

London Asbestos Support Awareness Group

NEWSLETTER

FOR ANYONE AFFECTED BY MESOTHELIOMA OR OTHER ASBESTOS RELATED DISEASES

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London
Asbestos Support
Awareness Group

Registered Charity No. 1174543

0808 278 2515

www.LASAG.org.uk



“Bucket List” Trip to the Hashemite Kingdom of Jordan

By Ron and Simone Ollier

We recently went on a “Bucket List” trip to The Hashemite Kingdom of Jordan, to see our son who has been working out there since the beginning of November. In the 3 weeks notice we gave him of our intending visit, he arranged the most wonderful holiday we could have ever imagined.

We arrived at Queen Alia International Airport (Amman) at 10pm on the Monday night, and to his apartment in Amman by about 11.30pm. We were out again by 7am the next morning for what can only be described as a whirlwind holiday.



We started by visiting the Baptism Site of Jesus Christ on the bank of the River Jordan, the first of many amazing sites we were to see. People are still baptised there to this day as we were to see. We stayed there walking the quite large site for a couple of hours and then set off again to visit the Dead Sea, the lowest sea in the world, being 481metres below the sea level of the Mediterranean Sea. We did have a little paddle in the Dead Sea but it was unusually cold and windy. There were a couple of brave people in the water, which was very interesting to watch as they were very high in the water.

We then set off on our travels again, this time to visit the southern city of Aqaba through the desert for hours and hours on dead straight roads. There is a surprising amount of life going on at the side of the desert roads from little shanty dwellings to quite plush shops selling loads of souvenirs to willing foreign visitors. We had a meal in Aqaba and then set off back in a northerly direction until we reached our destination for the first night. Wadi Rum (Wadi meaning valley in Arabic). This was to be so surprising in the middle of the desert surrounded by mountains. We arrived at Camp Aladdin and by 4x4 as it is inaccessible to cars. We were shown to our tent which was a site to see. Built like a yurt and had a big plastic sightseeing window, it also sported full air conditioning and a built in shower, it was truly amazing. Our meal was to be at 7pm and was a traditional Arabic meal. It was cooked underground in a big metal drum and covered in sand until ready, when it was uncovered there was a big cheer from all as the food was lifted out. It was mainly Lamb and Chicken with lots of other side dishes in a buffet style. A little later it was served to the whole site and we ate it in a traditional tent completely lined with red and black patterned blankets. It was truly wonderful.

The next day kicked off at 6.30am for breakfast, again Arabic comprising of fruit cheeses and omelettes with tea or coffee. Then off we go in the back of a 4x4 around Wadi Rum to see some of the wonderful scenery and visit another tent to have some Arabic tea and be sold more gifts. We also bought the traditional Arabic squares to wear on our heads, which they tied for us. We will never

manage to put them on like that again, but the photos were worth it. We were then taken in the 4x4's around the desert again where we were shown some of the locations for the 1962 film “Lawrence of Arabia” and were met after that by our next experience, Camels. We mounted these Camels in a somewhat ungainly manner but managed to stay on for a half hour ride. We were led through the desert at a nice walking pace by our camel driver. Very strange

sensation on a camel but wouldn't have missed it for the world. After an even more ungainly dismount we left Wadi Rum to travel further north to the ancient city of Petra where some of the 1981 film “Raiders of the lost Ark” was filmed. We took a ride down to the city in a horse drawn carriage as my shortness of breath would have made the 1 km distance too much. The carriage ride was fast and a little scary, but fun. To see a complete temple carved out of

a rock face was amazing. The rocks were very high and overpowering. We managed to walk a little of the way through the site where there were more street traders selling lots of wonderful gifts. We were supposed to spend about 3 hours there but it turned out to be about 4 hours. After a short drive we had a meal in the newer part of Petra before driving the remaining 225km back to Amman and our sons apartment for a well earned rest.

The next day we had a little later start and visited the city of Amman, the capital of Jordan. This city is huge and built on seven hills. The culture is very different to ours. We spent all day “Ubering” about as I would never have been able to manage the hills. We went to the old town where tourists don't normally go which was very interesting especially the street markets and some of the wonderful fruit and veg they were selling.

The last day our son took us to Jarash to visit the Roman ruins of the Great Temple of Zeus and the large site of surrounding Roman buildings. This site is great to explore as most of it is accessible and not roped off. We finished up on the Friday night at a traditional Jordanian Restaurant where we enjoyed some Jordanian cuisine.

Early hours of Saturday morning we were picked up for the journey home, which we did in style. “Club World”, now we can't travel economy any more...



Sadly, Ron passed away since writing the article, but he leaves us inspired and encouraged to plan our own bucket list adventure.

NEWS & EVENTS



Denise returns to the NHS to support COVID-19 efforts

Denise Hodges, Support Worker who recently retired as a Clinical Nurse Specialist at Medway Hospital to join LASAG has returned to the NHS to support her colleagues during the coronavirus pandemic. We are so grateful to Denise for her service to public health, and look forward to her returning to LASAG to resume her normal duties. Denise shares her thoughts on returning to the NHS below. **Thank You Denise, and Thank You NHS for taking good care of us.**

"If I was told when I left the NHS back in November, that I would be returning less than 6 months later, I would have laughed in disbelief. However, sadly, since then our world has changed so much.

I agreed to go back and help as a Clinical Nurse Specialist for Mesothelioma and Lung Cancer because one of the Lung CNS's had been redeployed to ICU. On entering Medway Hospital for the first time the thing that struck me the most was the eerie silence! Normally when walking through the main entrance of the hospital there are crowds of people hurrying to and from appointments or visiting relatives, there were none. It was quite unnerving.

As far as the Mesothelioma/Lung Cancer Service has been concerned, it is mainly business as usual. Diagnostics are still going ahead, and sadly people are still being diagnosed with cancer every day. Unfortunately, clinical trials have been suspended for newly diagnosed mesothelioma patients, which is a shame as there are some great clinical trials on at the moment. However chemotherapy, surgery and radiotherapy are still being used where appropriate.

The real difference is that wherever possible patients are contacted via telephone, rather than being seen in a face to face clinic, in order to keep them safe. This has made life a little more difficult, especially for patients. It is hard to communicate the news of a cancer diagnosis to patients when you can't see their body language and they can't see yours. You try to reassure them via the telephone but it just isn't the same.

We are all concerned about getting COVID19 but for a mesothelioma or lung cancer patient the thought of getting this disease can be terrifying. One of the first things I did on re-joining the NHS was to contact all of the patients to try and give them as much reassurance as possible at a time when they desperately needed it. I also wanted to ensure that they understood the service was still running and they should use it and call if they were concerned about anything.

From a personal perspective, I have to say that I feel safer going to work at Medway Hospital than I do visiting a supermarket! I'm looking forwards to returning to LASAG soon."

Action Mesothelioma Day

This is an important date in our calendar as we join friends and family to celebrate and remember those who have lost their lives to mesothelioma. Last year we hosted our first event in Canterbury, and have included a few pictures below to remember the day. Unfortunately, due to current COVID-19 restrictions, we will not be able to host a gathering, but we are planning an alternative way to mark the occasion for AMD on Friday 3rd July 2020 .

Please let us know if you would like us to remember someone special to you



**Please Note: Support Groups are still suspended until it is safe for all to meet in public
Our Support Workers are available on the phone if you need to talk - 0808 278 2515**



ASK the Experts

In each issue, we have an expert panel answer your questions.

In this issue, we have focussed on questions relating to the coronavirus pandemic.

If you have a question you would like us to answer, please send it to:

ask@LASAG.org.uk - you can ask about anything from nutrition, treatment, exercise, sleep, research, trials, to carer advice, travel insurance, benefits or compensation.

Q. What is Shielding

- A. You're strongly advised to stay at home at all times and avoid any face-to-face contact if you're clinically extremely vulnerable to protect yourself.

Shielding means:

- Do not leave your house.
- Do not attend any gatherings. This includes gatherings of friends and families in private spaces, for example, family homes, weddings and religious services
- Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.

The Government is currently advising people to shield until the end of June and is regularly monitoring this position.

Q. Who is 'clinically extremely vulnerable'??

- A. People are regarded as extremely vulnerable if they are at very high risk of severe illness as a result of coronavirus (COVID-19), and may need be admitted to hospital. People with a range of long-term lung conditions (including people with mesothelioma, who are having active chemotherapy or radical radiotherapy) are in this group if their condition is severe.

Q. What if I didn't get a letter or text message?

- A. Most people with lung disease who are especially vulnerable to coronavirus have been contacted by letter or text message. But more letters may be sent following review by specialist clinicians and GPs and people identified in this way will get a letter shortly.

If you have not been contacted and you're concerned, you should discuss your concerns with your GP or hospital clinician. In the meantime, stay at home and follow the social distancing rules very carefully, or you could choose to make a personal decision to shield.

Register with the government for shielding support, even if you don't feel you need it. You can do this online (<https://www.gov.uk/coronavirus-extremely-vulnerable>), or by calling 0800 028 8327, the UK government's dedicated helpline.

For more information on the government's response to coronavirus, visit

<https://www.gov.uk/coronavirus>

Your Panel of Experts include:

- Professors
- Surgeons
- Oncologists
- Respiratory Physicians
- Cancer Nurses
- Pathologists
- Solicitors
- Benefits Advisors



Clinical Trials: Common Questions

By Louise Gilham (Mesothelioma UK CNS)

As a Mesothelioma UK Regional Nurse Specialist, I am often asked about clinical trials. Here are just a few.

What is a clinical trial?

Cancer trials are carried out to try to find new and better treatments for cancer.

Can anyone go onto a clinical trial?

Unfortunately not - due to inclusion and exclusion criteria. However we try to recruit as many people as possible.

Is it only drugs that are used in clinical trials?

Other than drugs, trials look at treatments such as surgery and radiotherapy. Others look at lifestyle, intervention of support and the way in which people are cared for.

I've heard / read that Clinical trials have different stages.

Clinical trials are divided into different stages, called phases.

Phase 0 - Aim to find out if a drug behaves in the way researchers expect it to from laboratory studies

Phase I - Trials are usually small and recruit only a few patients. The trial may be open to people with any type of cancer

Phase II - Trials for people who have the same type of cancer. Side effects are looked at, how to manage them and also the best dose.

Phase III - Trials compare new treatments with standard treatment. Standard treatments are those which are the best currently available. These trials involve more people and will be conducted in many hospitals and may be multi-national. Most phase III trials are randomised.

Phase IV - Trials are done after a drug has been proven to work and has been granted a license. They aim to find out more about side effects and the safety of the drug. They show the long term effects and benefits of the drug.

What is a placebo & will I know if I'm having one?

Placebos are often used in clinical trials as an inactive control so that researchers can better evaluate the true overall effect of the treatment under study without bias. Participants may not know if they are being given a placebo – this is known as “blinding”. However should the mesothelioma be progressing on the clinical trial and / or you are not tolerating treatment, your oncologist will discuss this with you and may considering other treatments.

How am I randomised?

This is done by computer selection.

Can I withdraw from a trial?

You can withdraw from a trial at any point and don't have to give a reason.

What are the possible benefits?

You may have a new treatment that is only available in a clinical trial. You may have more check-ups, tests and scans than usual, which you may find reassuring. You will be helping to improve cancer treatments for future patients.

What are the possible drawbacks?

You may have to do some trial paperwork. You may have unexpected side effects from the new treatment. You may have to make more trips to the hospital and trials may not be local. Travel bursaries may be available to help with the cost of this so speak with your nurse specialist.

Clinical Trials open to recruitment in Kent (More trials available within the UK)

BEST: Standard Chemotherapy plus Atezolizumab (Immunotherapy) and bevacizumab (targeted therapy) versus Standard chemotherapy and bevacizumab.

NEMO: Nintedanib - Targeted cancer drug

CONFIRM: Nivolumab (Immunotherapy) versus placebo

SYSTEMS 2: Radiotherapy

MARS 2: Chemotherapy plus or minus surgery

There are also other studies available which you may want to participate in.

MIMES: Interviews to explore the experiences of British Armed Forces personal / veterans with mesothelioma and their family members.

MAGS: Healthcare Workers whom have developed mesothelioma. Interviews for both clinical staff, such as doctors and nurses, and non-clinical staff, such as medical secretaries, cleaners, porters and maintenance staff.

Whenever you meet with your oncologist or Mesothelioma / Lung Nurse Specialist – always ask about clinical trials. Mesotheliomas UK are available to advise, provide information about clinical trials and any other mesothelioma information on: 0800 1692409 or www.mesothelioma.uk.com

WELL-BEING

Managing in isolation

A summary of helpful guidance from the NHS on mental wellbeing while staying at home is shared below.

Plan practical things

Work out how you can get any household supplies you need. You could try asking neighbours or family friends, or find a delivery service.

Stay connected with others

Think about how you can stay in touch with friends and family while you are all staying at home – by phone, messaging, video calls or social media – whether it's people you usually see often, or connecting with old friends.

Talk about your worries

It's normal to feel a bit worried, scared or helpless about the current situation. Remember: it is OK to share your concerns with others you trust – and doing so may help them too.

Look after your body

Try to eat healthy, well-balanced meals, drink enough water and exercise regularly.

Stay on top of difficult feelings

Try to focus on the things you can control, such as how you act, who you speak to and where you get information from.

Do not stay glued to the news

Try to limit the time you spend watching, reading or listening to coverage of the outbreak, including on social media, and think about turning off breaking-news alerts on your phone.

Carry on doing things you enjoy

Make an effort to focus on your favourite hobby if it is something you can still do at home. If not, picking something new to learn at home might help.

Think about your new daily routine

Think about how you can adapt and create positive new routines and set yourself goals.

Look after your sleep

Try to maintain your regular sleeping pattern and stick to good sleep practices.

Keep your mind active

Read, write, play games, do crosswords, complete sudoku puzzles, finish jigsaws, or try drawing and painting.

For the full article and further guidance, go to www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/ or ask your Support Worker for a copy.



Help is available if you have a medical condition which makes you vulnerable to COVID-19, especially if you are over 70.

If you, or someone you know, needs a hand with collecting shopping or prescriptions, you can call the **NHS Volunteer Responders** on 0808 196 3646 or visit <https://www.goodsamapp.org/nhsreferral> to request help.

Food deliveries are currently part of a national support service for extremely vulnerable people and organised by government in partnership with the grocery industry, local government and local resilience forums.

Contact us for more details, or if you need help to register.

Fundraising

Everything we do depends on the generous donations of our supporters. 100% of the money we spend each year comes from the people, companies and trusts who decide to support us. Whether it is putting a few pounds in the donation tins, donations in lieu of flowers, making a corporate donation or hosting an event, we are extremely grateful for your support.

In addition to one-off donations, here are some other ways you can support the charity

Regular Giving:

By choosing to give a regular monthly donation, you will be helping us to plan ahead and make long-term improvements for our beneficiaries and their families. A regular gift allows us to plan for the future because we know, day in day out, that we will have a steady income stream that we can rely upon.

In Memory Giving & Tribute Funds:

Giving in memory of someone is a very special way to commemorate their life by making a donation, holding a collection at a funeral or memorial service, setting up a tribute page, making a regular gift to mark a special date, such as a birthday, or taking part in an event or challenge in their name.

Leaving a Gift in your Will:

Gifts in Wills, large or small, are a wonderful way to support a cause you care about and to make a lasting difference. As well as leaving assets and possessions to loved ones, some people choose to leave a legacy donation to help support more people affected by mesothelioma and other asbestos-related diseases.

Volunteering & Fundraising Committee:

Whether it's organising a bake sale, helping with our Action Mesothelioma Day or Christmas celebrations, taking part in sponsored events or rallying family and friends to raise awareness and generate donations, we would welcome and be very grateful for your time and efforts.



Cash / Cheque

Post to: Farthings, Bridle Lane,
Rickmansworth Herts WD3 4JQ



Credit / Debit Card

Secure online payments at
www.LASAG.org.uk/donate



Transfer / Standing Order

Sort Code: 30-98-90
Account No: 18406368

I wish to make a donation to **London Asbestos Support Awareness Group** for £_____

Title:	Name:
Address:	
	Postcode:
Email:	Phone:

Please let us know how we can keep in touch with you by ticking the relevant boxes below.

I am happy for the charity to contact me by (tick all that apply): Post Email Phone SMS

giftaid it

Boost your donation by 25p for every £1 you donate by ticking the Gift Aid box *

I am a UK taxpayer and wish to Gift Aid my donation and any donations I make in the future or have made in the past 4 years.

*You must pay income tax equal to the tax reclaimed by the charity on the donation. If you pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all donations in that tax year it is your responsibility to pay any difference.

Support Groups

for anyone affected by mesothelioma and other asbestos related diseases

**Please Note: Support Groups are still suspended until it is safe for all to meet in public
Our Support Workers are available on the phone if you need to talk - 0808 278 2515**

Join us for coffee, cake and conversation at your nearest support group.

An opportunity to meet others living with the disease. Regular talks on topics including:

*Managing Diet, Clinical Trials, Hobbies & Interests, Benefits available, Alternative therapies,
Updates on new treatments, Advice on insurance, Health and Wellbeing.*

Our experienced staff together with specialist guest speakers and other professionals will be available to provide information, advice or a listening ear in a safe & private environment.

Sevenoaks

Third Wednesday of every month 2 - 4 pm

The Luggage Room
Bat & Ball Railway Station, Bat & Ball Road
Sevenoaks, TN14 5AP

marika@LASAG.org.uk 07880 201751

Canterbury

Second Tuesday of every month 2 - 4 pm

A.R.C.A. Hall
151 Ashford Road, Thanington Without
Canterbury, CT1 3XR

alison@LASAG.org.uk 07585 337230

Bexley

First Friday of every Month 2 - 4 pm

Baldwyns Park Baptist Church Hall
The Manse, Dartford Road
Bexley, DA5 2AY

marika@LASAG.org.uk 07880 201751

Isle of Sheppey

First Wednesday of every Month 3 – 4.30 pm

Harps Inn
Minster Rd, Minster on Sea
Sheerness ME12 3N

denise@LASAG.org.uk 07950 922874

Rainham

First Tuesday of every Month 3 – 4.30 pm

Rainham Cricket Ground
Berengrove Park, Berengrave Ln
Rainham, ME8 7NA

denise@LASAG.org.uk 07950 922874

Dagenham

Third Tuesday every month - 11 am - 1 pm

Toby Carvery Moby Dick
Whalebone Ln N, Chadwell Heath
Dagenham, Romford RM6 6QU

yvonne@LASAG.org.uk 07917 194454

Surrey

Third Wednesday every month 11 am - 12.30 pm

Maggies at The Royal Marsden
17 Cotswold Rd, Sutton SM2 5NG

yvonne@LASAG.org.uk 07917 194454

London

First Tuesday every month 11 am - 1 pm

Guy's Cancer Centre
Great Maze Pond, London SE1 9RT

Rachel.C.Thomas@gstt.nhs.uk 0207 1884758