

CLAN



THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS NEWSLETTER

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Plus lots of other news, thoughts, poems, letters and views



A WORD FROM THE EDITOR

HOT OFF THE PRESS!



Welcome the the very first July issue of *CLAN*! As we mentioned in the last *CLAN*, we have moved to just three issues a year: March, July & November. And there's plenty to read during these hot summer months. Malcolm Babb highlights that NALC now uses Zoom to provide individual support to individuals and caregivers. And, Zoom also features in the article on Professor Martin Birchall (Principal Patron of NALC) who gave his talk over Zoom in March where he spoke about recent developments in robotics including the Laronix which may well provide an alternative to the electrolarynx. Malcolm then develops this theme in his

article 'The Electrolarynx - Is It Still Needed?'

Shout at Cancer

There's also a musical theme to this issue with a review of the film 'Can You Hear My Voice?' It's all about the Shout at Cancer choir where many of the members share their stories of resilience in the face of overwhelming adversity. Finally, two requests: do take a look at the new NALC website and do let us know what your club is doing. We feature two clubs under News from the Clubs but there are so many more we would love to hear from!

Ian Honeysett
Ian Honeysett (Editor)

For all items for Clan:

Ian Honeysett (Editor), 53 Combe Road, Farncombe, Godalming, Surrey GU7 3SL
email: Honeysett@btinternet.com

For all other matters (including requests to be added to or removed from the mailing list): Vivien Reed (Assoc. Secretary), NALC, c/o The Ludo Press Ltd, 18 Wimbledon Stadium Business Centre, Riverside Rd, London SW17 0BA 020 7730 8585 info@laryngectomy.org.uk Website: www.laryngectomy.org.uk

The views expressed by the contributors are not necessarily those of the Editor or NALC. Great care has been taken to ensure accuracy but NALC cannot accept responsibility for errors or omissions.

Deadline for issue No. 166: 1 October 2023

NALC URGENTLY NEEDS YOUR SUPPORT

The easiest way to donate to NALC is via the Justgiving page: www.justgiving.com/laryngectomy-clubs . Typing 'Justgiving NALC' in Google also works well

To make a donation please complete and return this form to: NALC c/o The Ludo Press Ltd, Unit 18 Wimbledon Stadium Business Centre, Riverside Road, London SW17 0BA

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Notes from the President

Evolution

Nothing stays the same, change is constant and sometimes a little too fast for comfort. The COVID-19 pandemic led to many changes and not everything has returned to what we had before. Some support groups have not survived the long period when face to face meetings were impossible. Others grasped welcome changes such as the development of online meetings using platforms like Zoom. All the national head and neck support groups, such as NALC, The Swallows and Heads2Gether, continue to make use of this type of meeting.

A feature of the way NALC now works is that we can provide support to individual patients and caregivers using Zoom. It has some advantages, not least the ability for a laryngectomee without a new method of speech to 'talk' using the chat function. It is especially valuable where a patient has no laryngectomee group in their locality.

Royal College of Speech and Language Therapists (RCSLT)

NALC collaborates with the RCSLT in a variety of ways. Readers may recall many requests for help with research projects from SLTs advertised in *CLAN*. Usually they involve us sharing our experiences of the care pathway or living as a laryngectomee.

In recent months the NALC Executive Group contributed to a review and update of the public pages of the RCSLT website. Now these pages, and others, have been shared more widely within the head and neck community, seeking the opinions of patients, caregivers and other clinicians. It is encouraging to see the high value the RCSLT places on patient involvement in guiding its work.

A Busy Spring

I have delivered my usual presentations to Liverpool University radiotherapy students and prospective SLTs at City Lit, based in London. In April I gave a presentation to the Guys and St Thomas Trust area team about the work of NALC.

My work as a board member of the UK



The Beautiful Blue

Author Lucinda Hart introduces her new book.

Au revoir. The last words my father Chris said to me the night before his laryngectomy. It wasn't just a laryngectomy: he had to have his thyroid and parathyroid removed as well, and part of the pharynx. He was in theatre for twelve hours. Then, back in 2016, I was still a wannabe author. I had been attached to a top London literary agency for a year but nothing had come of it. I was still writing novels, one after another, in the hope that someone might be interested in something I wrote. And then, watching my father come to terms with his tracheostomy, I knew I had to write about a laryngectomy patient. That wasn't enough on its own, of course. I had to create a whole world, and so I turned to another area where you have to learn to breathe differently: swimming. I'd gone swimming as a child and never been able to let go of the float. I had never had any confidence – or a decent teacher. I tried again at 21 just before I went to university, by joining a group for adults. Again, it was a failure. At the age of 39 I decided to learn to swim once and for all, and this decision coincided with my father's surgery.

Saturations on Air

I realised there were similarities between the two situations: an acute awareness of the airway, and a new way of breathing. (I can now swim!) The manuscript was originally called *Saturations on Air*. The laryngectomy patient, Guy Lovell, is a radio presenter, someone who relies on his voice for his job, and suddenly that is taken from him. Meanwhile his wife Heather is learning to swim as a middle-aged woman. The book follows the lives and loves of the members of the adult swimming group, as well as Guy's terrifying journey through diagnosis and surgery to tracheostomy and a new voice.

I wrote the book alongside my father's experiences, although I spared Guy the worst of what happened to him. This was a book I never thought would interest any publisher: too odd, too gruesome almost. But shortly afterwards I was taken on by Vulpine Press for another novel, *The Broken Air*, and I showed them this manuscript. They said yes and I was overwhelmed. The book meant so much to me as by then my father had died and I was struggling with my bereavement and the experiences we as a family had gone through. My mother had lost her husband and my daughters their granddad. My littlest one was born only months before he died and will have no memory of him. I worked with an amazing editor to get the book into a better shape; the title has now changed to *The Beautiful Blue* and it came out 30 March. I know spoilers are frowned on, but it is important for me to say that things do not work out happily-ever-after for Guy.



Job Done!

In the last edition of *CLAN* we reported on Nigel Skilton's superb fundraising effort for NALC. He took part in a Hyrox fitness event in London on 1 May, part of a world-wide series. He wanted to push his body to its limits as part of his recovery from a laryngectomy and show there was no reason to stop taking on new challenges.

Nigel successfully completed the event and in doing so raised the magnificent sum of £780 for NALC. On his instagram page on 1

May he reported: *today I faced off against the Hyrox World Series of fitness racing. I am proud to say that I emerged victorious in the battle of mind, body and soul!*

NALC is delighted to share news of Nigel's success and we send him our thanks for what he has done for us.

www.justgiving.com/fundraising/nigel-skilton-hyrox

Head and Neck Cancer Coalition has mainly been focussed around restoring some sort of audit of head and neck patients, to inform future practice. Though new audits have been set up for other patient groups, NHS England does not appear to see head and neck as a priority.

Malcolm Babb





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Professor Martin Birchall

At the end of March, Martin joined us as a guest speaker at a NALC Zoom meeting.

Martin started by talking about his involvement with NALC extending back more than 20 years. He has been our Principal Patron and Medical Advisor for many of these years. However NALC is not the only beneficiary of his generosity, he also gives up time to support other charities. He has supported Shout at Cancer and its laryngectomee choir, led by the inspirational Dr Thomas Moors, almost from its inception. He has also worked with the Throat Cancer Foundation.



Can You Hear My Voice?



www.canyouhearmyvoice.com/about-the-film/

The Cancer Laryngectomee Trust, in association with Atos, secured the first screening of the film *Can You Hear My Voice* outside of London. The film was shown at a reception at the Gallery Oldham on Saturday 1 October 2022. "We had a fantastic day, everything went perfectly," they said. "We had a great turnout and we received some lovely feedback about the day. Everyone agreed it was a very moving, inspirational and uplifting film about laryngectomees. We are very grateful for all the help Atos and Gallery Oldham gave us in making the special day possible."

The film chronicles the one-of-a-kind Shout at Cancer choir in the UK, whose members have all had their voice boxes removed, as they prepare for their most ambitious concert – a sold-out performance at London's historic Tabernacle Theatre. The film includes songs popularised by Nina Simone, Tears for Fears & Louis Armstrong. Along the way, choir members' cancer stories unfold, revealing their struggles with self-identity, self-doubt and loss. Far from maudlin, it bears witness to the power of music and is a triumphant testimony illuminating a universal theme – the human capacity for resilience in the face of overwhelming adversity.

Produced & directed by Bill Brummel, a Peabody Award and International Documentary Award-winning filmmaker and five times national Emmy award nominee, who had his own voice box removed in 2016, due to the long-term damage caused by radiation treatments he underwent 22 years ago.



Sound Voice

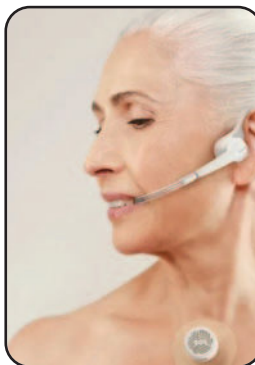
In his talk Martin spoke about another group Sound Voice whose work is described on their website with examples of the exciting and innovative projects they are involved with. In the project *I left my voice behind* you can see the involvement of several NALC members who you may recognise.

Sound Voice describe their work this way:

Working internationally with people with lived experience of voice loss, interdisciplinary professionals, arts venues, festivals and hospitals, The Sound Voice Project aims to understand the intrinsic value of the human voice and how it connects to our identity? What is a voice and what happens when it is gone?

Martin is a laryngologist and surgeon of international renown. He was part of the team that carried out a larynx transplant in New York in 2010. Transplants are unlikely to become a common procedure with other strategies being used when a larynx has to be removed. Ten years ago, a major focus of Martin's research and development work was centred on stem cells and tissue regeneration. Now the focus is on soft robotics with the ultimate goal being a robotic larynx. He showed us some remarkable recent developments in the field of robotics and has shared a link to a Youtube video. In the video (about 14 minutes) Jonathan Rossiter talks about his Row-bot, a robot that eats pollution. It is an eye-opening presentation, revealing the range of problems that robots may help us solve.

Martin also alerted us to a new device, 'Laronix', developed in Australia, which may provide an alternative to the electrolarynx for laryngectomees unable to have a speech valve.



LINKS

Sound Voice: soundvoice.org

Robotics: www.youtube.com/watch?v=CVdPhUPO5YU

Laronix: westchestermagazine.com/life-style/business/careers/laronix-white-plains

Benefits of New Product Range

A clinical study¹ funded by Atos Medical, a leading company in laryngectomy care, reveals clinical trial results that demonstrate a significant reduction in coughing, shortness of breath, and skin irritation in the patient group adhering to daily care routines with their Heat and Moisture Exchangers (HMEs). As a result of the patient's improved state, anxiety and depression were also reduced.



The newly published study is the first clinical study on Provox® Life™. It reported the following results with the patients using Provox® Life™:

- 36% reduction in forced coughing
- 26% reduction in number of days the HME had to be removed to catch their breath
- 39% reduction in average number of days with skin irritation

"Seeing the impact of the new generation HME devices on patient outcomes is encouraging, and it shows that by improving devices and supporting patients to use them in the best possible way, we can further optimize their quality of life," Dr. Claudio Parrilla and Dr. Ylenia Longobardi, the main investigators on the study state.

Objectives

The objectives of the clinical study were to evaluate the effects of the use of new devices (HMEs and adhesives) on pulmonary symptoms, adherence to HME use, quality of life, dermatological symptoms, and patient satisfaction in patients with a total laryngectomy. The study took place at the Catholic University of the Sacred Heart (Gemelli Hospital) in Rome, Italy. Between December 2020 and April 2021, 40 laryngectomized patients in Italy who routinely used HMEs and adhesives were enrolled.

Patients were allocated into Group A (6 weeks use of the new devices (Provox® Life™), followed by 6 weeks use of their usual devices) or Group B (6 weeks use of their usual devices followed by 6 weeks use of the new devices (Provox® Life™)). In both groups, after 6 weeks of using the new devices, there was a significant reduction in the daily forced expectorations and (involuntary) dry coughs, a significant improvement in all domains of the Cough and Mucus Assessment questionnaire (CASA-Q), an increase in the adherence to HME use, a significant reduction in shortness of breath and skin irritation, and significantly better scores in the anxiety/depression domain of the European Quality of Life Five Dimension instrument (EQ-5D) were found.

"Achieving these results underscores the importance of using better performing HMEs with high humidification capacities and good breathability. Improving pulmonary health and reducing the impact on the patient's daily life has a positive effect on their quality of life. Indeed 95% of the patients in the study reported they were satisfied with the results of the Provox® Life™ system," said Corina van-As Brooks, Vice President, Medical and Scientific Affairs, Atos Medical.

The Electrolarynx – Is It Still Needed?

At NALC, we were recently surprised when a representative of NHS England contacted us wanting a discussion about the provision of electrolarynxes for patients. For laryngectomees unable to have surgical voice restoration, or waiting for the surgery needed to make it possible, the electrolarynx (EL) offers an alternative option for speech. Esophageal speech (ES) is rarely encountered these days as the clinicians able to provide the assistance to learn how to employ it are very small in number.

NALC has consistently argued that an EL should be provided to every laryngectomee. There will always be patients who will not be eligible for valve speech, such as patients needing a gastric pull-up or complicated flap surgery. But even those with a valve will find there are times when valve speech is not possible. Base plates can cause irritation to the skin, even leading to sores, so may have to be left off for a while. At such times stoma occlusion may be difficult and an EL will facilitate speech. A build up of granulation tissue around the puncture may mean day surgery is required and again the EL will allow for speech during recovery. If valve leakage means a valve plug is used speech can continue by using an EL.

'Sweet Spot'

An EL is usually used by placing it on a 'sweet spot' under the chin. The vibrations produced pass through the tissue and vibrate the air in the throat, as the vocal chords did before surgery, facilitating speech. For some lymphoedema can mean the layer of tissue

does not allow vibrations to reach the air in the throat and speech is not possible. In the first weeks after surgery a similar problem may arise due to the swelling that is present.



Fortunately there are other ways an EL may be used. For some patients holding the EL against the cheek can work well. Others use an oral adaptor, with or without a straw, as shown in the picture. Some find using a straw inside the mouth uncomfortable and difficult and the 'voice' is difficult to understand. An alternative approach is to use the adapter held against the corner of the mouth without a straw, which works surprisingly well. There are videos on Youtube showing how to try such strategies to facilitate speech. It is disappointing to hear from patients struggling to find a voice who report their clinicians do not suggest these options.

The EL is hardly modern technology and it is surprising it has hardly been developed and improved in recent years. However, elsewhere in this newsletter you will see information about Laronix. This new device uses a new technology to produce vibrations of the air in the throat and may become a useful alternative.

Malcolm Babb

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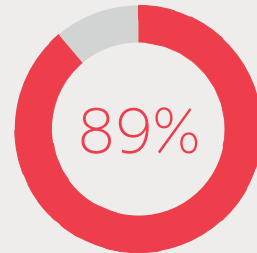
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New Substitute Voice

The voice is a medium we use to successfully interact with the outside world. Unfortunately, most people's voices change or even disappear after a laryngectomy. To improve these patients' quality of life, a team of researchers from the universities in Kaunas, Lithuania invented a new substitute voice evaluation index – it will detect pathologies in patients' voices faster and better.

Removal of the larynx – a laryngectomy, usually performed for advanced laryngeal cancer, dramatically changes the voice, which greatly alters the patient's normal life. Researcher of Kaunas University of Technology Faculty of Informatics (KTU IF) Rytis says that the change in voice after laryngectomy depends on the severity of the situation: "For some, the voice changes only slightly, while for others, it can be a life-changing situation. Imagine calling someone on the phone, emergency services, police, etc. – and the one you're calling does not understand anything. Or even not hear you – as the phone's noise removal system will cut it out".

Substitute Voice

"These types of surgeries require the removal of one or both vocal folds, part or even the entire larynx to remove a malignant laryngeal tumour. As a result, after oncological laryngeal surgery, the voice is extracted using only the laryngeal structures left after the operation, which are physiologically not intended for this – we call such a voice a 'substitute voice'," says professor Virgilijus Ulozas professor at the Lithuanian University of Health Sciences (LSMU). He emphasises that the quality of voice and speech deteriorates after such an operation, complicating the patients' communication possibilities and quality of life.

Artificial intelligence

Recently, researchers from KTU and LSMU published a study in which, with the help of artificial intelligence (AI) signal processing, it was possible to determine whether a patient has certain voice pathologies.

According to Maskeliūnas, the idea to study and determine the voice quality of patients after laryngectomy came from a medical team led by an expert in this field, Prof Ulozas. To facilitate and automate the post-operative process, the KTU researchers used AI technologies, which allowed them to conditionally replace an expert doctor, a very positive result evaluated in the clinical study.

"Usually, the doctor analyses the voice and provides an index of the impairment; patients themselves also fill out a questionnaire on how they perceive the quality of the voice. Voice signal energy, formants, and other parameters are also used when performing digital signal analysis," says Maskeliūnas.

According to him, this study is unique: "Previous studies have never successfully used artificial intelligence as an expert assistant in voice analysis".

According to the scientist, due to this innovation, the process after



surgery becomes automatised, which allows the installation of automated screening solutions, making it easier for doctors to follow and record the course of the disease and establish diagnoses.

Evaluation index is promising

During the research, the KTU and LSMU research team is glad to announce a discovery – the Acoustic Substitution Voice Index (ASVI), which will allow scientists to quantitatively measure and evaluate the patient's 'substitute' voice after oncological laryngitis using acoustic parameters of the voice signal and artificial intelligence methods.

"Until now, in medical practice, there was no suitable method to objectively and quantitatively evaluate the 'substitute' voice. Our proposed ASVI algorithm allows the evaluation process to be done automatically in a concise time," says Prof Ulozas.

He also believes that this discovery would allow the patient to perform a voice test at home or in a non-specialised medical institution if negative changes in the voice are noticed early. On the other hand, the professor emphasises that good ASVI indicators, in the absence of other complaints, would allow patients to avoid unnecessary visits to medical professionals.

Further Goal

The first clinical trials of the ASVI are also very optimistic. A further goal of the researchers is to develop a convenient, clinically acceptable prototype to measure ASVI in a real clinical setting. For example, it could be a mobile app available both to specialists and patients.

In the future, such automation of diagnosis will open up new possibilities. To determine the acoustic index of the "substitute" voice it will be enough to have a smartphone or any other device with an internet connection with you. After uploading an audio recording or just by talking, changes in the voice will be analysed, the system will show an estimate, based on which the further course of treatment will be decided.

*Technology Networks Informatics:
www.technologynetworks.com/informatics*

NALC has a New Website

NALC's website is over ten years old. So much has changed that it does not work well with social media or when accessed using tablets or phones.

A brand new site will be launched during September which will allow for better

access to our information resources, as well as being an easier and more enjoyable resource to use.

Getting to the site will use the same link as before:

www.laryngectomy.org.uk

Google and other search engines will direct patients and others to our resources as they did before the new site.

We would love to hear your views after viewing the website.

News from the Clubs

Glan Clwyd Hospital Laryngectomy Club, Bodelwyddan



Thousands of pounds have been donated to Glan Clwyd Hospital in Bodelwyddan by the hospital's Laryngectomy Club. The club, a support group dedicated to helping throat cancer patients and their families, raised £6,600 to buy equipment for the hospital at its Christmas charity dinner on December 9, 2022. Held at the Faenol Fawr Hotel, where the group meets every six weeks, the dinner included music, a raffle, and an auction, while Clwydian Walking Holidays also offered a generous donation.



Peter is on the right

Peter Holloway, from Penrhyn Bay, is chairman of the club, having undergone his laryngectomy at Glan Clwyd after losing his voice box to cancer. Former engineer, Peter, said: "I'm very proud because, for people who have to have a laryngectomy, I feel that we're there for them and so they're not on their own.

"We are only as good as the members that support the club to raise money to buy this equipment. They did have a support group, but of only three members. Now we have 28."

The equipment bought with the money raised will include nebulisers and electrolarynxes.

Charity Show

Clwydian Walking Holidays has raised £3,266 for the Glan Clwyd Laryngectomy

Chesterfield Club

After an Easter break during April, we have resumed our normal schedule of meetings. In June we welcomed regular visitors from Severn Healthcare who demonstrated a new version of the Romet electrolarynx and a new Day and Night HME (Heat Moisture Exchange).

Support groups for patients with rarer cancers tend to be difficult to find, whereas many localities have Breast Cancer or Prostate Cancer groups. Our group has sometimes supported patients (and their caregivers) who have a cancer outside of the head and neck category. A welcome recent initiative in Chesterfield has been the formation of a group meeting monthly for any cancer patient. Naturally, we will be collaborating with this group, which also has links with the Macmillan Centre at Chesterfield Royal Hospital.



Can You Help?

For some laryngectomees, recurrent chest infections can be a significant problem. The technical term for these infections is Lower Respiratory Tract Infection or LRTI.

NALC has been asked to assist with a study looking at a new treatment involving the delivery of nebulised antibiotics for patients experiencing two or more episodes of LTRI's in a year.

To maximise the patient experience contribution we can make, it would be very helpful to hear from laryngectomees who find such infections a real problem. Your experience could greatly assist the study. Please contact us if you are willing to help using info@laryngectomy.org.uk sharing your name and contact details. We can then get in touch when the researchers have questions to ask.

The actual process of recruitment into the study is not currently decided but will be clarified once the necessary funding for the study is secured.

Club, which will be used to buy nebulisers, electrolarynxes, suction machines and boogie boards for ward 7 and speech therapy at Ysbyty Glan Clwyd.

The money was raised through a charity show at Oriel House featuring the band Muddy Boots as well as through

donations. Clwydian Walking Holidays' managing director, Bob Eckersall, wanted to raise funds for the club after being impressed with their work. Peter Holloway and Dr Martin O'Donnell said: "We'd like to thank everybody, including businesses and private individuals, for their support in raising money for this equipment."