

Newsletter March 2022

A personal note from Carole Stainton, Trustee

Dear Friends

We hope you are all keeping well. Maybe now we can be cautiously optimistic that things are returning to something like normal or rather the New Normal as we keep being reminded. We are very pleased that Sandra Waddington has arranged a Summer Lunch in Blackpool on our behalf (see page 3 for details) and hope we can organise further social gatherings so we can meet up again before too long.

Thank you to everyone who responded to the request for donations in the September newsletter a magnificent total of just over £2000 was received. We are also grateful to the members of the Belmont Bowling Club for their continuing support through the charity competitions they organise.

The Health Secretary, Sajid Javid, wishes to obtain the views of cancer patients to contribute to the government's 10 Year Cancer Plan. The survey questions are shown in the newsletter and if you are unable to complete the survey online we would be pleased to receive your contributions by letter or email so we can submit them on your behalf.

Once again we are pleased to have news from Geoff Read of his life at the Chelsea Hospital.

Best Wishes

Carole Stainton, Trustee

Donation Form 2021

The continuing Covid pandemic has made 2021 another difficult year for all charities with fund-raising events not being able to be held. Once again members and supporters responded generously to our appeal in the September newsletter and we thank you all for your support raising just over £2000.

We also thank those who invite donations to the charity in lieu of flowers when a loved one passes away.

Unfortunately Virgin Money Giving has been discontinued so we can no longer receive donations through that scheme.

Amazon Smile does continue though which enables supporters to nominate CLT when purchasing from Amazon at no extra cost to the purchaser.

<https://smile.amazon.co.uk>

Contact us:

Website: www.cancerlt.org Email: info@cancerlt.org

Address: CLT, PO Box 618, Halifax, HX3 8WX

Charity Registration No 326653



This newsletter is
sponsored by Atos Care

Geoff's News from Chelsea

Geoff has now spent a full year as a Chelsea Pensioner and brings us up-to-date with the lead in to Christmas 2021 and the New Year.

One Friday night I attended the Classical Spectacular at the Royal Albert Hall... along with some others. That was superb! Apparently, they tour the show all over the world.

A colleague and I also ventured to Somerset House the other weekend to visit the Beano expedition. That was quite good fun and they even had Issue No. 1 on display.

Another venture was a visit to the Excel Centre over North Greenwich near the O2 Centre to attend a landscaping exhibition.

More interesting than that was our trip back by cable car over the Thames, catching an Uberboat at Greenwich North back to Battersea (changing at Embankment). Great fun.

By then, my colleague was a little tired... he is 80 after all... so we decided to taxi back to the Royal Hospital.

Despite being in civilian clothes, the taxi-driver refused any payment. How kind was that?



Me in "scarlets" with the waiter / waitress supervisor from our Great Hall.



Me with a colleague wearing "blues" and a restaurant owner in Kensington.

On Thursday, 2nd December I drove to Plymouth for a long weekend. Just a break away from here for a few days. With difficult driving back here in the rain and road spray though I won't be rushing back down there any time soon.

We had the annual cheese cutting ceremony and the stirring of the Christmas cake. Then there was the Christmas Jumper competition and carol singing.

In the Christmas Draw I won a posh box of deodorants but promptly gave it away as I don't use any since I had radiotherapy.

Our Governor gave his Christmas Address at our Christmas Luncheon on Christmas Day. Amongst other things, he announced it would be the King of the Belgians [https://en.wikipedia.org/wiki/Monarchy_of_Belgium] who would be taking the salute at our Founders Day scheduled for Thursday, 9th June 2022.

Imperial College at Charing Cross Hospital continue to treat me and my voice prosthesis. Its been leaking ever since I came here a year ago but they now seem to be on the right track. Hopefully, the New Year will bring forth some better results.

Take care and stay safe.
With best wishes,

Geoff

Geoffrey N. READ

Can You Help? 10 Year Cancer Plan

The Health Secretary, Sajid Javid, is keen to improve Cancer Services and is asking for cancer patients to give him any suggestions they have to change the way that services are delivered at the moment.

The questions he is asking are listed below. If you would like to respond you can complete an online survey using this link.

<https://www.gov.uk/government/consultations/10-year-cancer-plan-call-for-evidence>

If you would like us to put forward your views we will be able to do this. Please send us a letter or an email. We would like to make sure that your views are represented.

Questions to consider

- 1 Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?
- 2 Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?
- 3 Do you have any suggestions for how to get more people diagnosed quicker?
- 4 Do you have any suggestions for how to improve access to and experiences of cancer treatment?
- 5 Do you have any suggestions for how to improve after-care and support services for cancer patients and their families?
- 6 Do you have any suggestions for how can we maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?

Anyone can respond to the questions and it would be great to see services being improved for all cancer patients. The pandemic has taken its toll and we are pleased that the Health Minister understands this and wants to make changes for the better.

Summer Lunch Blackpool

The Blackpool lunch at the Imperial Hotel on Sunday 12th June is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel: **01253 899531**
Email: **waddington46@yahoo.com**

The Imperial have agreed to a special rate for any members who would like to stay overnight to attend the lunch.

They will offer £95.00 for single occupancy or £105.00 double occupancy based on a standard room with breakfast. When booking please make it clear you are attending the Cancer Laryngectomy Trust lunch on 12th June.





Belmont Bowling Club Charity Event

On 15th August the Belmont Bowling Club in Fleetwood held a charity bowling match and kindly donated the proceeds to the Cancer Laryngectomy Trust. For a number of years they have been holding these events and sending donations to the charity. We thank Brian Parker and his fellow club members for their continuing support.

Speak Easy Lanarkshire Ann Muir reports

On 19th December a Christmas lunch was held at the Bentley Hotel in Motherwell attended by 20 laryngectomees, carers and supporters. It was a lovely meal and so good to be able to relax - we had the hotel to ourselves and they serve great food. Following Covid rules everyone who attended carried out a lateral flow test before coming to the lunch and all was well.

I'd like to thank the Trustees of the Cancer Laryngectomy Trust and all members of the trust for the wonderful support you have give to the group and to members.



Trustees Report year end January 2022

The past twelve months have been a painful time for the Trustees on a personal level. On the 15th February 2021 we lost Wendy Thompson, our fellow trustee and dear sister. She always took her role as a trustee very seriously and as little as a week before her death she was discussing the Charity and her plans for 2021.

Our spring Newsletter included a tribute to her setting out the work she had carried out on behalf of the Charity. She is sadly missed. We are grateful to her husband Bill and their daughters Sarah and Helen for continuing to carry out some of the tasks that Wendy had dealt with up to the time of her death.

Although her death was not related to Covid, the rules about attendance at her funeral were affected. This reminded me of the difficulties faced by so many families during the pandemic.

Thankfully, the introduction of a vaccine has improved the situation considerably. Although we have not been able to hold any social events during 2021 we are planning to hold them in 2022. Afternoon Tea in the summer looks like a promising option particularly if the event could be held outside.

There is no doubt that the social isolation caused by the pandemic has been difficult for many people and we are hoping that we can return to a more normal routine so far as our social events are concerned.

One advantage of the pandemic has been the opportunity to spend more time on our hobbies. We have certainly enjoyed having more time to read books, listen to music and take walks with our labrador, Molly. Her favourite activity is swimming and visiting our local stream has been very popular. It is possible for laryngectomees to enjoy swimming provided the correct procedures are put in place. This was an activity Sydney, our founder, was not interested in pursuing but for some it can be a great relaxation. Let us hope that 2022 will be year when we can return to a more normal level of activity.

Ros Oswald, Trustee



Ros sitting at her square piano with Molly the Labrador



Ros playing the organ at Steventon where Jane Austen's father was the Rector



Ros and her husband Chris at their local Cafe celebrating their 41st wedding anniversary

“

Having come from the low of the cancer diagnosis, through the tough treatments, I feel grateful to be able to stand on top of the world and enjoy life.



In August 2012 I noticed that I was coughing up small bits of muesli in the morning on my way to work after breakfast and becoming more breathless when playing squash. A small lump appeared on the left side of my neck, and I decided to get it checked out. The GP was reassuring but felt that I should see a consultant which I subsequently did. Initially he thought it was a small cyst but 'scoped' me there and then. I remember his words, 'I change my mind, it looks like something more serious'. Cancer was confirmed by CT and MRI and biopsy proved it to be a stage 4a. With the pathology suggesting an aggressive cancer with a poor prognosis.

I entered a trial and received the higher dose treatment arm for radiotherapy and chemotherapy over a shorter than normal period of time. The treatment resulted in severe superficial burns with narrowing of the gullet

requiring me to be fed through a RIG tube. I had an episode of severe sepsis requiring hospitalisation before beginning my 'recovery'.

I had Christmas dinner sitting at the table with my family but could only chew to 'taste' the food before spitting it out and having my liquid feed. Despite this I slowly recovered but walking was difficult. We live near the sea and there is a flat promenade where I learnt to walk again. Initially from one lamp post to the next and gradually building it up. It took a lot of effort and determination to persevere, and Golf was a great rescue as I could use a 'buggy' and be outdoors.

Over the months and years that followed I began 'hillwalking' with my wife and friends and was doing quite well until midway through 2015 when I started to become more breathless.

I was having frequent chest infections and severe coughing bouts during eating. Due to recurrent pneumonias and increasing difficulties I had to be admitted to Hospital where despite high dose steroids and nebulised adrenaline the only option was for a temporary Tracheostomy. This was done with hopes of reversal and didn't present too many problems as speech could be maintained by occluding the stoma.

At that time, I used the shorter fenestrated tracheostomy tubes with neck ties. It required regular cleaning and good hygiene.

However, I kept aspirating and making slow progress and it became clear that my only option was to consider a permanent Laryngectomy.

This was done in March 2016 and after a long stay (waiting on a fistula to close) I slowly returned to walking and golf. At this time, I was using adhesive baseplates and HMEs. Unfortunately, my skin reacted with a bad contact dermatitis. The team at Countrywide/Atos suggested several approaches using cleansers and barrier creams with change to the 'sensitive: adhesive plates. Despite this I had to use a Laryngectomy tube with ties, periodically in order to let my skin settle. I received a suggestion to try using a button 'stud' which after the correct measurement and fitting has totally removed any skin problem.

I became much more active and returned to golf and hillwalking, climbing 'Snowdon' in June 2016 and starting on regular visits to the Lakes. Despite using the Xtramoist or Xtraflow HMEs I found it difficult on steep inclines and would often have to remove the HME in order to recover. The advent of COVID meant a lot more staying at home but the new 'micron' HME added reassurance when meeting people, but it was too bulky and hard to stay in place with a 'stud'. I heard about the new 'Life' range and wanted to try them but had to wait for the 'stud' to be approved.



It's been amazing as I find my level of activity has increased using the Provox Life™ Go HME during a routine day and sleep is great with the Provox Life™ Night HME. However, the biggest benefit was with the Provox Life™ Energy HME as I can use it on strenuous activity without the need to remove it. I also use the Life protect as it is more discrete and adds to confidence when socializing.



I did a couple of smaller climbs locally before returning to the 'Lakes' to tackle Blencathra (Saddleback). I was able to get to the top of it's 2,848 feet despite a drop in temperature to minus 2 and strong winds. I attach a photo at the top showing me wide the new Life energy in place.

Having come from the low of the cancer diagnosis, through the tough treatments, I feel grateful to be able to stand on top of the world and enjoy life.

Martin O' Donnell

Provox® Life™ Breathe better, whatever you do

"Really well thought out
and great for me I have a
deep irregular stoma these
products fit better and
reduce phlegm."

Provox Life™ User

89% of people preferred using Provox Life™ Adhesives*

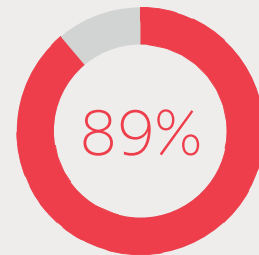
Provox Life™ clover-shaped adhesives are designed from high-performance materials to suit a variety skin types and stoma contours, providing you with a personalised solution.

Provox Life™ adhesives incorporate a soft, low profile coupling which gives an audible click to confirm that your HME is securely in place. For those who switched to using Provox Life™ Adhesives, they discovered:

- ✓ Ease of finding the right adhesive
- ✓ Less skin irritation
- ✓ Softer, flexible low profile coupling
- ✓ Better adhesion for an airtight seal
- ✓ Compatible with all Provox Life™ HMEs

Preferred Provox Life™ to their previous Adhesives

after 12 weeks*

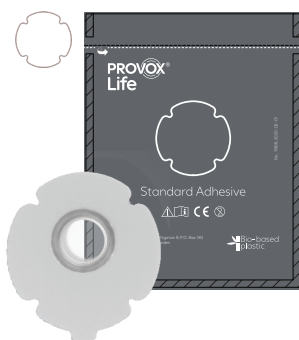


*Provox Life™ Experience Program, 2021, Data on file.


Provox Life™ is rated 4.5 star



for customer satisfaction



 **Call us**
0800 783 1659

 **Email us**
info@atos-care.co.uk

 **Visit our website**
www.atos-care.co.uk

Atos
Breathing-Speaking-Living