Cross Party Group on Asbestos
Date: 10th May 2017 - 18:00 to 20:00

Attendees:
Dawn Bowden AM – Labour
Huw Irranca–Davies AM – Labour
Dr Dai Lloyd AM – Plaid Cymru
Cenric Clement-Evans – NewLaw Solicitors
Julian Cason – Slater and Gordon
Dr Richard Attanoos - University Hospital Wales
Nick Blundell – UNITE
Bob McLaren – Mesothelioma UK
Kim Barrett – Irwin Mitchell LLP
Gareth Morgan – UCAC
Lee Campbell Cancer Research Wales
Tim Cox – NASUWT
Joseph Carter – British Lung Foundation
Lowri Morgan – NewLaw Solicitors
Dr Zsuzsanna Tabi – Cardiff University
Philip Gower – Simpson Millar
John Evans – Santia Asbestos Management
Jo Barnes-Manning – AASC (Asbestos Awareness and Support Cymru
Simon Fleming – FBU
Marie Hughes – Greater Manchester Asbestos Victims Support Group
Rachel Iredale - Construction Industry Training Board
James Powell – Tenovus Cancer Care
Dave Bezzina – AMSS Dawn Bowden AM

Apologies
Jayne Bryant AM – Labour
Jeremy Miles AM – Labour
Bethan Jenkins AM – Plaid Cymru
Simon Thomas AM – Plaid Cymru
Nick Ramsay AM – Conservative
Phil Markham – UCU
Mike Payne – GMB
Carla Murphy - BMA
Lorna John AASC
Rhian Edwards Tenovus Cancer Care
Sarah Morgan Mesothelioma UK
Simon Jones Marie Curie

1. Welcome

DB welcomed everyone to the meeting and introduced herself as the elected chair of the Group. She noted she had been elected in absentia but was pleased to take on the role. She noted it was great to see that everyone had come together this evening to discuss asbestos and its impacts. The aim of the group is to provide a voice aimed at politicians; to provide information, to raise awareness,

to inform about measures that could be put in place to prevent exposure, to learn about research and effective treatment and to look at advice and services to meet the needs of sufferers and their families. The aim of the meeting this evening was to consider work that had already been carried out, an update on where we currently are, and to identify areas to be taken forward.

DB apologised that she would need to leave the meeting early this evening due to prior commitments in her constituency but would ask CCE to chair in her absence.

2. Immunotherapy as a potential novel treatment in mesothelioma

ZT introduced herself and delivered a presentation covering immunotherapy in general, research breakthroughs, immunology in mesothelioma specifically and on the work carried out by her research group. A brief summary of issues is included below.

ZT explained how the immune system worked. She noted sometimes cancer cells grow in the body without detection by the immune system. At other times the cancer cells are detected, the immune system reacts and that is when patients suffer symptoms and visit their doctor for investigation.

There was a case involving of a gentleman who had been diagnosed with melanoma but had lived cancer free for 16 years. He died following injuries sustained in a car accident and his organs were donated. Two patients who received transplants developed the exact same strain of cancer as the deceased.

The focus used to be on trying to boost the immune system but this has now changed to trying to allow normal function of the immune system.

A molecule discovered in 1992 had been trialled. Human trials commenced in 2006. The trials were carried out on patients who were deemed ‘incurable’; they had been resistant to other forms of treatment. Those trials had a high success rate with patients responding well to treatment. In mesothelioma patients trials had started with treatment every 3 months but this was then increased to every 3 weeks. These trials are currently ongoing. Since records began there have been around 8,000 recorded trials into mesothelioma.

The aim of current trials is combination immunotherapy using two different checkpoint inhibitors or a checkpoint inhibitor combined with other treatment, such as chemotherapy.

Reference was made to Mavis Nye, a patient who had been treated with PD1 inhibitors with success. Whilst the treatment did not cure Mavis, it has stopped any progression of her condition. Recruitment is still ongoing for these trials. The aim of the trial is to treat around 1000 patients; around 500 have been treated to date. Mavis is the only success story so far.

CCE explained Mavis’ exposure to asbestos was through washing her husbands’ work overalls and noted it was worth following her on twitter @grandmamavis.

ZT advised that unfortunately many patients are forced to pay a lot of money for private treatment and at present we are unable to identify which patients will respond to treatment positively. 2-3% of patients respond terribly to treatment but it is not known why. Further research is needed to identify the right patients for treatment and to establish a biomarker. Due to the nature of the disease the time for treatment is limited; patients don't have time to go through 2 or 3 rounds of trials. The aim is to be able to genetically categorise types of cancer and combine treatment with immunotherapy.

Their current research involves modelling immune resilience of mesothelioma in vitro.

They have carried out a SKOPOS trial which is a tumour antigen trial conducted from Velindre Cancer Centre. The aim was to kill mesothelioma cells using T-Cells. It is anticipated that 70% of patients will be susceptible to T-Cell treatment. The treatment is designed to kill cancer cells but not normal cells. This is combined therapy where patients receive immunotherapy and chemotherapy. Treatment commences with 3 doses of the vaccine; this is in order to generate an immune response before the immune system is knocked out by the chemotherapy. 26 patients took part in the trial but it took 2 years to recruit that limited amount. The trial was deemed a success but they wish to carry out further analysis of the results.

Future research plans include studying tumours for treatment in vitro in a petri dish. It is impossible to carry out all combinations of treatment in clinical trials, but if we can learn to identify the profile of patients then it would help identify the correct treatment.

The funding for the research expires in August 2017. If further funding cannot be obtained, this will end mesothelioma research in Cardiff.

(At the end of the presentation DB thanked ZT and made her apologies as she had to leave)

CCE noted that as far as he's aware approximately 100 people in Wales alone are diagnosed each year with mesothelioma. He asked out of interest whether the patients in the trials were from Wales or Wales and England.

ZT advised most of the patients involved in the trial were recruited from Velindre, but some were from other areas of the UK. Mesothelioma UK had advertised the trials. There had been some initial difficulties setting up the trials as there had been a dispute as to who would pay for the chemotherapy treatment.

DL explained that he is an AM but also a GP. He asked whether the research team had any sort of collaboration in place with genetic research.

ZT explained that genotyping for mesothelioma was being carried out in Leicester, where they have a trial drug to treat mesothelioma. ZT has been asked by a member of the Leicester research team to assist with immunotherapy work.

Leicester does carry out immunotherapy trials but is dependent on the Cardiff research group.

DL explained that he was wondering whether there was any prospect of cross funding between the two in the future.

CCE referred to a recent reception he attended where Dr Jason Lester raised concerns with getting patients on to clinical trials. He had invited Dr Lester to write to the group to consider the issue. CCE asked whether this was due to funding or whether there are other issues we need to be aware of.

ZT explained one issue is information not reaching all parts of the country, and another was travel. For example, their trial involved 13 vaccines in total, for a patient is in North Wales that means a lot of travelling back and forth for treatment. In addition to vaccines there are blood tests which need to be processed within a matter of hours. One solution might be to train people in North Wales to carry out the process up until the point that bloods can be frozen and sent down to the research group in Cardiff. The trial was being conducted on a shoe string so funding was a problem.

RA noted that eligibility is also an issue at point of source. This is a wider issue across all clinical trials. In order to join a trial you have to meet the eligibility criteria, e.g. you have a certain type of tumour, your cancer is at a particular stage, you have received no other treatment etc.

LC agreed that there in difficulty in ensuring that trials reflect a real clinical setting. As a member of the Cross Party Group for Cancer they've sourced a lot of information from the Velindre trials unit which concerned issues establishing service contracts which was impacting treatment. For example, if you had a patient in Swansea or North Wales you would find that the pharmaceutical company or the clinical lead would want access to all documentation such as scans, pathology blocks and reports etc., which meant service contracts have to set up between the different Health Boards in Wales. This can add an extra cost of up to £800 per patient. Welsh Government has been made aware of these issues and plans were in place to address these concerns, but LC was uncertain how far things have progressed.

RI advised it was normally possible to claim VAT back for drug testing in certain circumstances, e.g. if treatment is provided in a mobile setting you can reclaim VAT.

JC thanked ZT for her fascinating presentation. It is a tribute to her research team that this work is being carried out in Wales rather than one of the big London hospitals. He asked when is it anticipated that immunotherapy will be provided as mainstream treatment, to be prescribed routinely.

ZT advised this was already happening with melanoma, and it is the way forward, but there's still something missing and further research is required. As mesothelioma is a rare cancer, others cancers are likely to get there first due to

lack of funding. For example, radiotherapy can't be used well in mesothelioma and maybe it is a different type of chemotherapy that is required.

JC noted that the medical hope this brings patients is invaluable and it is very exciting.

RA advised this type of treatment is also being used in America with mesothelioma patients. He referred to a case of one mesothelioma patient who is doing very well 5 years on. He explained that until recently mesothelioma has been considered a homogenous disease where a fatal outcome was expected in around 12-18 months. The disease is now considered heterogeneous; one key area of research is young women of a certain age and background who are responding to treatment very well. The difficulty comes down to the individual patient and uncertainty over how they will respond. The focus is now on targeted treatment rather than broad based treatment.

CCE noted that in terms of his clients this is very important as it is about extending life. Private treatment costs could form part of a legal claim, until treatment becomes available on the NHS. Sharing information regarding successful outcomes will attract more investment; it is a snowball effect. He asked ZT how the group could assist the research team in terms of providing a voice focused at the Assembly. What can the group do?

ZT has been studying immunotherapy for 15 years; it would be a great shame if lack of funding brought that to an end. The way research works is difficult; you are dependent on external grants. 2 doctors have already left her team to go into more stable jobs in industry; they can't cope with the long hours and working on short contracts. The Cardiff research group contains the most expertise in immunotherapy in the whole of the UK. They need their research work to be more sustainable and reliable, in order to ensure they can attract the best people.

CCE noted the need to support this kind of work and share the expertise we have in Wales.

BM highlighted the need to raise the profile of mesothelioma in Wales and funding was needed for different research projects. His wife suffered peritoneal mesothelioma and passed away last September. Treatment provided in America offers a medium survival rate of 5 years. There is a centre in Basingstoke that carried out the same surgery but it is not well known. Their funding was withdrawn in July 2015; that was a retrograde step. Most people will now have to sell their house to fund treatment in the USA. There is a tendency for mesothelioma to be considered a hidden disease with funding withdrawn or lowered. This is very concerning.

LC noted that oncological surgical research is woefully underfunded but it is the most successful type of treatment for cancer. It is no coincidence that the best survival rates for lung cancer was in the South East, which happens to have the most specialised thoracic surgeons for lung cancer.

BM advised experts need to be given the opportunity to practice their surgery. Treatment for peritoneal mesothelioma is different; the tumour is in the abdomen not the chest. His wife had been referred to a thoracic expert but it was not a thoracic issue. Mistakes were subsequently made in determining the correct type of chemotherapy treatment.

RA noted surgery as the most significant move forward in any form of treatment for mesothelioma, but another element of cancer is predisposition syndrome. You look at individual cases, you review records, you look at types of tumour, e.g. melanoma tends to indicate a genetic type of germline, which tend to do much better. In isolation they are bad cancers but they do much better than the typical mesothelioma. These are evolving areas – identifying different types of mesothelioma, identifying patients as being different. The UK has the highest rate of mesothelioma in the world.

CCE noted the discussion had been very useful but suggested we move on to the next item in the agenda as time was limited. He again thanked ZT for her presentation.

3. Date of future meetings

CCE suggested 3 or 4 meetings a year. The aim is to meet more regularly than has previously been the case in order to build momentum. DaB noted that realistically it will not be practical to hold the next meeting before September due to the summer recess; the summer recess will always be a consideration. He suggested that if we want 4 meeting we go for May, September, January and April but if we want 3 we go for May, September and January. It was agreed that dates for future meetings should be decided now as it can get difficult to manage diaries and book rooms. It was agreed that we would focus on September and January for the time being. DaB will circulate dates by email.

4. Confirmation of Officers

CCE explained the need for a minimum of 3 AM's from different political parties in order to constitute the group. The group currently has representation from Labour, Plaid Cymru and UKIP. DaB noted that discussions are in place to try and recruit a Conservative AM to the group. There is currently an audit of how cross party groups are working so we now need to re-register. CCE noted DB was elected as chair in the previous meeting and proposed that unless anybody else wanted to be put forward or had any objections she remain as Chair. This was agreed. It was also agreed that CCE continue as secretary.

5. Minutes of the meeting held 21 September 2016 and Matters Arising

CCE referred to the previous minutes, a copy of which had been distributed to all present.

An updated was provided in respect of the Right to Know Asbestos in Schools petition. The petition is due to be reviewed again by the Petitions Committee of the National Assembly on 23rd May. This is the 15th time it will be considered which shows the importance that the Petitions Committee has attached to it. He

will be responding to an executive summary prepared for the consideration of the committee.

The current situation is that a representative from the civil service in Wales now attends the Department for Education Asbestos in Schools Steering Group in England. The Department for Education Asbestos Management in Schools Data Collection report was published in February. This voluntary data collection provided a partial picture of the management of asbestos in schools, in England. The Secretary of State had agreed with the recommendation to seek assurances from **all** duty holders who have a responsibility for the management of asbestos in their schools, in England, to improve the DfE understanding of the management of asbestos in schools. "All duty holders will be expected to undertake the necessary due diligence checks, to ensure that the assurances they provide are based on evidence from all their respective schools."
There are draft proposals for assurance management which would not be mandatory but it s expected all duty holders with participate.

CCE read an extract to illustrate that it was clear that Steering Group was focused on asbestos in schools in England.

> "Although not mandatory, as the department does not have the powers to compel all duty holders to complete the assurance process, it is expected that all duty holders (approximately 3,500) will participate in the assurance process. We intend to validate our list of duty holders against other sources to ensure that they are all captured. We would expect that this approach should then cover the estimated 25,000 schools, in England. The department will communicate the importance of managing asbestos effectively and will set a clear expectation in this communication that all duty holders participate in the assurance process."

CCE also referred to the recent report of the House of Commons Committee of Public Accounts which had heard evidence including that school children in Sunderland had been exposed to asbestos leading to them being hosed down.

CCE read the following recommendation from the report entitled Capital funding for schools

> "7. **The Department still does not know enough about the state of the school estate,**
> **meaning that it cannot make well-informed decisions about how best to use its limited resources.**
> The Department now has a better understanding of the condition of school buildings after completing a survey of the estate in 2014. This property data survey estimated that it would cost £6.7 billion to return all school buildings to satisfactory or better condition, and a further £7.1 billion to bring parts of school buildings from satisfactory to good condition. Much of the school estate is over 40 years old, with 60% built before 1976. The Department estimates that the cost of dealing with major defects will double between 2015–16 and 2020–21, even with current levels of investment, as many buildings near the end of their useful lives.

> The property data survey did not assess the safety or suitability of school buildings or the extent of asbestos. Over 80% of schools responding to a separate survey by the Department had asbestos, with 19% reporting that they were not complying with asbestos management guidance. However, only a quarter of schools responded to the survey, meaning that the Department does not have a complete picture. The Department estimates that it would cost at least £100 billion to replace the entire school estate which it believes would be the only way to eradicate asbestos from school buildings. The Department is undertaking a second property data survey but, until this is complete, it cannot assess reliably how the school estate is changing and does not know the extent to which its funding is helping to improve the condition of school buildings."

The Right to Know Campaign highlights the issue in schools in Wales. On 1st November 2016 the Minister of State for Schools Nick Gibb, in response to a written question from Amanda Solloway MP regarding the removal of the presence of asbestos from school sites in England and Wales advised,

"Policy on the effective management and removal of asbestos at Welsh school sites is devolved to the Welsh Government, but in England it is one of the department's priorities in order to ensure that our schools are safe for children and teachers."

CCE will again highlight this issue before the Petitions Committee. JC and CCE met with the Cabinet Secretary for Education Kirsty Williams AM in November and raised issues of responsibility. They were told that it is not a matter for Welsh Government as it falls within the remit of health and safety. CCE maintains that no-one is taking responsibility for schools in Wales.

SF queried what involvement HSE had in this, e.g. would they take an issue to court if a risk register hadn't been kept. CCE explained it was his understanding that prosecutions are few and far between. More usually prosecutions were brought against private individuals rather than local authority.

JE noted that every parent expects to be able to send their child to a safe school and not be exposed to a class 1 carcinogen. He said there has been some good work done in certain local authorities who are complying with asbestos legislation but he's also aware of others that aren't complying. It has often been his experience that HSE are very supportive. He notes that in an ageing population the young should be the priority; we will see more and more cases of mesothelioma as people are being exposed from a young age and this makes them more vulnerable. CCE by reference to the findings of the Committee on Carcinogenicity agreed that the greater life expectancy of younger children meant that they were at increased risk from asbestos exposure, but noted that the jury was out on the issue of susceptibility relating to developing physiology.

JE stated that in any event the priority is to make schools safer; it is not just about enforcement. He has seen some cases where a lot of good work has been done but others where action should have been taken to protect the public. Buildings should be safe. It is not necessary to remove all asbestos but it does need to be

kept in good condition. There is a need to train people but often there just isn't the right level of support, e.g. managers in private schools. CCE noted this was also an issue with academies in England.

RI said that focusing on schools is restrictive and that we also need to consider other public buildings such as community halls and libraries etc. There needs to be a national register for all buildings noting the likelihood of disturbance. There tends to be a lot of shouting about safety in construction but not so much focus on health, but for each safety death there will be around 100 health deaths. Wales should lead on a wider risk register.

CCE without disagreeing with RI noted that the focus on schools because children and young people act in a way that adults don't.

TC noted that HSE class most schools and most public buildings as low risk. With significant cuts to funding there are no resources to carry out inspections in the way they're used to. The local authority also has an obligation to inspect. There have been some local authorities that are very good with asbestos but again there have been massive cutbacks, and schools don't have the expertise that the local authority used to have. The main focus of the union is on schools but it is important to consider all public buildings.

CCE said that information about local authority schools in Wales is included on the Right to Know website www.righttoknowasbestos.org. He referred to Lucie Stephens who lost her mother Sue Stephens a school teacher to mesothelioma last summer. She has been campaigning hard on the issue and has made a lot of freedom of information request in relation to the presence of asbestos in schools.

TC noted that a condition survey should be factored into the 21st century schools funding programme and there had been a further announcement today which announced further funding for schools. There is money in the money but asbestos doesn't figure at all.

JC advised that in their meeting they were told that it is down to the schools to put in their requests and to cite asbestos as a supporting reason for their funding application. They did try to convince the Cabinet Secretary that asbestos should be enforced as a consideration and that centralised records were important but they were told it was the local authority's responsibility. The money is more likely to be used by a school to construct a new building to replace a mobile unit than to make an existing building safe.

RA explained that from a scientific perspective, observed correlations between asbestos related disease and dose are based on historical occupational exposures, and these exposures to asbestos are many orders of magnitude more than is observed in any ambient background. Regulatory bodies regard the observed correlations between asbestos and disease as showing a non-threshold linear dose model. Accordingly, if accurate, the only measure of no risk is no exposure. Observed correlations between asbestos disease and dose apply at exposures over 15 fibres cc years (an index of cumulative dose) – risks of disease below this dose may be estimated by mathematical extrapolations.

Mathematical extrapolations of risk of disease from historical high dose observed exposures - effects to present day low dose ambient exposures are interpretive estimates but no disease has actually been observed following such exposures. RA works with an international mineral analytical laboratory in Cardiff. He noted 98% of the population born after 1980 will have measurable levels of asbestos fibres in their lungs computing to 30 or 40 million fibres – these reflect fibre dose for persons following ambient and not occupational exposure. In effect there are many asbestos fibres in our lungs. We only scientifically know about disease following heavy occupational doses. This is irrespective of the additional known factors affecting disease such as fibre type. We know that amphibole fibres are more dangerous than chrysotile fibres.

In response to a comment made regarding teachers and asbestos, RA stated that simply interpreting case numbers of persons/workers with mesothelioma and concluding a causal effect may be misleading if no control groups are examined. You have to be sure if you are looking at teachers that there is no exposure outside of school – can you rule out other exposure – childhood, environmental?

JE – you have to consider where a person grew up, the experiences they've had in the past etc. He recalled a leisure centre in the area he grew up which had an asbestos roof which was falling down. You have to ask – have I been exposed in a leisure centre, library or other public building? If one fibre could kill us we'd all be falling over. But going into a school and finding damaged asbestos boards is unacceptable. The bottom line is we need a safe place to work. It is not an HSE enforcement issue. There needs to be a lot of liaising with HSE. The Assembly has control of educational buildings, they should be able to say we can make these buildings safe.

6. Any other business

JBM advised she looked at the point of view of the patient carer. Very often exposure occurred years ago but these are the people living with the illness now. Hearing about the research trials and the hope it gives to these people is huge. That can have a positive impact on quality of life. The need for further trials is imperative. Some suffers do not have a very long journey but hope is important. As a carer for her own father she recalled an occasion when her dad called his sons into the room and told them "for god's sake wear your masks at work". It would be a massive undertaking to remove all asbestos but we can make buildings safe. Complacency is not acceptable. When travelling to Cardiff she had passed road workers who weren't wearing protective masks. She got out of the car and told them off. Despite the laws that are in place, the training and guidance that is given, how do we overcome complacency in an effective way to ensure precautions are put in place? Raising awareness is imperative, as is continuing to fund trials. Families are being destroyed by asbestos conditions.

MH advised that her point of view was similar to JO and that being present at tonight's meeting, hearing wonderful initiatives and raising awareness was brilliant. She would be reporting back to the Form with a positive outlook.

BM spoke about the aims of Mesothelioma; a charity that provides a national specialist resource centre for mesothelioma. Their aim is to provide specialist information, support and education and to improve care. They aim to integrate with the NHS and provide a specialist nurse at the point of need. A brand new specialist nurse has recently been appointed in Wales. They are based in the Glenfield Site in Leicester; it is a small space but a wonderful charity. Their role is to provide information and education and to go and offer support to sufferers and their families. His first gig in this new role is to give a talk and present prizes at a charity swimming gala. He looks forward to future meetings.

7. Work Programme 2017

CCE noted it was important this wasn't just a talking shop. The aim is to implement a work programme. We need to consider what we can do, what action can we take aimed at politicians to raise awareness. One example is ensuring that patients outside of South Wales aren't forgotten about. People should be able to access the best treatments available wherever they are geographically. As time was pressing those present were invited to feed back to CCE and DaB in respect of ideas on what steps can be taken to start making a difference.

DaB noted the discussion around the 21st century funding programme in schools raised interesting questions in terms of an increasing amount of public buildings being outsourced.

NB noted that accountability falls to the duty holder in a public building, but liability wouldn't transfer if the service is outsourced. Where does that leave people?

CCE and KB advised it would depend if the person bringing the claim was employed or not as that has an impact on the insurance position. With an employer you would claim against the employers' liability insurer at the time of exposure, if public liability insurance applies it would be the insurer at the time the disease manifests itself. It is not straightforward; it is down to the way the insurance contracts are written.

NB noted that in social housing they may deem a building safe to go in because it's been tested, but in fact it is a house on the next street which has been tested. Sloppiness leads to problems.

The meeting then came to a close and it was agreed that DaB would circulate dates for the next meeting.