PEGS is a support group for anyone whose health has been affected by exposure to pesticides.

Quarterly December 1998

PEGS

Pesticide Exposure Group of Sufferers

Newsletter 1

This is the first PEGS project newsletter for members comprising the proceedings of the PEGS seminar held in September. Future issues will include contributions from members about their experiences, news about medical treatments, legal matters, and pesticide legislation. Please send any feedback and suggestions to Alison Craig.

PEGS SEMINAR 5

Wednesday, 16 September 1998 Friends Meeting House, London

Introduction Enfys Chapman, coordinator, PEGS

Apologies from the other two founders, Frances Boulton, Heather Cameron.

Peter Beaumont, Pesticides Trust

Welcomed members and speakers.

PROFESSOR ANDREW WATTERSON

Director of Centre for Occupational and Environmental Health,
De Montfort University, Leicester

My brief is to look at what has been happening in last ten years. I feel as though I am suffering from 'parrotism'! We have been reiterating the problems and the solutions for ten years or so. PEGS and the Chapmans have been tenacious and have achieved much, and we thank them. They have always been positive and have communicated with government agencies, with chemical companies, with medical professionals, and scientists, and they have always wanted a dialogue to take things forward.

There are some promising signs that momentum building up. Are the ministers going back to tackle important issues, or are they going backwards in defeat. We will see. In the draft version of *Developing an Occupational Health Strategy for the UK*, HSE, there was a section saying 'ten years ago it would have been difficult to predict the emergence of important issues such as E coli 0157, nvCJD, OPs, repetitive strain injury, back pain and stress'. But pretty much all of them were being flagged up. There were groups of people concerned about them, and no-one was listening. So there is a problem with institutional inertia. What we have been seeing for a long time is pusillanimous set of civil servants who have not been addressing the problems as they should have been. Many people would expect the HSE to be advocates of workers' health. What has happened very often - but it is changing - is that they have dismissed the people as cranks, not taking them seriously.

Progress lies in:

- using *sentinel* events, for example, the campaign by Christa Hagstedt, Swedish occupational physician, to find out what information GPs had for diagnosing pesticide poisoning
- involving the workforce
- recognising that risk management is *not* value-free

Should use precautionary principle

- all scientific work is incomplete

The PEGS project provides information about pesticides, and puts exposure sufferers in contact with one another and with sympathetic professionals

The Pesticides Trust

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- cannot ignore what we *do* know

Lack of progress:

- we still have food producing industries setting standards on pesticides - will the new Food Standards Agency take it on?
- no precautionary policies - though some industries years ahead of legislators
- no information to fill research gaps on mechanisms of toxicity, impact of pesticide cocktails, immunotoxicity, reproductive toxicity etc

The World Health Organisation strategy is that it is cheaper to *prevent* health and environmental problems by going upstream and seeking to find sustainable approaches in use of chemicals.

The perpetrators of contempt for human and animal life - the pesticides industry - still have too close a relationship with the Health and Safety Executive and the medical profession.

DAVID FARRANT

Dow Agro Sciences

What has changed in last ten years?

Pesticides industry has changed:

Increased regulatory activity - the development of the Pesticides Safety Directorate, FEPA and COPR and a European Registration Scheme. Increased monitoring includes improved user education, changes in products and applications, crop assurance schemes, pesticides forum, the HSE's Pesticides Incident Panel, and a move to Integrated Crop Management.

Better training for users, such as certification schemes for spray operators, and British Agrochemicals Association campaigns.

Products can now be applied in grams per hectare rather than kilos per hectare, and packaging has improved. COSHH and protective clothing have improved safety.

DR HOWARD MASON

HSE Laboratory, Sheffield

Referred to HSE's monitoring of 2800 blood cholinesterase subjects from different occupations and situations. Blood cholinesterase levels are meaningless without a baseline comparison, which can vary between people. The efficiency of hormone is the important factor. The return to baseline can take 30 to 40 days after exposure, or for some people, 100 days. Low level exposure can lead to OP residue build-up in fat, which can cause problems for monitoring. Individuals may have different genetically determined 'safe' levels but his work cannot say that is 'safe'.

JOHN WILSON

Chemical Injury Information Network, USA

The CIIN was formed nine years ago, by my wife, Cynthia Wilson, and has members in 35 countries or more. Our newsletter is *Our Toxic Times*.

The CIIN takes pride in being able to provide reliable information that is not only educational but that can be successfully used in legal confrontations. That is an area that gains in importance as more and more people become victims of toxic exposures.

Cynthia was diagnosed in the autumn of 1987 with Multiple Chemical Sensitivity, caused by long-term, low-level exposure to formaldehyde. She started trying to find out 'What did the government know about the health effects of toxic chemicals and when did it know it?' Her research stayed within the confines of mainstream research and became the framework that has made CIIN such an effective clearinghouse on toxic human health issues. She wrote the book *Chemical Exposure and Human Health.*

CIIN was the first group not to align itself with any particular medical discipline. The first advantage of this is that detractors of Multiple Chemical Sensitivity have not been able to dilute CIIN's basic message by discrediting our group by association. We have also had access to more government agencies than any other MCS support group.

Our ultimate goal is to mainstream MCS.

PROFESSOR KENTON MORGAN

Liverpool University Dept of Vet Med

What are the alternatives to OPs in relation to blowfly strike and sheep scab?

Scab: decline from about 2000 cases a year in 1900 to less than 200 a year in 1990 - very good epidemiological record. The State Veterinary Service record has been exemplary. Eradicated scab until 1972, then sheep imported from Ireland and a few cases seen since. Before deregulation, *had* to notify of scab cases, now don't have to, so levels may have risen up to around 2000 cases a year again. The only control for scab is that you can be prosecuted for an animal welfare offence.

Ecology of parasites and host susceptibility: little is known. Still cannot even grow the scab mite *off* the sheep. Research long overdue.

May in future be a vaccination for sheep scab.

Blowfly: the larvae spend the winter underground. Could the fly population be reduced as an alternative control of blowfly strike?

The philosophy is changing and increasingly accepts the presence of low levels of parasites.

DR VIRGINIA MURRAY,

National Poisons Information Centre, Guys

The National Poisons Information service in London is one of seven services around the UK. The others are based in Birmingham, Leeds, Newcastle, Edinburgh, Belfast and Cardiff. The information about each patient is recorded at the time of the enquiry. This record will include the name of the doctor who called, of the staff nurse, of the medical practitioner who has rung, and, wherever possible where we can take it, the name of the patient who has been exposed. This information is then entered onto a confidential database which is held by the Unit under the Data Protection Regulations. This information is what we then base our Annual Report on, which goes to the Department of Health. We also pass the summary information onto the EC, for the annual deposition in the EC on numbers of poisoning enquiries we've received.

Pesticide enquiries are a relatively low number of this total, approximately 1000-2000 per annum. These then need to be broken down by duration of exposure, symptoms. One of our staff has been given the task of following on all these enquiries, wherever we can, to try and determine the outcome. This is then collated, to build our information, to make sure we can understand more about

the problems of pesticides about which we have received enquiries about and also to make sure that this data can then help to generate information which can then be fed back to government departments.

I am very glad that Dr Karalliedde has come with us today. He is on short-term secondment with us and we are truly honoured that he has joined the London Medical Toxicology Unit to assist us in research in this area. The research that goes on into acute pesticide exposure is incredibly difficult and complex to collate and pull together, and the information we can generate over a period of time is one of the things which Dr Karalliedde has been good enough to assist us in.

How do we transmit this information to other agencies? Well, we can only provide them with numbers. We can't provide them with names, because of patient confidentiality, which is extraordinarily important. This system is similar in the other Poisons Information Centres, but they are smaller with fewer resources, which causes us concern.

There has been a major review by the Department of Health of national poisons admissions services which was agreed by the DoH Chief Medical Officer Jeremy in April this year. The aim is to try and have - I am told - three poisons centres across England which will belong to Birmingham, and, we are told, that they are thinking of closing Leeds and transferring some of those resources to Newcastle. Medical toxicology is a completely under-supported, under-recognised resource in this country.

Questions from the floor

David Farrant, Dow Agro Sciences: One of the problems for us as manufacturers is the lack of information coming back. Am I right that there is no common database between the Poisons Information Centres?

Dr Virginia Murray: It hasn't been done to date.

David Farrant: And basically, from what I'm aware, we don't get reports back of even the number of incidents, not even about our own products, so it is an area in which we would be interested to learn more.

Dr Virginia Murray: We'd be delighted to cooperate, but we wouldn't do it by product, we'd do it by generic group.

Joanna Wheatley: About ten years ago I was a NFU rep. I was contacted by a good many farmers who were desperately ill. They thought they were going to get some kind of recognition and help from your Unit. One of the things they had to do was to fill in a 120-page questionnaire of psychiatric questions, such as 'Does your face change when you look in the mirror?', 'Do you dress in an affected fashion?', 'Do you believe in UFOs?', etc. Why did you do this?

Dr Virginia Murray: We are very much a research unit. Our job is to try and understand what is happening and why. One of the major complaints with pesticide poisoning was that it is all in the mind. We had to try and prove that it wasn't. In order to do that we have been working with psychiatrists, partly to address that issue and partly, because so many patients came to us in a very distressed state, to assess whether or not we could actually help them through other means, because unfortunately the record for toxicology is pathetic. Unlike our colleagues in microbiology, who have antibacterial drugs, we have few antidotes. They are effective at the time of exposure, with the exception of the trace elements where we can actually chelate and remove those more effectively later. Our job is to try and pull this data together and to contribute to the literature, not only in the UK, but elsewhere in the world. We have been trying to develop systems and we are very grateful to those who came, because they provided us with help in trying to work out what to do next.

We have been working in collaboration with a psychiatrist who is part of the team. We have reviewed the questionnaire and many of the questions have since been dropped from the initial issues. We've tried hard to find more appropriate tools that will feed better research questions.

There is no ideal solution. The best solution is prevention.

We try extremely hard to recognise the toxic insults, and to minimise the harm by perhaps removing someone from exposure, or improving PPE for those in occupational situations, and discussing it with relevant agencies. Our job has been very much to try and develop techniques that have not been available from other medical toxicology sources, and we are very grateful for your support in coming to the Centre. We have managed to set up some systems which have improved the lives of some sufferers, haven't we Enfys.

Enfys Chapman: Yes. I should think about ten people have complaints against the Poisons Centres, and I can think offhand of probably 50 people who have benefited greatly, and from the psychiatric support as well, because your psychiatrist is very helpful.

Dr Virginia Murray: We requested from the DoH resources to set up an information line for members of the public, but they said we could only provide information to the medical profession and emergency services. But you do have a new resource: NHS Direct. Milton Keynes have started one and there's another starting in Lambeth, and there's one starting in Manchester, where you might be able to get information and advice. It is being run by nurses, so they can at least take initial concerns and initial information. It will ultimately be, by Frank Dobson's request, something that might spread much further afield. We hope the nurses will be trained through the NPIS, so they will be aware of some data, and we are reviewing the data they will hold.

As a result of the review, we are also at last doing an outreach programme to medical professionals including A&E departments, which have not so far been trained on how to respond to poisonings, a big concern of ours. The third most common reason for admission to A&E is poisoning (anything from paracetamol to carbon monoxide). We hope by doing so we will get many more samples taken at night time, because we are expanding our laboratory services. At the moment we are running a test period for 3 months to include better analyses. We've had a major drive to develop new techniques. We can't tell you that it's really going to be a new service until January.

In USA there are 35 accredited poison units meeting in Florida at the moment. They are trained in dealing with all chemical exposures - pharmaceutical, plants, fungi, all pesticides and other environmental exposures.

From the floor: There's a difference between acute poisoning, which is being recognised more and more now, and chronic poisoning. The day to day problems of chronic poisoning year after year is what we take to our GPs, the ME Association helpline, the Cardiomyopathy Association, and we don't usually get any help, except from people who are fellow sufferers.

Many of us over the last decade have been driven to consulting private doctors about all this, because of the complete brick wall in the NHS. Is this not one of the reasons why you are having such problems with your reporting back?

Dr Virginia Murray: The private doctors are just as likely to ring us up, but they don't tell us they are charging you. We don't charge them - we wouldn't dream of it. We do document and we feel it is important to feed back this information to the manufacturers and so on. We have been limited to working with the Pesticides Inci-

dents Appraisal Panel (HSE), which is a wonderful resource.

From the floor: I still feel very much alone with the voluntary organisations in my 25 to 30 year illness, and I do think it is time we received relevant treatment from the NHS. The research should already have been done, it shouldn't just be starting up at this stage. An awful lot of us have been spending limited resources which we will be needing in our old age on private treatment.

Question from Professor Morgan: Could labels be more specific - animal poisonings caused by ignorance.

Dr Virginia Murray: We will discuss that and see what is possible.

From the floor: Could the NPIS tell the Samaritans the best way to help exposure victims? They are the only people available at night.

Dr Virginia Murray: We don't have links with the Samaritans at present, but perhaps someone could come and talk to us and we'd see what we could do.

From the floor: Who funds the NPIS? Are you completely independent of the drug companies?

Dr Virginia Murray: The NPIS is funded directly by the DoH, though we have taken on some work from pharmaceutical companies for extra funding. Some of the work is also paid for by coroners because we want the cause of death to be absolutely clear if a poison is associated with it. Dr Volans, Director of Guys and St Thomas', is funded in half by working for the Medical Division, and the other half from the NHS for the information service. I get half funded for the information service but also for the chemical incident response service, a new service we have had to set up for the DoH to look at chemical incidents, disasters, fires, land contamination, food poisonings etc, for which we charge the 73 Health Authorities £2,500 each per annum. The research funds come from anybody, such as the British Library, the Chinese Herbal Medicine and Education Centre at Kew. Other research programmes we have been looking at include drug abuse. That is funded from within the Unit, as was the pesticides project. The only funding we have received from outside for a pesticides project was from the VMD when we did our initial study to look at acute exposure to sheep dips resulting in acute poisoning: not at all surprising but we had to prove it.

We also have Dr Wilkes, who works half time for Zeneca and comes to work with us for one half day every two weeks.

OPEN QUESTION AND ANSWER SESSION

Joanna Wheatley: What do people here want from PEGS?

From the floor:

- Diagnosis
- A network of local support groups
- A newsletter
- A support telephone line
- Practical advice and testing to legitimise
- Disseminating independent information to, for example, schools
- Intercommunication with, for example, GPs

From the floor: Does the panel think that public pressure for pesticide reduction will overtake our society's love affair with pesticides created by intensive agriculture before Multiple Chemical Sensitivity becomes a national disease?

David Farrant: I think it has happened. Public pressure is having a big impact and will continue to do so. It's affecting both the regulation of our business and everything else.

Dr Virginia Murray: MCS is not just caused by pesticides. We are grateful for the pressure because HSE is now in a much better position to respond actively and we have been able to delegate more staff to do this work. So please keep it up.

Chris Wise, NFU: There are a lot of external reasons why pesticide usage will fall. The speed at which it falls is dependent on a good many things, and world trade factors will have a lot to do with it. There is a great willingness in the farming community to reduce use, and this country leads in that respect.

John Bouckley HSE: I think it will depend on pressure from the paying public. My personal view is that if there is a downturn in the economy, there might be a total reversal, because people want cheap food.

Alan Dalton, T&GWU: Patients in general and support groups for sufferers of asbestos poisoning, solvent poisoning, RSI - all of which have been denied by the medical profession - have held the same debates, and have had the same anger. These groups have forced all of us on this platform to be responsible. I'm optimistic in this sense.

Enfys Chapman: I'm optimistic. Things have changed so much in the last ten years, so just keep getting together, people.

From the floor: Glyphosate - was told by doctor allergy, but she is concerned about toxicity.

John Bouckley, HSE: We investigate all alleged ill-health incidents a year. HSE enforcement agency only - not medical experts. Pesticides not main HSE concern but we recognise political and public concerns about them.

***Enfys*:** Malathion used in headlice products the most complained about substance to PEGS; glyphosate second most complained about.

From the floor: Hugh Berger - shame on those who do not enforce the law against those who misuse pesticides. Do we have to sit here and listen to your half-truths. You patronise and degrade patients. HSE compliance being used by misusers of pesticides in court of law against us, even though their pesticides caused my daughter's and my illness.

Alan Dalton T&GWU: Last year's Pesticides Report: of over 80 cases investigated, the only one confirmed child which had had pesticides poured all over them - several highly qualified doctors confirmed that exposure had taken place. In another case fine only imposed because otherwise HSE would have been taken to court - mother of child was barrister.