

# Newsletter September 2019

"To help improve the quality of life for all neck breathers"



Dear Friends,

Well summer seems to have arrived at last. Bill and I have just returned from Germany where it was very hot and there didn't seem to be any air conditioning of the buildings. We were visiting a town called Lengo which is twinned with Beverley, a market town not far from us. We were celebrating 40 years of the twinning relationship with the Mayor of Beverley signing the Golden Book linking the towns together to maintain friendship between people of the areas. While in Germany we were talking to a fireman about Larrys and he was very interested and said their training covered their special needs. We also left a copy of the Travel Guide with him to show to his colleagues.

As you might have noticed there are no raffle tickets as we are not having Race Night this year. We would still appreciate any donations which you might be willing to send to support our work for laryngectomees and enclose a donation form with a Gift Aid declaration.

We were very interested to hear from Dr Qaraghuli about the new treatment for head and neck cancers which he is developing. As you read about this later in the newsletter perhaps you might feel you are able to assist him by describing to him your experiences with the treatment you have had. If you feel you can help please contact him directly.

Just before our trip to Germany we were at the wedding of Ros's daughter in a village church near Frome in Somerset. It was a lovely family occasion with Carole's grand-daughter as flower girl.

Our next trip is to St Albans for the grave service which I wrote about in the March newsletter. Following that we are looking forward to meeting members at the charity Bridlington Lunch.

Hoping you are getting out and about and enjoying the countryside. Please let us know of any experiences using the Travel Guide.

Best Wishes,  
Wendy Thompson, Trustee

## Christmas Lunches

After the much appreciated Summer Lunches we are now busy planning Christmas Events.

The lunch in Halifax which will be held on Wednesday 4th December at Windmill Court is being arranged by Carole Stainton contact at CLT, PO Box 618, Halifax, HX3 8WX email: [info@cancerlt.org](mailto:info@cancerlt.org)

The lunch in York at Novotel. York YO10 4FD will be held on a date yet to be arranged. If you would like to attend please contact Wendy Thompson, 10 Meadow Drive, Market Weighton, York, YO43 3QG Tel 01430 871561 email [blwnt@outlook.com](mailto:blwnt@outlook.com)

The Blackpool lunch at the Imperial Hotel on Sunday 8th December is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531 email [waddington46@btinternet.com](mailto:waddington46@btinternet.com)

A lunch for Swindon area members is to be arranged by Ros Oswald. For further details contact Ros at 17 Kandahar, Aldbourne, Wilts SN8 2EE, [the.oswalds@hotmail.co.uk](mailto:the.oswalds@hotmail.co.uk) Tel: 01672 540619



## The Lary All Stars

Carole Stainton was pleased to be invited by Anne-Marie Smith, Specialist Speech and Language Therapist, to speak to The Lary All Stars support group. The group serves laryngectomees in the Calderdale and Kirklees area. Carole spoke about the founding of the charity and the work currently being carried out to support laryngectomees and enjoyed the friendly atmosphere of the group.



## Extract from Annual Report to Jan 2019

During 2019 we became aware of difficulties some of our members were suffering. This related to people who use the electrolarynx machines. It was apparent that some hospitals were struggling to find funds for the provision of an electrolarynx for patients who needed them. The machines are not cheap, costing upwards of £400. Therefore, there were people who needed a machine but could not afford to buy one themselves. In addition, for some people, the machine needed was a replacement. The electrolarynx is a very robust machine and can last for many years.

It was a major concern for us that people who had had a laryngectomy many years ago might not be able to have a replacement electrolarynx for reasons of cost. The decision about funding equipment such as this is taken by each local commissioning group. Therefore, it is not surprising if there is regional variation. However, it is obvious that to go from having an electrolarynx to not having one will be a very difficult and potentially depressing experience. The National Association of Laryngectomy Clubs wrote to each of its clubs in 2018 to find out how widespread the problem is. Information was received which related to eleven hospital trusts. Out of those eleven, five were experiencing funding difficulties for the provision of an electrolarynx.

Because surgical voice restoration has improved a great deal, the electrolarynx has become less commonly used. However, there are still patients for whom the electrolarynx is the best solution because of the way in which the surgery has to be carried out. From a purely financial point of view, the electrolarynx is less expensive than the costs incurred as a result of surgical voice restoration. The estimated annual cost of prosthesis management for those who have undergone surgical voice restoration is £600 per year. Given that an electrolarynx may well last for more than ten years it is clearly an inexpensive option.

The best solution would be for all commissioning groups to take the view that the provision of an electrolarynx for every laryngectomee in need of the machine should be automatic. This is certainly not the current position. As trustees we have made information available about the difficulties to an Ear Nose and Throat trainee doctor who is wanting to undertake research. We shall see how much progress can be made regarding this difficult topic.

Ros Oswald, Trustee

## Virgin Money Giving

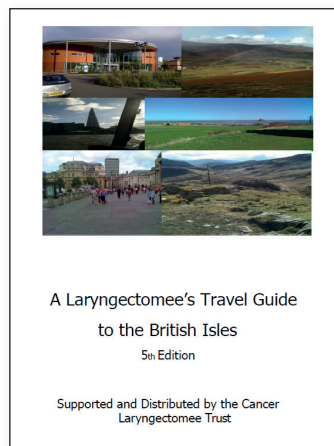
In the past we invited members who were fundraising on our behalf or making a donation to the charity to use the online system MyDonate which was provided by BT.

This scheme has now been discontinued therefore we have registered with a new scheme being provided by Virgin Money. To access the scheme a link has been created on our website [cancerlt.org/donation](http://cancerlt.org/donation)



## Travel Guide Updates

Please note the following updates apply if you have a printed copy of the 2017 Travel Guide:



### **Darlington/ Middlesbrough**

Delete Darlington as all valve changes now take place at Middlesbrough with new telephone numbers: 01642 854039 or 01642 854497

### **Leicester**

Open valve clinics are held at the Leicester Royal Infirmary, ENT Dept, Balmoral, Building Level 1 Havelock Street Leicester LE1 5WW

Mon 10 -11.30 (half hr slots) Thurs 13.30 to 15.00 (half hr slots)

For out of hours you can attend the Kinmonth Unit also located at Balmoral Building level 1 and they can advise.

### **Peterborough**

The hospital is now called Peterborough City Hospital and contact is ENT outpatients on 01733 677081

The Travel Guide can be downloaded from our website [www.cancerlt.org](http://www.cancerlt.org). To receive a printed copy of the 2017 Travel Guide please send a SAE with a 1st or 2nd class stamp on it, marking the outer envelope Travel Guide. Please ensure the envelope you send measures at least 6" by 8.5" (160mm by 220mm). Send your request to CLT, PO Box 618, Halifax, HX3 8WX. We have had positive feedback about the Guide but also need to receive negative feedback where the Guide is out of date. Updates can be sent to [info@cancerlt.org](mailto:info@cancerlt.org).

## Amazon Smile

The Cancer Laryngectomee Trust has registered with the Amazon Smile scheme and we hope that anyone who purchases from Amazon will join in the scheme and select our charity for their support. Please remember that the name of the charity is The Cancer Laryngectomee Trust when you are choosing which charity to support.

### **The following information comes from the AmazonSmile website:**

What is AmazonSmile?

AmazonSmile is a simple and automatic way for you to support a charity of your choice every time you shop, at no cost to you. When you shop at [smile.amazon.co.uk](http://smile.amazon.co.uk), you'll find the exact same low prices, vast selection and convenient shopping experience as [amazon.co.uk](http://amazon.co.uk), with the added bonus that Amazon will donate a portion of the purchase price to your selected charity.

How do I shop at AmazonSmile?

To shop at AmazonSmile simply go to [smile.amazon.co.uk](http://smile.amazon.co.uk) from the web browser on your computer or mobile device. You may also want to add a bookmark to [smile.amazon.co.uk](http://smile.amazon.co.uk) to make it even easier to return and start your shopping at AmazonSmile.

How do I select a charitable organisation to support when shopping on AmazonSmile?

On your first visit to [smile.amazon.co.uk](http://smile.amazon.co.uk) you need to select a charitable organisation to receive donations from eligible purchases before you begin shopping. We will remember your selection, and then every eligible purchase you make at [smile.amazon.co.uk](http://smile.amazon.co.uk) will result in a donation.

# Photothermal Approach to Treat Head and Neck Cancer

Dr Mohammed Al Qaraghuli would like to hear of your experiences in your cancer treatment. He writes:



Head and Neck Cancer affects 600,000 people every year, including over 12,000 patients in the UK. Various factors can trigger this disease, such as smoking, alcohol consumption, and repetitive viral infections. The current treatment approaches rely on surgery, chemotherapy, radiation, or targeted biotherapies. However, these treatments can be either invasive or not very effective.

We have recently established a Glasgow-based biotech company called SiMologics. We design a class of targeted biotherapies, called photothermal therapy, which is composed from biomolecules called antibodies and very small gold particles. This approach can provide a method to burn cancer cells, and treat Head and neck cancer in an effective and non-invasive way.

Albeit being at an early stage, and will require product development time, we are keen to speak to cancer patients to gain their insight into their experience with the offered treatments. In addition, we are looking to speak to oncologists and surgeons to get their valuable opinion about the currently utilised treatments, and use these discussions to optimise our approach. If you are happy to have a short conversation with us, kindly contact Dr Mohammed Al Qaraghuli through this email address ([m.alqaraghuli@simologics.co.uk](mailto:m.alqaraghuli@simologics.co.uk)). Alternatively, you can send us a short description of your experience with head and neck cancer, and the utilised treatments, by post through the following address: (SiMologics Ltd, The Enterprise Hub, Level 6 Graham Hills Building, University of Strathclyde, 50 Richmond Street, Glasgow-UK, G1 1XP).

Dr Mohammed Al Qaraghuli (founder of SiMologics) has worked as a Research Fellow at the School of Medical Sciences at the University of Aberdeen to optimise the development of therapeutic antibodies. He then worked at the University of Strathclyde as a Visiting Researcher in the Strathclyde Institute of Pharmacy & Biomedical Sciences. He then moved to the Department of Chemical and Process Engineering-University of Strathclyde to develop low-cost and efficient diagnostic kits that enable the instantaneous detection of pathogens and contaminants in food chains. In addition to academia, Mohammed has worked in two biotech companies based in Aberdeen (ImmunoSolv and Scotia Biologics) to develop and characterise a set of diagnostic antibodies.

SiMologics has been developed through different entrepreneurial acceleration programmes like the Develop programme of the BioCity- Glasgow, the Rising Stars programme of the University of Strathclyde, and the Royal Bank of Scotland Entrepreneur Acceleration programme). This has enabled us to win various awards like:

- The Best Customer Discovery Prize at the BioCity 12-week Develop programme, November 2017.
- The Most Promising Technology Prize that was awarded by investors during the BioVale-BioBase4SME (North-West Europe) BioCamp, York-UK, June 2018.
- Scottish EDGE entrepreneurial competition, Round 14 winner, June 2019.

Mohammed Al Qaraghuli  
Founder, SiMologics

# Join us at a local laryngectomy community event



Every month Atos Medical and Countrywide Supplies host local laryngectomy groups across the UK.

They are called 'MyVoice' events because it's all about you and your needs. At the same time, it's a great opportunity to get to know other people living with a total laryngectomy in your area.

#### Why attend an event?

- Get to know others living with a total laryngectomy in your area
- Meet your local Atos Medical product specialist
- Learn about topics specific to your needs

"I enjoy the monthly meetings and find them very interesting and well presented"

- MyVoice event attendee



If you are interested in attending one of our MyVoice events please email [events.uk@atosmedical.com](mailto:events.uk@atosmedical.com) alternatively call **0800 783 1659**

**Atos** Atos Medical  
Your voice

## We are Countrywide Supplies

We offer a range of expert services and support, to help you navigate your way through your laryngectomy or tracheostomy journey.

### Dedicated Customer Care Representatives

Receive specialist support from your experienced customer care representative, who is dedicated to understanding your individual laryngectomy or tracheostomy needs.

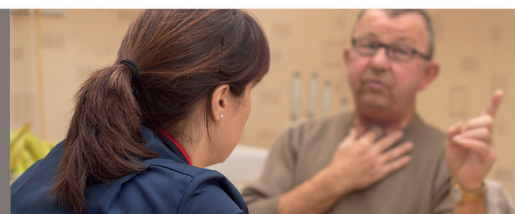


### Delivery direct to your door

Reliable and easy-to-use product delivery service, along with additional support when you come home from hospital. We also offer a text service to let you know when to expect your delivery.

### Passionate Head and Neck Specialist Nurses

Each nurse has extensive knowledge of neck stoma care, and can support you with care and advice about daily routines and the products you are currently using in the comfort of your own home.



Join today or find out more about us at [www.countrywidesupplies.co.uk](http://www.countrywidesupplies.co.uk) or call us on **0800 783 1659**

 **Countrywide  
Supplies**



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Phone / Fax: 01422 205522  
Charity Registration Number: 326653