

DERBYSHIRE ASBESTOS SUPPORT TEAM (DAST)



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June/July 2016

Welcome to the May/June Newsletter

£5 Million for Mesothelioma Research



Asbestos Seminar by Yvette Oldham, DAST Ambassador and Supporter

I attended the Asbestos Seminar in London which was part of the All Party Parliamentary Sub Committee on

Asbestos on Tuesday 22nd March with Joanne Gordon, DAST Co-ordinator. The Seminar had been organised by Laurie Kazan-Allen in conjunction with Graham Dring of the Asbestos Victims Support Groups' Forum. The purpose of the meeting was to discuss the UK government's failure to provide funds for research into mesothelioma. This dreadful disease kills more than 5,000 individuals every year.

As long ago as December 2014 at the first James Lind Alliance meeting in London, it was claimed that 'funds were available but suitable research proposals were not being received'. Yet at the beginning of May, Birmingham hosted the world's foremost conference of professionals due to the 'cutting edge work of scientists'.

However, in this year's March budget it was announced that £5 million would be provided to establish a National Mesothelioma Centre of Excellence - the funds being obtained from penalties inflicted on banks. This was wonderful news to all involved in mesothelioma from sufferers, carers, support teams and key players. There was no mention of how the funds would be distributed but there was a 'whisper' that the money would go to Imperial College, London at the suggestion of Imperial College's Professor, Sir Anthony Newman Taylor, CBE. At the meeting, Professor William Cookson of Imperial College confirmed that this was indeed the case.

Many questions followed from various persons in the chamber and suggestions were made that talks should be held with all concerned regarding the siting of the National Meso Centre for Excellence - bearing in mind that the highest incidences of the disease were not in the London area and that much research is going on elsewhere in the country. Professor Cookson said that it was good to hear from people involved in the struggle to support people for whom safety had failed. We will have to wait for future announcements and decisions.

Mesothelioma Stories

Trevor Barlow, a mesothelioma sufferer, then recounted his story of 'Living with Mesothelioma'. He began by saying that it is the responsibility of Government to 'protect from enemies' and the 'care and well-being of the public'. He said he thought the purpose of the meeting was to 'find a way forward to save lives'.

Mavis Nye then spoke of her exposure to mesothelioma and of the treatment she is receiving to keep her well.

Mesothelioma UK

The next speaker was Liz Darlinson from Meso UK. She gave the background of how Meso UK was created in 2004 by Macmillan to set up as a charity. They started with a Freephone, being on the Web, publishing a newsletter and providing Education and Information. They are now involved in trials and collaboration and there is better news and better survival times. Liz went on to say that asbestos is found in 50 countries, the UK having the highest number of sufferers in the world. Meso UK have a list of all the trials and are keen to support sufferers of peritoneal mesothelioma. She said that there should be equitable access to trials and care and that they are hoping to have 28 Nurse Specialists eventually.

iMig

The talk centred around Patient and Carer Day on 2 May. It was agreed that there is a need to improve life for sufferers and that the £5 million should be ring-fenced to address the cancer that 'WE' have caused! There needs to be a harnessing of expertise globally with a need to engage

industry. Huge thanks were expressed by all for the £5 million.

The next to speak was Dean Fennell, Professor of Thoracic Medical Oncology, University of Leicester. Professor Fennell is also the President of International Meso Interest Group. He began by saying that this is the 'Dawn of a New Era' for effective Meso Therapy. He said that:

- 1) It has been over a decade since new treatments were approved
- 2) There is no approved next stage
- 3) Need to discover ways to boost the immune system
- 4) Need to identify individuals for whom certain treatments will work

Professor Fennell 'held the floor' by talking of medical procedures – far too technical for me to explain fully. My best advice is for more information on research trials please contact Mesothelioma UK who produce a list of trials along with their newsletter. <http://www.mesothelioma.uk.com>

What I can say is that 'These new approaches are showing great promise targeting mesothelioma as more knowledge is being gained regarding genomics. Now is the time to accelerate research with the hope of successfully treating this cancer'.

All the assembled were suitably impressed by the research and the results. We all hope that these improving results must surely offer hope for persons on trials and sufferers in the future.

Dave Trigg of DAST asked how much funding is required for ongoing research.

The next speaker was Dr Kate Hill, Senior Researcher at June Hancock Memorial Fund. She said that there

had been research into changes in patient care over the last 25 years – some trials were not successful. It was far back in 2003 that Pemetrexed/Cisplatin were approved as a treatment. She continued that 'this is a great opportunity for ring-fenced funds and we need to consider wisely the best way of spending the £5 million.

We need to:

- Review current knowledge/research
- Create partnerships/share ideas
- Build research capacity
- Encourage collaboration
- Prioritise the needs of patients/carers and clinicians
- Discuss improvements as per patients priorities highlighted by the James Lind Alliance research

British Lung Foundation

The final person to speak was Ian Jarrold of the British Lung Foundation. He stated that £4 million had been spent on mesothelioma research over the last 5 years but was being held up by lack of funds. He said that the need is to 'bring professionals together to develop a cure for meso. The message is clear to the research community – there is a need to increase projects for research and success is obtained by collaboration. Melanoma kills the same amount of people yet mesothelioma has received two thirds of the funding'.

In conclusion.....

To sum up, it was a very interesting and informative meeting which promised hope for the future.

iMig 2016 CONFERENCE BIRMINGHAM 2 MAY 2016 by Dave Trigg, Chair of DAST and Ambassador



On a lovely May Bank Holiday, Natalie Woodward, Angela Sharpe and myself met up with Dave Fisher from our panel solicitor firm, Thompsons, in the main reception area of the International Convention Centre, Birmingham which was the venue for 'iMig 2016'. iMig, The International Mesothelioma Interest Group, is an independent international group of scientists and clinicians working to understand, cure and prevent mesothelioma.

We were there to listen to, and hopefully take some part in, a fringe meeting being held during the main conference lunch break.

The meeting, '**How Much Cancer Does Chrysotile Cause?**' was Chaired by: Jim teWaterNaude, South Africa, and Laurie Kazan-Allen, United Kingdom. The two speakers were Julian Peto, London School of Hygiene and Tropical Medicine, United Kingdom & David Egilman, Clinical Professor, Family Medicine, Brown University, Providence, R I. USA.

Both speakers produced several charts and graphs supporting their arguments but I was lost as to the content of most of it because of the

speed which they went through the explanations. They both criticised each other and at the same time complimented each other, it was a little bit bizarre at times, at least to me.

The interesting part came in the Q & A Session. Most, if not all the questions put to the speakers were from members of the Asbestos Victims Support Groups' Forum.

Tony Whitston managed, eventually, to get a response which was direct and not wishy-washy to his question "Does Chrysotile cause mesothelioma"? "Yes or No"? After asking 3 or 4 times he got the answer "YES".

Other points raised by the audience were 'campaigners were attacked as being hysterical'. Stop attacking campaigners and say that "all asbestos kills". "Asbestos is dangerous, now there are alternatives, let's get rid of it now"!

I said that I could not believe the propaganda put out by the chrysotile producers that their processes are safe. This was based on my experience at my workplace where we came across dust in our manufacturing processes but could not contain it.

We also met Linda Reinstein, Linda is the co-founder of the [Asbestos Disease Awareness Organization](#), (ADAO). The four of us had met Linda on other occasions, Natalie and Angela in Washington. D. C. and Dave Fisher and I at London Hazards AMD event in London.

Dates for your Diary

**Action Mesothelioma Day - Friday
1st July 2016**

**From 11am to 1pm
Cinema 2, Floor 2, Quad, Market
Place, Cathedral Quarter,
Derby DE1 3AS**

Speakers will include:-

- Dr Hadfield – Respiratory Consultant
- Colin Smith – Mesothelioma Patient
- Health, Wellbeing and Mindfulness – Peak House Practice
- 'Forget-me-not' Song

Followed by message ceremony and procession outside the Quad for photographs and Bubble Reflection

We will be reflecting on the lives of those who have been diagnosed with Mesothelioma and those who have lost their lives to the disease.



Food will be served in "The Box", Floor 2 after the Reflection. (Lift is available to this floor).

If you would like to book a place, please contact DAST on

01246 380415 or email:

joanne.gordon@asbestosupport.co.uk

**Mesothelioma in the Midlands –
Monday 17th October 2016 from
11am – 4pm at the Spot, Wilmot
Street West, Derby, DE1 2JW.**

Speakers will include:-
Liz Darlison – Mesothelioma UK and
Sheree Hall – Macmillan Lead Cancer
Nurse

**Lincoln Cathedral ‘Reflection and
Celebration of Life’ –
9th November 2016**

Projection of names to ‘celebrate’ and
remember Mesothelioma victims in the
East Midlands followed by “Reflection
and Celebration of Life” in the Chapter
House.

**DAST Meeting – 2nd December 2016
at the Spot, Wilmot Street West,
Derby, DE1 2JW 11am – 1.00pm**

As it will be getting near to Christmas
by then, this event will be our second
DAST social of the year. Back by
popular demand will be ‘Move it – or
Lose it’ along with entertainment - the
beautiful singing voice of Jayne
Darling from Get Happy!

AGM 10am – 10.30am.

Fundraising Section

Walk a Mile for Meso



The 2016 Walk a Mile for
Mesothelioma weekend will begin on
Friday 9th September. As in previous
years, the DAST team will be walking
their mile through the Forest
Recreation Ground in Nottingham. We
will meet at 11.00am on Friday the 9th
outside the park café. You are all

welcome to join us and don't hesitate
to bring along your children and pets!
The Forest Recreation Ground has its
own tramstop (the DAST team travel
down by train and tram and find this an
easy trip) or there is a very large car
park.

Of course we would love it if some of
you organised your own walks.
Several wonderful supporters got
together with friends and relatives and
walked around local parks and nature
reserves last year. All together, they
raised over £4,000 which gave a
brilliant boost to our funds.

To ask for a sponsor pack, contact
Sarah on
sarah.walters@asbestosupport.co.uk
or call 01246 380415.

Waitrose



Thank you very much to shoppers at
Waitrose in Buxton, who donated their
green Community Matters tokens to
DAST. Waitrose staff member Julie
Atkinson presented Sarah with a
cheque for £460.

Our Asbestos Heritage

We now have a roller banner and
leaflets for the Our Asbestos Heritage
project. We would like to get these into
museums and heritage sites. If anyone
can help with this, please let us know.

Craftivism

Our Memory and Message Patchwork is really starting to take shape now – if you have purchased hexagons to decorate please don't forget to send them in so we can add them to the project. This is an ongoing project so you can purchase a hexagon at any time. To decorate your own, the blank hexagon costs £2.50. If you would like Sarah to sew on a reflection rose and a set of up to 3 initials, the cost is £5.00.

- Donate online via VirginMoneyGiving or The Big Give websites
- Buy a William Bear, a William Badge or a Reflection Rose
- Recycle your used stamps, mobile phones and HP ink cartridges
- Consider leaving DAST a gift in your Will (please ask for information sheets)

Thank you

DAST News – Round-up

Asbestos in Schools

The Asbestos in Schools memory stick and booklet is achieving its aims. We have had requests for copies from the teaching unions and we are currently looking for more funding to buy more memory sticks. We are also looking for a new school building in the East Midlands to launch the project. If you have any contacts please let DAST know.

Shay Boyle, our Project Worker, attended the NASUWT Conference over the Easter holidays and stated that the project was well received.



Website

The DAST website has had a revamp – please drop by and have a look. We think it is much more friendly on the eye and easier to navigate. www.asbestosupport.co.uk

Ways to Donate

Please send cheques payable to DAST to 34 Glumangate, Chesterfield, S40 1TX

- Make a regular donation by standing order – ask us for a form

May Day

Chesterfield has one of the largest May Day processions in the country and this year was no exception. There was a great turn-out from the voluntary



sector which was good to see. We were joined by Thompsons Solicitors for help in carrying the DAST banner.

Joanne Gordon with Reuben Greenwood Thompsons Solicitors



Neil Baines, Thompsons Solicitors with his son, William, one of the youngest supporters on the march.

Coffee Morning – 22nd April

The Coffee Morning on 22nd April in Chesterfield was well attended and everyone found the opportunity to chat really helpful.

Thank you to UKATA for hiring the room and providing the refreshments. Also thank you to Sue Glover, Lung Cancer Nurse Specialist from Kings Mill Hospital for coming along and offering support to mesothelioma patients and their families.

If you would like a Coffee Morning in your area please contact us. Also if you have any ideas for great venues please let us know.

Joanne's Sponsored Walk – 14th May

It was a perfect day for a 30-mile walk which Joanne and her sister-in-law did in 8 hours whilst Joanne's husband, Simon, did a 30-mile run, being 5th to complete this. Thank you to everyone who donated; the amount raised to date is £1500



Lindsay Guest, Joanne Gordon, Simon Gordon with their "Hobo" medals.

Alan Salmon Memorial Concert

On 14th May 2016 Newmount Brass Band hosted a Memorial Concert in memory of Alan Salmon, who was diagnosed with Mesothelioma for two years before he sadly passed away in November 2015. The concert was to raise money for Macmillan Fund 14001 and DAST and Alan's family were delighted to say that they raised £1071 in total, meaning DAST was presented with a cheque for £535.50.

Thank you very much to Alan's family for their fantastic fundraising.



Newmount Brass Band



cheque for £382.95 from the event. Thank you very much to everyone involved.



Mrs Salmon and her daughter Rachel presenting the cheque to Joanne

“Celebrate with Music”

Joanne and Audrey (DAST Volunteer) attended "The Celebrate with Music" event on Saturday 4th June at St Luke's Church in Derby. It was nice to see some familiar faces so thank you for your support.

We had a great night. There were both funny and moving performances and a showcase of amazing talent. The event was in memory of the late Revd Graham Sillis and the event was attended by his family.

The musical celebration raised over £765 and proceeds are to be split between DAST and St Luke's Church, which means DAST will receive a

Volunteering for DAST

Community Champions

Could you become a community champion? We are looking for volunteers to become community champions. The role involves speaking about DAST and the services we offer. This could involve ensuring leaflets and posters are prominent in public places such as GP surgeries and libraries. Perhaps holding a stall at community fetes or events or speaking to the media to tell your story.

Events

We would also like volunteers to help out at DAST events. This could include meeting and greeting, helping newcomers to feel welcome, selling merchandise or sharing your story.

Fundraising

If you would like to help us raise funds, we have a fundraising pack which we can send out to you. Here are a few ideas, coffee morning, cake sales, sponsored walks or swims, race nights.

If you would like to volunteer for DAST, please contact us on 01246 380415.