in an ENT group in Fort Worth, Texas. She is an integral part of the team involved with helping new head and neck cancer patients from the time the individual is diagnosed, through surgery and for rehabilitation follow-up after discharge from the hospital. She issues a written prescription to attend her support group within the ENT practice as soon as patients are able to get out. Once a patient attends the group, Katrina, gets them involved in other activities in addition to their speech classes. They have a laryngectomee choir that is most impressive and has performed for the Texas Laryngectomee Association at several annual conferences. In a time when people seem more reluctant to participate in activities outside the home, Katrina has found a way to get her patients involved and active in their own rehabilitation.

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About The IAL News

The IAL News is published four times a year by the International Association of Laryngectomees. Information provided by the IAL News is not intended as a substitute for professional medical help or advice, rather as an aid in understanding problems experienced by laryngectomees and the state of current medical knowledge.

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.

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IAL Items Available
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- Orange Emergency Window Stickers (English)

"Laryngectomees Loving Life" DVD
(35 mins) ($10 donation requested)
(May also be watched on website)
- “First Steps” Available to download from the IAL website

Have a good idea
or
a helpful hint?

We welcome laryngectomees and caregivers to submit ideas that would be helpful for other laryngectomees.
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Susan Reeves, administrative manager of the IAL, feels that an SLP gains so much experience and knowledge when they get involved with laryngectomy support clubs. The SLPs learn volumes from the club members that is not available in their academic training. Specifically, the unique ways laryngectomees learn to adapt to the challenges they face in the absence of SLP or club support. The SLP learns that laryngectomee patients require so much more than merely learning a new way to speak. This surgery affects the laryngectomee, and additionally, their whole family, with an impact on the whole community. Susan reported that once she was exposed to the vast information pool and hands-on experiences at her first IAL meeting, it changed her as a speech language pathologist and it initiated her lifelong commitment to the rehabilitation of this unique population. She feels clubs offer camaraderie among members, but more importantly, it improves the insight and compassion of the participating SLP.

In 1989, I participated in the speech therapy group held weekly at the Dallas ACS under the guidance of Jessie Hart and Martha Reed. At that time, after an SLP or a laryngectomee Speech Teacher attended the IAL Voice Institute and passed the exam, they were required to clock a minimum of 30 hours of direct patient contact working on speech rehabilitation under a supervisor. With Jessie’s help, I completed this requirement and became very familiar with the unique challenges faced by new and all laryngectomees. This included esophageal speech, alaryngeal devices, TEP, and changes in breathing, eating and returning to their normal lives. Because of the ACS speech therapy group, I was invited to attend the Dallas Lost Chord Club. It meets monthly to this day, except for the summer months. I saw the positive impact it had on its members, new laryngectomees and their families. The Dallas Lost Chord Club has a strong commitment to educating the community, volunteering in the Great American Smoke Out, and speaking to young students in school about the results of smoking. Like Susan Reeves, helping the laryngectomized patient has become a life-long / career-long commitment for me. I was the lucky one for all I learned through the Dallas Lost Chord Club. As a bonus, members were always willing to demonstrate and help me teach this information to graduate students in Speech Pathology. I still attend the Dallas Lost Chord Club regularly 25 years later.

In summary, Laryngectomee Support Clubs go by many different names and are organized many different ways. Some are organized and led by Speech Pathologists, others are organized and led by laryngectomees who are dedicated to helping those who come after them. All involved are positively affected through helping each other, embracing the information the medical community has to offer, and sharing the experience with local speech language pathologists. The benefits to the SLPs are innumerable and I challenge those trained SLPs to involve themselves with their local Lost Chord Clubs. Volunteer your time and expertise with the club, refer your new laryngectomees and ask for assistance when needed. Offer to share your experience with new SLPs. Encourage your patients and provide them with information on where to join a support club to enrich and ensure their total rehabilitation. You will most certainly reap the rewards. Tell us about YOUR club!

Check your Club listing

U.S. clubs should check their listing on the IAL’s web site. Review your club information at www.TheIAL.com under Club Resources and then select Club Search. Click on the map for your state. The IAL and other club listings is a method many new laryngectomees use to connect with us all. Please send corrections to: Office@theial.com

Thanks for your help in keeping the list up to date!
IAL Positions Open

The IAI has need of laryngectomized people that are willing to work and serve the membership of our organization.

There is one vacant slot that needs to be filled at Baltimore in the IAL Annual Meeting.

There are two board member positions up for reelection.

People running for the board need to submit a brief biography, a picture and club endorsement to be presented to the nomination committee. The candidates need to present their information by April 1, 2015.

The information may be submitted to:
IAL
925B Peachtree St. NE
Suite 316
Atlanta, Ga., 30309-3918

Visit www.theial.com for all specifics for the application for a position on the IAL Board of Directors.

Greetings from New Editor

By Marina Shankle

My name is Marina Shankle, and I teach English, Journalism and Yearbook at Performance Learning Center in Concord, NC. I will be assisting IAL President Wade Hampton with designing the newsletter and putting it together.

I have a Bachelor’s in English from Pfeiffer University in Misenheimer, NC, and I enjoy anything that has to do with the written word—reading, writing and even proofreading. Lately, I have been reading the IAL newsletter and learning about all that the IAL does.

If you have any ideas for the newsletter, feel free to get in touch with me through email. You can reach me at marina.shankle@gmail.com.

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Myths and Truths: How to manage eating following laryngectomy

By Candy Moltz, MS, CCC-SLP, IAL BOD Member-at-large

A recent article in the IAL Newsletter provided a discussion of the many possible complications following laryngectomy surgery, chemotherapy and radiation therapy. Myths and Truths will attempt to present practical information and resources to facilitate improved eating and swallowing in the presence of dysphagia following laryngectomy. Proper nutrition is the primary goal, but everyone wants foods that taste great and goes down effortlessly. How can that be accomplished when surgery has changed anatomical structures, radiation therapy has inhibited saliva and altered peristalsis, and chemotherapy has interfered with the desire to eat? Although this is a simple review of only a few of the very complicated swallowing problems experienced by many laryngectomees, let’s contemplate what can help. Everyone wants to enjoy eating, and maintain their nutrition and ultimately return to health.

There are many nutritional resources to assist head and neck cancer patients during their chemo and radiation therapy. One may merely Google head and neck nutrition, diet changes during/following chemo-radiation, or Dietitian, diet textures, or patient education for diet changes, eating and drinking after treatment, and there are many articles and resources at your fingertips. One superb article is Nutritional Management for Head and Neck Cancer Patients by S. Schoeff, D. Barrett, C. D. Gress, and M. Jameson in the September 2013 issue of Practical Gastroenterology. It has an excellent review of nutritional management, enteral feeding and PEG tubes vs oral feeding during and after treatment. The article stresses the need for an interdisciplinary team to address meeting individual nutritional requirements, and how best to accomplish that. They also point out “the importance of the quality of life (QOL) as a primary treatment outcome, and there is still significant progress to be made in the area of dysphagia prevention and treatment, which is a key factor in QOL.”

The National Dysphagia Diet (NDD) was created in the 1990s out of a need to provide an understandable standardization of terminology to describe liquid/food consistencies. The NDD helped to create consistency across the food industry both in manufacturing and foodservice operations. The food properties need to be objective, measurable, and include all foods within the diet continuum, solids and liquids. Debbie Zwiefelhofer, RD, LD, is president for Nutrition Affairs LLC, Minneapolis, MN (www.NutritionAffairs.com) and in her article “Making Dysphagia Easier to Swallow”, she describes clearly the basic forces of chewing and swallowing and rates foods according to specific criterion. The food criterion include: Adhesiveness, Cohesiveness, Firmness, Biteability, Hardness, Springiness, Viscosity and Shear. The forces of chewing include: Compression, Adhesive, Tensile, Shear, and Fracture. Basically, these terms talk about how one manages to chew and swallow various kinds of foods and liquids from the lips all the way to the stomach. Ms. Zwiefelhofer then carefully describes the four levels of the National Dysphagia Diet. They are:

Level 1: Dysphagia Pureed For moderate to severe dysphagia. The diet consists of pureed, homogenous, and cohesive foods. Foods should be “pudding like.” Any food that requires bolus formation, controlled manipulation, or chewing should be excluded.

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Continued

Level 2: **Dysphagia Mechanically Altered** For mild to moderate oral and/or pharyngeal dysphagia. This level consists of all foods from level 1, plus foods that are moist, soft-textured, and easily formed into a bolus. Pieces can be no larger than one quarter inch. This is a transition level from pureed texture to more solid foods and some ability to chew is required. The ability to tolerate mixed textures at this level will be individualized.

Level 3: **Dysphagia Advanced** For mild dysphagia. This level consists of most textures except very hard, sticky, or crunchy foods. Foods should still be moist and in “bite-size” pieces at the oral phase of the swallow, more chewing ability is required.

Level 4: **Regular Diet** All foods allowed as tolerated.

NDD Liquids are described as:

- **Thin**: No alteration
- **Nectar-like**: Slightly thicker than water, the consistency of un-set gelatin
- **Honey-like**: A liquid with the consistency of honey
- **Spoon-thick**: A liquid with the consistency of pudding

As one can see, this allows for understanding in diet terminology across the health care disciplines and makes it easier for the layperson to understand as well.

With this information in mind, explore the foods and liquids that have been prescribed safe for you and how you might prepare them. You may require knife and fork for cutting solid foods smaller. You may need to use a manual chopper to chop up the food, or you may consider a blender to puree the foods to facilitate your swallow. You may also need to add more moisture. Adding more moisture, as in more water, gravy, yogurt, juice to your foods will make them easier to swallow.

The following recipe books are very helpful in creating nutritious, easy to chew and swallow meals for people experiencing dysphagia following laryngectomy surgery or undergoing chemo/radiation therapy.

- **Eating Hints for Cancer Patients**, offered by the National Institutes of Health through the US Department of Health and Human Services
  - I-Can’t-Chew Cookbook by J. Randy Wilson Delicious soft-diet recipes for people with chewing, swallowing and dry mouth disorders
  - randyw94@mymtnnhhome.com

- **The Dysphagia Cookbook** by Elaine Achilles, Ed.D
  - Great tasting and nutritious recipes for people with swallowing difficulties, published by Cumberland House Publishing 2004

- **Eating Well Through Cancer** by Holly Clegg and Gerald Milelello, M.D.
  - Easy Recipes and Recommendations During and After Treatment, published by Wimmer Cookbooks, 1-800-548-2537.

Ohio State University Comprehensive Cancer Center uses a patient education handout called the **High Calorie, High Protein, Pureed Diet for Head and Neck Cancer Patients**

patienteducation.osumc.edu This includes food groups listed in Best, Good, and Avoid categories.

Each of these publications offers insight and tasty, nutritious meals that cater to the unique problems that laryngectomees face every day when they try to eat. Each author includes a disclaimer that states one should check with their doctor or health care team for approval of their diet for safety and nutrition. When resuming oral feeding once it is deemed safe by your physician, SLP or dietitian consider these tips outlined in numerous locations, including but not limited to: UCSF Medical Center Nutrition Tips for Head and Neck Cancer Patients, and

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A block of rooms is set up under International Association of Laryngectomies. The rate is $99.00 plus tax until May 19, 2015. The hotel’s standard rate will apply after that date.

Important: Use the link below for reservations made online

https://www.starwoodmeeting.com/StarGroupsWeb/res?id=1405235413&key=20DF1A97

(This is important because reservations made at other website links will not get the discounted rates):

Discounted Room reservations can also be made by calling these hotel phone numbers:

(Toll Free) 1-888-627-7147

(Local)410-321-7400

Be sure to tell them that you are reserving the room for the International Association of Laryngectomies. Otherwise you will be charged the standard rates.
IAL Annual Meeting (June 11-13, 2015) and Voice Institute (June 10-13, 2015)

The recommended method for registration and payments is online at:
http://www.Theial.com
Mail in registrations: Please use this form

Check box for the event you plan to attend. Attendees must choose between the Annual Meeting or Voice Institute. Do not register for events.

☐ I plan to attend the Annual Meeting
☐ $100 per person (On or before May 17, 2015)
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OR

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☐ $120 New Laryngectomee  ☐ $120 Non Laryngectomee After May 17
☐ $400 Speech Pathologist On or before May 17
☐ $450 Speech Pathologist After May 17
☐ $200 Undergraduate/Graduate

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Second Attendee (please print) __________________________ Laryngectomee? Yes ☐ No ☐
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Phone Number(____) __________________________ Email __________________________

☐ Check here if you require assistance, have dietary restrictions, or need special accommodations to attend the meeting because of physical limitations. You will be contacted for other information.

Mail in registration forms must have check or money order payable in U.S. dollars to the International Association of Laryngectomees. Mail to IAL, 925B Peachtree Street NE, Suite 316, Atlanta, Ga. 30309

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Macmillan Cancer Support - Changes to Eating After Treatment for Head and Neck Cancer.
1. Eat more frequent, smaller meals, 6-8 times per day.
2. Add protein shakes to the diet for the added nutrition needed while undergoing treatments and to promote healing.
3. Add cancer fighting foods; plenty of fruits and vegetables, red berries and green tea.
4. Consider fish oil in liquid or capsules. They contain natural anti-inflammatory properties.
5. Ask your doctor about nutritional supplements and if they are right for you.
6. Avoid foods that cause discomfort.
7. Go for high calorie foods that contain a lot of protein (such as meat, fish or cheese).
8. Cook with butter or oil.
9. If your mouth is sore, or swallowing is difficult, try soft foods such as milkshakes, custards, scrambled eggs or mashed vegetables.
10. Avoid foods that may irritate your mouth, such as spicy/salty foods, citrus fruit or drinks and tomato sauces.
11. If taste has changed, once your mouth is no longer sore you can increase the flavor of food by using marinades or strongly flavored seasonings and herbs.
12. Choose foods that look and smell appealing to you.
13. Mix food with sauces to make them easier to swallow.
15. Drink water intermittently through the meal to add moisture to facilitate the swallow.
16. Eat calorie dense foods. If you have lost weight, or need to gain weight, consider what may increase your caloric intake, i.e. butter, mayo, gravies, yogurt, oil, et cetera.

Although it is not easy, returning to oral food intake following laryngectomy surgery or chemoradiation therapy is critical in resuming normal activities of daily living and ensuring a good quality of life. Laryngectomees rarely have to worry about aspiration, since the airway and esophagus have been surgically and permanently separated. However, getting food and liquids to pass easily from mouth (chewing without teeth or with new dentures) into the newly created pharynx and upper esophagus (changes from surgery and radiation therapy) and then down to the stomach (with possible reduced peristalsis) requires practice and systematically increasing texture and bulk.

Liquids come first, then shakes (thicker liquids) and puddings, scrambled eggs, mashed potatoes, soft cooked vegetables, soft breads and ground meats, casseroles, and all with added liquids to help them pass easily from mouth to stomach. Keep an eye on your calorie intake and follow the dietitian’s guidelines for the appropriate nutritional intake to maintain your individual health and weight.

Most importantly, choose not to allow your eating and swallowing difficulties to prevent you from enjoying the socialization around the dinner table with family and friends. Bon Apetit!

For a review of a dysphagia-friendly recipe, see page 14.

Attention: Speech Language Pathologists
If you are listed in the IAL’s Directory of Alaryngeal Speech Instructors, please check it to make sure your information is current. These listings can be found under Speech Resources at www.theial.com. Click on “Find an Instructor”. Report any problems to: office@theial.com
Dysphagia Cookbook Review
By Katherine Hampton, Caregiver

As the wife of laryngectomee, Wade Hampton, I am constantly looking for new ideas for meals that are easy to chew and swallow. In Candy Moltz’s article she references the cookbook, The Dysphagia Cookbook, by Elayne Achilles, Ed. D.

The recipe I chose to test was the “Little Ham Loaves”, on page 40. Other than the chore of finding all the attachments to my meat grinder, the rest of the recipe was relatively easy to prepare. The final result of the taste test was pleasantly surprising. Although the brown sugar and vinegar basting sauce had a potent smell during the cooking process, it melted down into a delightfully mild sweet n’ sour combination that helped keep the loaves moist inside.

The final ham loaves had the consistency of hamburger. This recipe would not be suitable for the laryngectomee who requires pureed foods. Everyone in the family enjoyed the ham loaves and Wade was able to chew and swallow it with very little difficulty despite his esophageal strictures.

The strong points of this cookbook are that it provides a number of fresh ideas for sauces and mechanically softened foods. On the downside, many of the recipes require a food processor to prepare. Overall, I have enjoyed this cookbook and look forward to testing out more of the recipes. The Dysphagia Cookbook is available for purchase through Amazon.com

Little Ham Loaves (page 40 of The Dysphagia Cookbook)
Ingredients
1 1 1/2-pound pork steak, ground in the processor
1 1-pound ham steak, ground in the processor
1 cup breadcrumbs (made from stale whole wheat bread pulsed until fine in the processor
1 cup milk
2 eggs, beaten
Pepper
Sauce:
1 1/2 cups brown sugar
1/2 cups vinegar
1/2 cup water
1 teaspoon dry mustard
Preparation:
Preheat the oven to 375 degrees. In a large bowl mix the pork, ham, breadcrumbs, milk, eggs, and pepper. Roll into small loaves (oval-shaped, about 2x4 inches) and place in a 9 x 13-inch baking dish. Bake for 15 minutes.

Meanwhile, make the sauce. In a large saucepan combine all of the ingredients for the sauce, and boil for 5 minutes. Reduce the oven temperature to 350 degrees and bake the ham loaves for 30 minutes more, basting with sauce every 5 minutes. Serves 6 to 8.

The Importance of the “I” in the IAL
By Paul Evitts, Ph.D., CCC-SLP, Member, IAL Board of Directors

When asked to write a short column and given complete freedom about the content, my thoughts were all over the place. After narrowing down some choices, I figured I’d stick with my strengths and start a column on what’s going on in the world of research and laryngectomee rehabilitation. When I went to my favorite medical search engine – www.pubmed.org (arguably the most comprehensive medical search engine and free to all) - and searched using the terms ‘alaryngeal speech’, what initially struck me most was the number of different countries represented in the research articles being published in the last two years. Research articles from the USA were there of course but so were research articles from Turkey, Canada, Hungary, Brazil and China. In fact, one journal devoted four articles on the current state of laryngectomee rehabilitation in four different regions: Hong Kong, USA, South America, and Australia.

All this led me to start thinking about the IAL and the importance of the “I” in the name. I can only assume that years back, there was much more of a collaboration among support groups in different countries. Hence the “I” in the first place. After scanning through some past issues though, the “I” seems to have lost its weight. Given the advances in technology and social media, my hope is that we can change this. Just doing a quick search on Facebook, I found support groups in the United Kingdom and India. Sending the IAL News is easier –and cheaper than ever since we can email it or people can access it over the web. Future issues could include descriptions of other clubs and their successes. I’m sure a wise man somewhere once talked about the value of learning from many rather than a few. Hopefully future issues will help put the “I” back in the IAL. Stay tuned!
Clubs Involvement in Patient Rehabilitation Through “The Laryngectomee Guide”

Perhaps the single most beneficial act that IAL clubs do is their ongoing efforts to reach out to new laryngectomies. One club that has done an exceptional job in helping new laryngectomies is the Nu-Voice Club of Dayton Beach, Florida. This club has developed a packet called “The Laryngectomee Guide” that offers a comprehensive overview of information that is important for rehabilitation.

David Ross, laryngectomee and member of the Nu-Voice Club of Daytona Beach, stated this endeavor was undertaken to help offset the lack of educational and support materials generally available to the Laryngectomee community. He has compiled the 4 sections of the information package that his club has compiled and reproduced for new laryngectomies and their caregivers.

1. The American Cancer Society’s (ACS) website literature describing the various types, causes and treatments of Laryngeal and Hypopharyngeal cancers. This information can be accessed from the website www.cancer.org. In their search box, type **Laryngeal and Hypopharyngeal Cancer**. This will bring up a wealth of articles that can be printed off for use in the packets. Please note that ACS authorization is required to copy and distribute their web site material.

2. The IAL’s “First Steps”, which provides information regarding the various methods of laryngectomee voicing and general post surgery care. A copy of this booklet can be downloaded from the IAL website at: http://theial.com

3. The Florida Laryngectomee Association’s Question and Answers, which is a compilation of anecdotal information, written over many years primarily by laryngectomies and their caregivers. Much of this information will be found nowhere else.

4. The IAL’s “Laryngectomees Loving Life”, a 26 minute video demonstrating the positive side of living life as a “Lary”. (The video can be ordered from the IAL. The video can also be viewed online by going to http://theial.com and then clicking on the video link from the homepage.) Additionally, local commercial media production companies can produce DVDs of the video for about $1.00 per copy in quantities of 25 or more.

Dave Ross says that they have the packets commercially reproduced and then members of their club assemble them. The cost per package runs about $6.50 and is covered by club member donations. Dave states that “distribution costs are nominal because only a few are direct mailed to patients. Most of the packets are personally delivered to the various medical facilities in our area that then hand them out to their patients.” One area hospital, Shands Medical Center at the University of Florida in Gainesville, has been a major user of this packet and gives it a high five. New patients that live in our general area often contact and become involved in our club as a result of their having received this packet from their doctor.”

Due to HIPAA regulations, medical personnel are no longer able to give the local laryngectomee club the names and contact information of laryngectomee patients. Providing local clinics and doctors with a packet of information is a way for clubs to reach out to patients. This may be the only way that laryngectomee patients learn about the club and are able to find their local groups, as well as receive information critical to their understanding of what is about to happen to them and the recovery/rehabilitation process.

For more information on the materials available, contact Dave Ross at daveross37@earthlink.net, 386-295-4714 or Dave White at davezplace3@cfl.rr.com, 386-788-0337. They will be happy to provide digital files of the printed materials.
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Attention All Newsletter Readers!

Dear IAL Newsletter Readers:

The IAL office has been in the process of updating our newsletter mailing list. We are asking that you respond to us in order to remain on the mailing list to continue receiving the newsletter. The mailing list will be amended for the April IAL Newsletter.

The bottom half of this page is a form for you to fill out. If we receive the information back by mail, that means that you would still like to remain on the list and receive the newsletter. You may also respond and let us know that you’d like to stay on the mailing list by emailing our office at office@theial.com. If you choose to send an email message, please include all the information found on the form below. You can still read and download the IAL Newsletter from the website even if you decide not to remain on the mailing list.

The IAL appreciates your support to continue its service. We are proud of our 63 year history of aiding in the rehabilitation of laryngectomess. All of the work being done is for the laryngectomy community, its supporters, professionals and care givers. If you have any questions, feel free to call our office at 866-425-3678.

Please fill out the form below to continue receiving the IAL Newsletter through the mail.

Mail to: The IAL 925B Peachtree St. NE Suite 316 Atlanta, Georgia 30309-3918

Or email to: office@theial.com

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