Submission to People's Inquiry – 91
Exposure:
Oral testimony:

(Currently unassigned)

End

Submission to People's Inquiry – 92
Exposure: n/a
Dr Ulrich Doering
Oral testimony transcription only

End

Submission to People's Inquiry – 93
Exposure: lived & worked in spray zone
Penny Hulse
Oral testimony transcription only

End

Submission to People's Inquiry – 94
Exposure: lived in spray zone
Peter Malcouronne
Oral testimony

Submission: Peter Malcouronne
Wednesday, March 22, 2003

I'm here on behalf of my mother, Vivien Shapcott, who died last July of motor neurone disease. It was my mother's belief that her disease may have been caused, or perhaps triggered, by the Foray 48b Painted Apple Moth spray programme.

I wrote a story about my mother's illness, and our quest for some answers, or at least a few numbers, in the January issue of *Metro* magazine (copies of which you have before you).

It's a long and often meandering tale and I certainly don't expect you to read it now! So let me start with a bit of background:

1. My mother lived on Henderson Valley Rd, beside an abandoned 18-acre orchard. The plane would often spray the orchard, then come back a little later for a "double-up" dose. Her exposure to the spray, therefore, would've been higher than most.
2. Mum worked as a special needs teacher at Kelston Girls High School. She would often get sprayed again while she was work.
3. She reacted badly to the spray. Her breathing was invariably affected: she would be short of breath, sometimes suffering an asthma-like reaction. She had severe diarrhoea. She vomited once. And when she inadvertently rubbed her eye (after touching the spray-flecked roof of her car), it streamed for a fortnight.
4. She was diagnosed with motor neurone disease (MND) in December 2004.
5. She died of motor neurone disease in July 2005.

As you're probably aware, there is no known cause of motor neurone disease. But environmental factors are suspected, with organophosphate pesticides in particular, being likely suspects.

Just three MND clusters worldwide have been found, including the Gulf War veterans cluster identified by Dr Robert Haley from the University of Texas Southwestern Medical Center. Haley's study, published in the prestigious journal *Neurology*, found that veterans from the first Gulf War were three times more likely to develop MND.

The likely cause? Haley: "The best thinking in the ALS (MND) research world is that ALS only occurs in people with a rare genetic susceptibility. If you have that genetic makeup and you are exposed to many years of environmental toxins of one kind or another – and no knows what they are – then you get ALS."

Haley noted that some Gulf War vets had been exposed to sarin gas. "And guess what sarin gas is?" Haley asked. "It's an organophosphate pesticide."

My mother, a woman with a keen interest in science, was well aware of the possible link between the spray and MND. Her suspicions were fuelled by rumours of other people with MND who lived nearby. The young man in this 30s who lived a couple of hundred metres from my mother on Henderson Valley Road. The friend of a friend who lived a couple of kilometres away in Oratia. The two parents from Swanson School who had been diagnosed in the last 18 months. The friend of Mum's home-helper.

The speech therapist who came round to help my mother with her dysarthria (slurred speech from weakened throat muscles) said that she saw "about 10" MND patients out West. "I've never had more than one at a time," she said, shrugging her shoulders. "It's weird." Then a nurse from West Auckland hospice told Mum that they had "six or seven" MND patients on their books, again many more than they'd had before.

Of course, you have to be very careful when trying to make a causative association between an event, such as the PAM spraying, and a possible outcome — a surge in MND cases.

And so this became a story about numbers. How many people in West Auckland had MND? And had there been in increase in incidence in recent years? Astonishingly, no one knew. No one could tell us how many West Aucklanders had MND. More astonishingly still, the authorities blithely dismissed the possibility of a cluster, while freely admitting they had no idea how many people had MND.

As you may already have heard, in February 2005, Hana Blackmore and Meredith Youngson requested that the Auckland Regional Public Health Service initiate a cluster investigation into the prevalence of motor neurone disease in West Auckland.

They heard nothing back for six months. Blackmore complained to the office of the Ombudsman who replied, on July 12, (coincidentally the day mother died) that the service "had been in touch with both Ms Blackmore and a neurologist working with the regional neurology service.

"It appears that no increased incidence of MND has come to the service's attention."

But Auckland Public Health hadn't contacted Blackmore. I asked Dr Virginia Hope, medical officer of health for ARPHS to explain how the possible cluster had been discounted: "A former Medical Officer of Health from ARPHS (David Sinclair) made some enquiries early this year and I believe the opinion given to him by a neurologist indicated there was no awareness of a change in the rate of MND diagnosis in West Auckland," she wrote back to me. "The Motor Neurone Disease Association have also indicated to me earlier in the year that they are not aware of any sudden changes in rate in Auckland."

I pressed the issue of a West Auckland cluster with the MNDA's Sue Leader and received a blunt reply: "There isn't one." She's even more emphatic when I asked her about a possible link between the PAM spray and MND. "There is no link. There is no link. There is no link."

But how could the MNDA say this with any certainly without knowing how many people in West Auckland have the disease? Surely the only way to establish, or to dismiss, a cluster is to work out what the numbers are and compare them to what they you might expect them to be.

I could not get the numbers. But then, just before my story went to press, Dr Alison Charlston, head of the Auckland MND Clinic, told me that she now knew how many West Aucklanders had MND. Dr Charlston had spent the past six months trawling through her records, in her own time I might add. As far as she could tell, there was no cluster.

I reported her findings in my story, but I must confess to feeling a little uneasy. While I in no way wish to impugn Dr Charltston's expertise, I did wonder about the methodology used. As far as I know, there is still no historical data available that would allow even the simplest comparisons to be made.

I was never going to be able to prove that my mother's MND was caused by the spray. But that's almost beside the point. The onus should not be on ordinary people, people like my mother, to categorically prove that the spray is dangerous. It ought to be on the authorities, the New Zealand government, to prove that it is safe.

This they were never able to do. Indeed, there is considerable evidence that it's far from safe.

In early March 2005, my mother was passed a copy of the manufacturer's instructions for Foray 48B by a woman who'd been given the document by a friend who worked at the wharf where Foray 48B was unloaded. The instructions were stuck to the side of the 1000-litre vats of the spray. While the Government wouldn't tell West Aucklanders what was in the spray — that was commercially sensitive information the

American manufacturer didn't wish to share — we had been told that we had nothing to worry about. So it was with mounting fury that my mother read aloud to me the instructions inside the document.

"Keep unprotected persons out of the treated areas until sprays have dried."

"Do not apply this product in a way that will contact workers or other persons, either directly or through drift. Only protected handlers may be in the area during application."

"Do not enter or allow worker entry into treated area during the restricted entry interval (REI) of 4 hours."

For Mum, this document was the smoking gun. "It's disgusting what they've done to us," she seethed. When she filled out a medical insurance form in April, she put in "painted apple moth spray" as the "cause" of her illness. And when a well-meaning soul parroted the official line that the spray was a naturally occurring organic spray, Mum sneered: "Yeah, natural and organic all right. Just like anthrax!"

The angry reaction of a dying woman? Perhaps. But my mother was not an unreasonable person. She wanted answers, but accepted she might not get them. But she did not want to go to her grave with the knowledge that this spray, the spray that had caused her so much discomfort, could be used again, without the consent of those who had to wear it.

I'll finish with her words:

Trust us. Trust us they said. The spray is safe. Only it wasn't. And I'm left wondering why it is that a New Zealand government would place the interests of an American chemical company above the interests of its own people. To this, I have no answer.

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APPENDIX 1

MOTHER OF ALL BATTLES
(Un-edited version of the article published in *Metro* magazine, January 2006)

When Peter Malcouronne's mother died of motor neurone disease four months ago, she was convinced her illness was one of a "cluster" of cases caused by the moth spray programme in West Auckland. He describes her last battle and his search for the figures that could finally confirm or dispel his mother's suspicions.

In the end, I guess, my mother needed someone to blame for her death. Ravaged by motor neurone disease, she went from being the healthy, headstrong battler I'd loved and fought with for 34 years — the mother who once memorably proclaimed herself a mother to be feared and revered — to a withered, crippled old woman. She couldn't walk without the help of a walker. She couldn't eat properly. She had trouble breathing. She had to be lifted into bed.

The destruction of Vivien Shapcott took just six short months. No one thought she would succumb so quickly. Though just 5ft 2in, my mother was a formidable woman — the Blonde Bomber — and her bullishness would fill a room. She was a fighter, she'd bow to no one, and she'd take on all sorts of causes.

Like the infamous Sandal Wars. Last year, the Board of Trustees at Kelston Girl's High School decreed that sandals would no longer be part of the school uniform as the girls were wearing them, straps down, like jandals. Mum, a special needs teacher and also seventh-form dean at the school, feared for the girl's feet on hot summer days. The board buckled.

A few months ago, she took them on again over plans to change the school's name to Kelston College for Girls. Too weak to type, she dictated her disdain to me. The proposed change was, she said, pretentious and unnecessary. "This is not Remuera," she raged. "This is West Auckland!" Mum lost a narrow points decision this time — the school is now called Kelston Girl's College.

Now my mother circled the wagons for one last glorious battle. She became convinced that her illness was caused by Foray 48B, the painted apple moth spray that had rained down from West Auckland skies 47 times over the past few years. She had heard stories of a cluster of motor neurone cases in West Auckland, stories that enraged her. She vowed to fight those responsible. She conspired with activists, met the Mayor, bailed up local MP Chris Carter at an eco-fair and even appeared on television. Her last months disappeared into a furious storm of clusters, chemicals and rates of incidence. She took on this fight the way she had always taken on fights: wholly and inexorably and with a force and energy that consumed all those around her. Nothing could shake her when she was determined.

I have written this story, or at least a similar story before, in the pages of this magazine. My father died of prostate cancer in 2000 after a long, painful two-year struggle. It's a beat I'd rather not be covering. But I promised my mother that I would continue her fight, that I would research this supposed cluster, sift through the anecdotal evidence and try and find out, authoritatively, how many people have motor neurone disease in West Auckland. Incredibly, disgracefully, no one seemed to know.

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The story starts a year ago: three days before Christmas 2004. Mum called a family meeting at her Henderson home. My two youngest brothers, Matthew then 20, and Alex, 15, were already at home, possibly playing Counterstrike, and they had no idea anything was wrong until they saw the evident distress on my mother's face as she walked up the drive towards us.

Up until 2004, my mother had enjoyed pretty good health. But towards the end of that year she'd started feeling tired. Really tired. She also noticed weakness and tingling in her right arm, something that was attributed to stress or RSI. She was given an arm brace that didn't seem to help much, but she wasn't too worried. The Christmas holidays were just around the corner, time in her words, to "recharge the batteries."

But by December Mum was having trouble walking up hills. She had difficulty unscrewing jars and was missing the odd note when she played the church organ. She was unable to blow up a balloon at a kid's birthday party. She also had strange muscle twitches in her legs. Reassuringly, there was a likely culprit — a campylobacter infection Mum picked up her after eating some half-cooked chicken. It seemed she had post-infectious inflammatory neuropathy, which sounded dastardly and was debilitating, but only temporary. To confirm this diagnosis, a neurologist arranged for my mother to have an MRI scan, lumbar puncture and electromyography (EMG) test. All fairly routine.

She went into Auckland Hospital to get the results. The neurologist said: "I wish I could tell you that you had cancer of spine," she said. "You have motor neurone disease."

Now my poor sob-racked mother was trying to break this news to her four sons. In her hand, scrunched up, she held several MND brochures. I'd later read through them, read that MND is an invariably fatal paralytic disorder caused by the destruction of motor neurones in the motor cortex, brain stem and spinal cord. These motor neurones control the muscles that enable us to move around, speak, breathe and swallow: with no nerves to activate these muscles, they gradually weaken and waste.

I would learn that motor neurone disease is actually an umbrella term for several variants of muscle-wasting, neurological disease. The most common form, in around 70% of cases including my mother's, is Amyotrophic Lateral Sclerosis (ALS). The unwieldy moniker is revealing. Amyotrophic is derived from classical Greek — A is "no", "myo", muscle and "trophic" translates to "nourishment." No muscle nourishment.

Mao Zedong died of motor neurone disease. So did the actor David Niven, the bluesman Leadbelly, jazzman Charles Mingus and Lou Gehrig, the famous first baseman, who died in the late 1930s (MND is also known as Lou Gehrig's Disease in the US). Perhaps the most celebrated MND case is the theoretical physicist Stephen Hawking. In a sense he represents the ultimate expression of the disease: his body has dissolved, the muscles wasted away, leaving behind a brain (until recently it was thought that MND did not affect intellect, memory or the senses though new research suggests that half of all MND patients suffer some cognitive degeneration). But in other respects, Hawking's experience is entirely atypical: diagnosed in 1963 when he was in his early 20s, Hawking was unusually young. He is also the longest known MND survivor, having lived with the disease for 42 years. Since the average lifespan of a newly diagnosed MND patient is just 14 months, this is a remarkable achievement.

More commonly, MND follows a predictable and savage path. Yale University's Department of Neurology:

"The primary symptom of ALS is one progressive weakness, usually beginning in the legs… Eventually the weakness spreads to involve all four extremities, the muscles of the trunk and abdomen, and the bulbar of the face, mouth and throat. Muscles of eye movement and bowel and bladder sphincters are not affected in ALS… sensation, co-ordination and cognition are also spared.

"The course of ALS is one of relentless progression and spread... Death from ALS results from weakness of respiratory muscles. When patients reach the stage where they can no longer breathe on their own, they are faced with the choice of either indefinite mechanical ventilation or imminent death."

With a prognosis this dire it's fortunate that MND is incredibly rare, a "one in a million" condition. Well that's the popular perception anyway. Its prevalence is relatively low: between five and seven people per 100,000. But the incidence — the number of new cases added in a year — is relatively high: between 1.45 and 2.7 per 100,000. MND patients don't tend to last long.

Remarkably, no one seems to know how many New Zealanders have MND. There are no reliable stats. While the Motor Neurone Disease Association (MNDA) collects information on people with MND, they concede that "not everybody diagnosed with MND is aware of, or referred to us, and indeed, some people choose not to receive this support".

MNDA National Executive Officer Sue Leader says that they work with between 160 and 180 people per year, though she estimates the total number of MND patients nationally at between 250 and 300. Since MND is not a notifiable disease and there is no national MND register, Leader says her estimate is based on international etiological data. "There's been no particular studies in New Zealand."

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Those first few days were a surreal time. We had our traditional family Christmas, which I filmed for the first time. "Put the bloody camera away," my mother snapped. "I'm not dying. I'm not some bally monkey at the zoo." My youngest brother and I both had our birthdays in early January and these were unbearably sad occasions, though we all pretended we were having a great time.

A couple of weeks after her diagnosis, Mum was visited by a fieldworker from the MNDA. The fieldworker, an older woman whose daughter had died of MND, made the mistake of saying she'd bring along a hospice nurse "next time". My mother was incensed. "I'm not dying of motor neurone disease," she proclaimed. "I'm living with it."

This would become her mantra, something she would grimly hold on to in spite of all evidence to the contrary. I did my best for her. I spent hours on the net, navigating my way through shameless quackery – quantum boosters? – trying to find out more about this disease. I came across the website of Jarrod Cunningham, the 35-year-old former All Black trialist who had been diagnosed with MND in 2002 while playing rugby professionally in England. Cunningham takes a holistic approach to his illness that he says is based on Chinese Chi philosophy. He exercises heavily, training six days a week on a Power Glide machine that works his body's muscles. He also has massage and acupuncture three times a week. "Exercise is vital," he told me by email. "There is a saying: "If you don't use it, you lose it." This applies to your brain, mind and muscles."

Cunningham's approach to regenerating muscles made sense to me. If you can strengthen part of a muscle surely you can compensate, at least for a time, for the other parts of the muscle that are weakening. The so-called experts think otherwise. "There's a misapprehension of what's going on," says the MNDA's Sue Leader. "It's not the muscle dying, it's the motor neurones that cease to communicate to them and they atrophy for that reason. It's not the muscle per se."

For his part, Cunningham has nothing to do the MNDA. "The MNDA, here and in the UK, have no idea how to help PALS (people with ALS)," he says. "Giving someone a wheelchair doesn't help — it programmes their mind to give up and their body to shut down."

My mother was more attuned to Cunningham's philosophy. I encouraged her to start an intensive exercise programme — water-walking, exercycling, weights, even goddamned Pilates. But Mum was finding it increasingly difficult just to shower. The disease was there for all to see: you could watch the fasciculations — muscle twitches — in her calves and arms from across a room. This sensation would stop my mother from sleeping and also caused her considerable psychological anguish: she could never forget, for more than the briefest moment, that she had MND.

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Nor could we forget. MND seemed to be in the news all the time. In late January, the terribly sad case of Andrew Morris, the 39-year-old Hamilton man who wanted to starve himself to death, featured on *Close Up*. Mum tuned in and watched this poor man, ravaged by MND, lurch around with his walker, and try, unintelligibly to talk. "As soon as I was diagnosed, I was a walking dead man," Morris, via his caregiver, told the *Herald*. "There is no sense in putting everyone though more suffering. Once quality is gone, I don't see any point in longevity."

There was the possible MND cluster in Nelson where seven port workers have recently died of motor neurone disease. The fumigant methyl bromide seemed to be a common factor but a study conducted by Ed Kiddle, Nelson medical officer of health, argued that these deaths were due to chance (interestingly, Kiddle's "methodology" has since been criticised by Canterbury University pro-vice-chancellor Ian Shaw).

In March, *Close Up* ran a more positive story. Willie Terpstra, the bubbly 64-year-old woman from Rotorua was off to China for an olfactory ensheathing cell operation: cells from aborted foetuses were to be injected directly into her brain. Some of the initial reports were almost miraculous: those who couldn't walk were said to walk again, those who couldn't talk, talked once more.

Mum would later meet Willie and, inspired, decided that she, too, was going to go to China. I was tasked with finding out more about the procedure. What I learnt wasn't encouraging: the maverick surgeon Dr Hunag Hongyun offered no follow-up care, didn't track his patient's progress and his work hadn't been peer reviewed. He hadn't done a double-blind study and the contact email address — iloverosepink@yahoo.cn — hardly filled one with confidence. I kept most of this information to myself, not wanting to ruin my mother's Chinese dream. She was so sick by then she couldn't have travelled anyway.

When Mum was diagnosed, she'd been given a life expectancy of one to five years, but it was becoming apparent that she would struggle to even make the year. Her form of MND was particularly aggressive. It usually starts in the extremities — the legs or the arms — but my mother's MND attacked her torso. Her back and chest muscles wasted away and she couldn't hold herself up, even when she was strapped inside a corset. Her diaphragm was weak — she had trouble breathing — and her ribs kept popping out. She couldn't sleep. And yet, in spite of all the evidence, Mum pressed on as if things were normal. She got an electric wheelchair and a special microphone so she could continue teaching. It was stubborn, brave, almost heroic, but it was also delusional. Her disease was moving relentlessly -- every day she was weaker than the day before -- and yet no one seemed to know what to do. I decided to write her a letter.

"Our family is in real crisis," I said. "We're muddling along at the moment, all of us, as if oblivious to what is happening before our eyes. You could say its denial; you could say its despair... (but) there is little urgency. There is less co-operation. There is no plan.

"We need a plan because without one your life, and ours too, is being ruled by your illness. It is the last thing I think of before I go to sleep each night and the first thing I think of when I wake. Of course, my pain and sorrow is in no way comparable to yours, but this feeling of utter impotence, of being unable to do anything to help you or slow the progression of this disease is overwhelming."

I tossed out a few Nike slogans, told her how we had to regroup, fight this as a family, take the power back. I talked about taking her to Gisborne where she'd never been, and getting *The Office* and *Les Miserable* out on DVD (someone had told me that comedy and music are the last pleasures of the dying). I even dared mention the *hospice* word.

It was probably just as well that I didn't send the letter.

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As hopes of a miraculous cure faded, my mother's attention turned elsewhere. By March, two months after her diagnosis, my mother had decided that the cause of her motor neurone disease was the Painted Apple Moth spray, Foray 48B. Like many other West Aucklanders, suffered from asthma-like symptoms, nausea and diarrhoea after each spray run.

Her suspicions were fuelled by rumours of other people with MND who lived nearby. The young man in this 30s who lived a couple of hundred metres from my mother on Henderson Valley Road. The friend of a friend who lived a couple of kilometres away in Oratia. The two parents from Swanson School who had been diagnosed in the last 18 months. The friend of Mum's home-helper.

The speech therapist who came round to help my mother with her dysarthria (slurred speech from weakened throat muscles) said that she saw "about 10" MND patients out West. "I've never had more than one at a time," she said, shrugging her shoulders. "It's weird." Then a nurse from West Auckland hospice told Mum that they had "six or seven" MND patients on their books, again many more than they'd had before.

Hana Blackmore had also heard the rumours. The 61-year-old independent community health researcher and anti-spray campaigner claimed to have identified a possible cluster of MND cases in West Auckland in early 2004.

Blackmore had heard from a source — a friend of a health professional caring for a recently diagnosed patient — that there had been "some sort of a statistical paper" published recently that she'd seen and that "horrified" her. "It showed that, up to Christmas (2003), 25 new cases have been diagnosed in West Auckland alone," Blackmore says. "As the generally accepted figures for MND are 1-2 per 100,000, this is either a horrendous misquote — or we have a disaster on our hands."

Blackmore hasn't been able to confirm this story. Neither have I. But it was consistent with the gathering weight of anecdotal evidence that seemed to be all around us. It was almost the proof that my mother sought.

You have to be very careful when trying to make a causative association between an event, such as the PAM spraying, and a possible outcome — a surge in MND cases. But although medical professionals are at a loss to explain what causes MND, environmental exposures and stressors believed to be at least partly responsible, and Mum (with me cast as her researcher) was already schooling herself on historical cases where an increased incidence of the disease coincided with prolonged chemical exposure. One study we latched onto, published in the prestigious journal *Neurology*, found that veterans of the first Gulf War, who may have been exposed to sarin gas, were three times more likely to develop motor neurone disease.

Then in early March, my mother was passed a purported copy of the manufacturer's instructions for Foray 48B by the woman who did her eyebrows – who, it turned out, had been given the document by a friend who worked at the wharf where Foray 48B was unloaded. The instructions were stuck to the side of the 1000-litre vats of the spray. While the Government wouldn't tell West Aucklanders what was in the spray — that was commercially sensitive information the American manufacturer didn't wish to share — we had been told that we had nothing to worry about. So it was with mounting fury that my mother read aloud to me the instructions inside the document.

"Keep unprotected persons out of the treated areas until sprays have dried."

"Do not apply this product in a way that will contact workers or other persons, either directly or through drift. Only protected handlers may be in the area during application."

"Do not enter or allow worker entry into treated area during the restricted entry interval (REI) of 4 hours."

For Mum, this document was the smoking gun. "It's disgusting what they've done to us," she seethed. When she filled out a medical insurance form in April, she put in "painted apple moth spray" as the "cause" of her illness. And when a well-meaning soul parroted the official line that the spray was a naturally occurring organic spray, Mum sneered: "Yeah, natural and organic all right. Just like anthrax!"

My mother was on the warpath. She would be the public face of the campaign to ensure that MAF never sprayed again. She would bring the Government down.

In June, Mum appeared on TVNZ's *Sunday* programme where she vowed to stop the spray plane from taking off: "The bastards will have to scrape me off the runway."

"Did they have to use that bit?" she grimaced as we sat watching the telly together, she in her modified lazyboy chair provided by the MNDA.

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I have kept a bunch of my mother's phone messages. Every 10 days I have to re-save them. Some are mundane — "We're taking Grandad out to Valentines... Would you like to join us?" or "There's a shirt sale on at Hallensteins — two collared shirts for $40! ". Others are typically forthright. "How do you ever expect to get a girlfriend when you write rubbish like that?" she says in response to what I considered the definitive article on bachelor theory. But her last message, received July 11, says simply: "Pete. It's Mum. Give me a buzz."

My mother was calling from Waitakere Hospital. Cunningly, I'd ordered her a super-large if somewhat soggy hospital dinner that she had no interest in and so Mum had called me in to eat it.

Now I listen to this last message again. My mother's voice is croaky. She gasps for air. Three days earlier she'd been admitted to hospital with severe breathing problems. She was unable to walk and could barely stand. But Mum had been put on to oxygen and things seemed to be improving a little. After I'd polished off her pudding, we went for a walk along the mile-long corridors of the hospital. I asked her how she'd met my father and she told me, barely audibly, for the first time. Apparently some guy fancied her, but he was stuck with another woman and so he enlisted my father to drag Mum along to a dinner as a sort of fall guy. Unfortunately, for the cunning lothario, Mum and Dad fell for each other.

When I remarked that this usurper would never have been a match for my father's roguishness, Mum rolled her eyes, shook her head, cranked her motorised wheelchair up to full power and took off at 8.4km/ph leaving me in the dust. Good old Mum. We'd have her back home tomorrow.

Mum died on the morning of July 12th, 500 minutes after she left her last message. She was 56.

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Before she died, I promised my mother that I would keep the fight going, that I would investigate the mystery of the West Auckland cluster. And in the months after my mother's death, I found myself becoming as angry and immersed as she had been. How could the authorities blithely dismiss the possibility of a cluster in West Auckland while freely conceding that they didn't actually know how many people had MND? No wonder rumours and conspiracy theories were swirling.

On February, 2005, at a meeting of the Auckland Regional Public Health Service (ARPHS), Hana Blackmore and Waitakere Healthlink rep Meredith Youngson formally requested that a cluster investigation be initiated into the prevalence of motor neurone disease in West Auckland.

They heard nothing back for six months. Blackmore complained to the office of the Ombudsman who replied, on July 12, (coincidentally the day mother died) that the service "had been in touch with both Ms Blackmore and a neurologist working with the regional neurology service.

"It appears that no increased incidence if MND has come to the service's attention."

But Auckland Public Health hadn't contacted Blackmore. I asked Dr Virginia Hope, medical officer of health for ARPHS to explain how the possible cluster had been discounted: "A former Medical Officer of Health from ARPHS (David Sinclair) made some enquiries early this year and I believe the opinion given to him by a neurologist indicated there was no awareness of a change in the rate of MND diagnosis in West Auckland," she wrote back. "The Motor Neurone Disease Association have also indicated to me earlier in the year that they are not aware of any sudden changes in rate in Auckland.

I pressed the issue of a West Auckland cluster with the MNDA's Sue Leader and received a blunt reply: "There isn't one." She's even more emphatic when I asked her about a possible link between the PAM spray and MND. "There is no link. There is no link. There is no link."

But how could the MNDA say this with any certainly without knowing how many people in West Auckland have the disease? Surely the only way to establish, or to dismiss, a cluster is to work out what the numbers are and compare them to what they you might expect them to be. Since the MND Association, by their own admission, didn't know the exact numbers, it seemed odd that Public Health would cite them as an "informal through informed" source.

To get a handle on the numbers, you would need to trawl through neurology records, something that won't happen unless there were enough cases to warrant the expense. Yet there is no way of knowing the prevalence of MND unless you have an investigation. A classic Catch 22.

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Unsatisfied, I contacted Dr Alison Charlston, head of the MND clinic at Auckland Hospital. I'd first met Charlston, a kind and open-minded woman, a fortnight after my mother's diagnosis. Just days before this story was due to be filed, she finished compiling a database of MND patients in the greater Auckland area, a task which took her six months and had to be done in her own time (Charlston has just two hours a week set aside for MND work).

"I'm the only person who would have any idea what the numbers are," she told me. She acknowledges the concern about the supposed West Auckland cluster had been a factor in her compiling the database. "I'm very aware that there's been a lot of hype about this and people are very, very angry," she said. "If I look at the data and the incidence of new cases of motor neurone disease, then there's no evidence whatsoever for of any sudden increase in the number of motor neurone disease patients, either overall or in any particular geographic area.

"To the best of my knowledge, there is no need for alarm."

So how many Aucklanders have MND? "It varies, of course, from year to year. But at any one time, the prevalence is pretty much as you would expect. Between 70 and 80 cases in the greater Auckland area. That's about what you'd expect for a population of a million."

West Auckland, with a population of 189,000 in 2004, could expect to have about a fifth of these cases. "As far as I know," Charlston says, "there are 16."

In other words, there isn't, and never was, a cluster. So why do people think there is? "I think it's been a bit like Chinese whispers," Charlston says. "It started as a sort of rumour and it grew. The first I heard of people were talking of an extra two or three cases. By the end of it, I was being told that there were 28 new cases. And this happened over a period of about six months."

And the alarming "report" which announced 25 new cases? "That's absolutely untrue. That is bunk."

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Now four months after my mother died, hardly an hour passes without me thinking about her last night at home. Terrified about choking to death, she asked me to stay the night with her. I put a mattress down on her bedroom floor and tried to sleep. Part of me wanted this night to last forever, for Mum to somehow hang on and stay here with me, for me, just as she always had. Part of me yearned for morning. While I was exhausted, I knew I wouldn't sleep. I got up and watched my mother, her tired face lit by the bedside lamp she insisted leaving on, listened to her breathe — a staccato "ah-ah-ah-ah" rasp — and wondered how things could possibly get worse. And then I remembered a nurse telling me that sometimes MND patients cease moving altogether, that at the end they'd lie there on a bed, only able to blink. We still had some way to go.

Suddenly I was angry with her. Really pissed off. I was sick of hearing about her bloody illness, something she seemed to almost commentate upon. I wish she had the stoicism of my father who hid his pain from us and confided only to his journal.

And yet since my mother had no partner, no one to hold her close at night, and because she'd stubbornly, stupidly refused hospice care, the burden fell to her sons. My 16-year-old brother, Alex, left school to look after her. It would be up to us to wash her with a flannel each morning, dress her, gently raise her arm to roll on some deodorant, heat the wheatie bags for her dislocated ribs, try and force her to swallow the meal drinks she hated, help her to the loo five times a night then lift her back into bed, all the while listening to her tell you how things should be done.

I was angry, too, about her painted apple moth campaign that I felt had consumed her last reserves of energy.

Now I am more accepting. Now I think, well, I never found the information she hoped for, never took the authorities down, but I did get her some kind of justice. There may not be a cluster of MND in West Auckland, but because eof the agitation of people like my mother, we now know how many people in this city actually have the disease. Its public profile has been raised. And Dr Charlston's database may help researchers understand more about it. It's something.

But I wasn't thinking about any of this as I sat there watching my mother, seeing that it wasn't even 3.00am on her alarm clock. I just wanted this all to be over. But I also wanted time to stop.

I don't know what I was thinking. The whole situation was a shambles. Just a few nights earlier, Mum had got me to type up her school reports. She would dictate the comments for each girl, and I think there about 70, but first she would give me a potted history of each girl. Sometimes her dictates were critical, but then she'd tell me to chop it out because, she said, the girl in question would get a hiding from her parents if she got a bad report. It took us several hours to do this and I couldn't help feeling that there were other things like writing a will that she should've been spending her time on.

Two weeks after her death, I went along to the school's memorial service. The school's hall was packed with girls, some absolutely bereft. Two of her students spoke. One talked of how she'd been a bad kid, off the rails, who hated school. But Mum, she said, was like a mother to her. It was thanks to "Mrs Shapcott" that she was now in one of the top sixth-form classes. After this girl's tearful speech, I felt I understood my mother, her mad campaigns and misplaced priorities, a little better. And I felt proud.

(published in *Metro* magazine, January 2006)

End

Submission to People's Inquiry – 95
Exposure: lived in spray zone
Sandra Ethell
Oral testimony: Yes

SUBMISSION TO PEOPLE'S ENQUIRY - FOR THE PAINTED APPLE MOTH SPRAYING MARCH 2006

The massive ongoing aerial spray program conducted by the New Zealand Ministry of Agriculture and Fisheries to eradicate the painted apple moth in the West Auckland area was a dangerous exercise that disregarded people's health and wellbeing and violated human and civil rights.

I submit that the aerial spraying carried out by MAF with the approval of the government of New Zealand contravened the human rights of people in Auckland and particularly, West Auckland, Waitakere City, also known as "eco city". Two vital ingredients essential for human survival and wellbeing are clean air and water. This implies that access of all people to these two requirements are human rights.

In this submission I wish to talk about our human rights and how the PAM spray program violated them. Also, I will give a personal account of how the aerial spraying affected me.

The UN Declaration was formulated in 1940s when inclusive language was not the norm, so excuse the use of the masculine 'he' and 'him' when people are referred to.

The deliberate and mass aerial spraying of the populace in West Auckland with foreign matter contravenes the Universal Declaration of Human Rights. Nowhere in this Declaration, does it say the needs of trees are superior to the rights of people, nor does it say that in the interests of trade, it is legitimate to risk damaging the health of the people.

No, the Declaration of Human Rights says in ***Article 30***: *"Nothing in this Declaration shall be interpreted as implying for any State, group, or person any right to engage in any activity, or perform any act aimed at the destruction of any of the rights and freedoms set forth herein.*

It is obvious that deliberately polluting the air we breathe is against the wellbeing of the people. As well as respiratory problems and sore eyes, it is on record that the spray affected many people's largest organ, the one that protects the whole body, their skin.

The U.N. Declaration of Human Rights is all about the freedom, wellbeing and dignity of each human person. This surely means that our bodies must not be put under attack by Government agencies who wish to kill a moth.

The preamble to the Declaration of Human Rights says:

…recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.

How dignified and free are people when a government agency deliberately sprays substances that cause them to have spontaneous nose bleeds after spraying, when their skin gets itchy and red, when they are gasping for breath, when they become too ill to go to work, when their children have to be taken out of school, when they have to flee their homes to escape from what is raining down on their houses and gardens? To take away people's wellbeing and freedoms and create a situation of ill health is obviously unjust and undemocratic.

Article1. *All human beings are born free and equal in human rights. They are endowed with reason and conscience and should act towards one another in a spirit of human brotherhood.*

Did people responsible for the decision-making in the PAM project act in this way? No, but they spent lots of taxpayers money trying to convince us what a good thing the aerial spraying was and how safe it was. They lied to us and used our taxes on an expensive advertising programme to broadcast their propaganda.

***Article 2* talks** about how everyone has rights and freedoms… *"Furthermore no distinction can be made on the basis of the political, jurisdictional or international status of the country or territory to which the person belongs…"* In other words, the NZ Government or its agencies do not have special powers to allow the taking away of our freedoms and wellbeing.

None of us were asked if we would volunteer to risk our health and wellbeing for the good of plant life. We had no say and no freedom in this matter at all. Often those in charge took a coldly arrogant and condescending tone when we complained about the injustice of the situation. They steamrolled ahead.

Article 3 says *"Everyone has the right to life, liberty and security of person".* Being saturated in toxic material from the air attacked our life, liberty and security.

Article 5 *"No one shall be subjected to torture, or to cruel or degrading treatment or punishment".* I submit, that spraying toxic material on the population is a form of torture, is cruel and degrading treatment and has been proven to have punished many adults and children.

Article 6. *"Everyone has the right to the recognition everywhere as a person before the law".* I submit that spraying people was treating them as expendable objects.

Article 7 *"All are equal before the law and entitled without any discrimination to equal protection of the law."*

Unfortunately, so far, the law has not protected us. Imagine if we had telephoned the police and said we were under aerial attack. In some places neighbours are not allowed to light a fire because of the various dangers it might cause. We were repeatedly assaulted by the action of aerial spraying of toxins. An agency of the state made war on us.

Article 8. *"Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law".* Who could we go to stop the spraying and to protect ourselves? We were let down.

Article 10. *"Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal in determination of his rights…"* We did not see the New Zealand Government rushing to ensure that this would be investigated.

I submit that the mass aerial spraying in West Auckland also interfered with our rights under -

Article 12 which states that: *"No one shall be subjected to arbitrary interference with his privacy, family, home …"* The PAM spraying interfered with all these aspects of our lives.

Article 13 *"Everyone has the right to freedom of movement and residence within the borders of each state."*

We who were sickened by the spray were forced to move. Our freedom to live a normal life was severely curtailed. We were always wondering, is it a spray day, can I go out? Should I leave the area. Where is it safe to go?

Article 19 *"Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers."*

I would claim that doctors, scientists and MAF employees who saw dangers in the spraying, witnessed the health problems caused by it and disagreed with the MAF process should have been allowed to voice their concerns. If MAF used legal contracts to silence doctors and others then this is patently an illegitimate action and contravenes Article 19. Likewise if any of these people felt their jobs were at risk if they spoke out.

Article 21(3) *"The will of the people shall be the basis of the authority of Government…"*

It's time that the Government remembered that it is there solely to serve the wellbeing of the people and this includes protecting the natural environment using safe means.

Article 22 *"Everyone, as a member of society, has the right to social security… indispensable for his dignity".*

We heard the submission from a man on Wednesday, who lost his business which he had run successfully for years. The sole cause of this catastrophe was the spray programme which made him too ill to continue working. We heard how he would have had to lie to get ACC and say his illness was work related when it was not. He bravely refused to do that.

We heard how he and his wife had to go to the Inland Revenue department and deal with their tax bills. We heard how he could not access a benefit because his wife earned too much from her part-time job.

Is putting innocent law abiding people through this ordeal, promoting their social security and maintaining their dignity as persons?

Article 23 (1) *"Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment."*

We know lots of people had to be absent from work if their workplace was in a spray area or if they have been made sick by the spraying. Spraying over workplaces did not provide just and favourable conditions for those who worked there. In fact in workplaces people have to abide by health and safety regulations and wear protective clothing when handling much less toxic materials than Foray 4b.

Article 25
(Clause 1) ***"****Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services and the right to security in the event of unemployment, sickness, disability…"* As described, the spraying was done arbitrarily and people's standard of living, health and wellbeing were harmed by the spray programme.

(Clause 2) *"Motherhood and childhood are entitled to special care and assistance. All children … shall enjoy the same social protection."* When the PAM spray programme began, there was no special care for mothers and children. Pregnant women, newborn babies and youngsters were all enveloped in the toxic mist without a thought.

My youngest child asked me to tell you today, that her fellow students were drenched in the spray when they were having their lunch at Waitakere College a few years ago. This is obviously a direct violation of *Article 25, clause 2*.

In this community we have heard how children walking to school in the morning, having their lunch breaks and at other times were caught in the spray.

Spraying toxic substances on people was the sort of tactic Saddam Hussein used when he wanted to get rid of a group of people. But this is New Zealand in the new millennium. The decision makers have violated Article 25 of the Declaration of Human Rights and appear to lack basic ethics when they decided to use this spray in heavily populated areas.

You can see from this run through of the UN Declaration of Human Rights, the painted apple moth spray programme took our rights from us and many suffered because of it.

Personal account:

I have a chronic arthritis type health challenge, I have never smoked cigarettes and I'm semi vegetarian. As a keen gardener I garden organically.

Like many people, when the aerial spray programme was first talked about I was not too concerned. For the first year's spraying I was miles away in Auckland City most days. However, my activities changed, and about Nov 2003, one morning, I saw a low flying plane over my home and went outside to enjoy the spectacle. I had no idea that it was spraying pesticides. I was drenched in a sticky substance. Within minutes I was coughing, had sore eyes and had bronchitis type symptoms which lasted over three months, all through summer. This was something that I had rarely experienced and certainly never in summer before and never for a prolonged period.

Later, I saw that my car was covered in a sticky substance and the front windscreen had to be cleaned to allow visibility.

In spite of MAF spokespeople saying that the spray was safe and contained certain food ingredients, they set up a special medical service to help the hundreds of people made ill by the spraying. The food ingredients in the spray may be alright to eat but people were breathing in this sticky concoction which also contained live soil bacteria and pesticide. And their skin and eyes were being affected too.

If the spray was so safe why was thousands of dollars required for a special health service? Of course it could have been a way to keep control of people's complaints and contain controversy if only MAF employees dealt with people affected by the spraying. This raises ethical questions about the role of medical staff in keeping controversy at bay.

I attended the Aer Aqua doctor and was given strategies for avoiding the spray. It was suggested I shut the house up tight, stay inside and even tape around doors and windows if this would keep the spray out. So it was acknowledged that the spray was affecting me.

Unfortunately, even when taking extreme precautions, I still had a cough and frequently experienced sore eyes. I felt exhausted most of the time and the muscular aches I experience with the chronic condition I suffer from, intensified.

I developed a rash on my feet which my doctor said was dermatitis. I had never had this before. I still have it. I presume I got that because as a keen gardener I often walk around my garden to see what's happening. I didn't realize I should wear protective footwear to do so.

Whenever I could, I vacated the area and went to other parts of Auckland. I needed somewhere I could rest if required. It cost money in terms of petrol and having to provide food for the time away and often try and find a friend who was home and willing to accommodate me on a week day.

I remember having a coughing fit in the supermarket and saying to startled people when I got my breath back, its ok, I haven't got SARS, it's the PAM spray.

Of course all that time and until the end of spraying, our lives were controlled by whether it was a 'spray day or not'. Pets had to stay indoors, as we heard of animals having similar symptoms to humans, and even washing could not be hung out to dry. Remaining in a closed-up house on a hot day was suffocating.

I was on the list to be telephoned early in the morning, 5.30 a.m. to alert me that spraying was about to commence. Due to shifts in weather, times of spraying would be altered at the last minute and sometimes postponed for hours or days. I was not always kept up to date with this. However, anxiety levels did rise, as the reality of the situation was that people never really knew for sure, when and where, we were going to be bombarded with this toxic material.

Sometimes the system broke down and I was not phoned at all and would find myself in another part of west Auckland on business and there the aircraft would be, spraying overhead. This whole experience of being on tenterhooks was stressful and exhausting. I realized what it must be like living in a war zone.

One condescending comment circulating, was that people were merely getting anxious at the aerial acrobatics of the low flying aircraft and this was causing symptoms.

As I come from an airforce family I was not anxious about the low flying planes and I enjoy marveling at the expertise and the show they put on. It was amazing that the aircraft managed to skim over the tall pine trees that surrounded my house.

However, fears of an air accident were was not groundless, as one incident showed. Some of the planes used for spraying during the day, was used for the NZ Postal run at night. During this time, on a mail run, an experienced pilot who did PAM spraying during the daytime, was tragically killed when one of these planes crashed while doing the mail flight.

As it became more obvious that larger numbers of the population than expected, were experiencing ill affects from the spraying, many went to places out of the area, some organized by MAF. Towards the end of the spraying I was able to join a crowd of others at the "breakfast venues" set up by MAF. This required leaving home at dawn and traveling to another part of the region. This was extremely inconvenient as an adult with a painful chronic illness. However, I felt for those who had to get small children ready at an early hour and leave home in time to avoid the spraying. We were mainly seated at tables and while reasonable food and drink was provided there was nowhere to rest. It was often a noisy throng. It was good though to see the wide variety of people of all ages who had decided to evacuate during spraying.

On another occasion I could not attend a morning anti-spray protest held at the MAF Blockhouse Bay Centre so I went on my own in the afternoon to see if I could find someone to speak with. How I was treated on this occasion, reflected MAF's approach to dealing with the PAM problem and added to my sense of frustration and powerlessness.

At one point, I knew I was being recorded on a surveillance camera and I was talking to a MAF employee, a South African woman through a locked glass door. I asked her if she was New Zealand citizen. She said she was. I asked her if she thought it was strange that two New Zealand citizens were trying to talk to each other like this and why didn't she open the door so we could discuss the situation. I requested a time to meet with the Persons who decided that aerial spraying was the way to deal with PAM. She told me to look on the MAF website for answers to my questions. As she walked away, she said there would be no meeting. (On the MAF website there is no information on who to contact for a meeting or who is responsible.) That day I left the venue feeling tired and coughing, I realized that the MAF culture and these people were ruthlessly pursuing their goals with extreme arrogance and disdain for people.

I now find I am much more sensitive to chemicals. I was in a shop recently and someone was spraying the counter with cleaning solution and that started me coughing. This is a new development that I have noticed since the PAM spraying.

To summarise:

I have argued that the mass spraying of citizens with a cocktail of pesticide, bacteria and other substances raises questions about human rights violations, as well as the strategy by MAF of keeping the spray ingredients secret, of blocking free flow of information about their decision-making, of treating citizens who disagreed with their policies as though they were terrorists.

Politicians are responsible for this decision making. It seems that the health of vegetation, and trade interests, however admirable and economically important, take precedence over the health of citizens in New Zealand today. If economics is the main focus of the decision-makers, I'd like to make the point that ill health costs the country money too. The greater cost though, is the suffering it causes. In this case, needless suffering.

Down the track, if people's health problems connected to the spraying, continue, I expect there will be much hand-wringing but it will be pointless if people have chronic ill health. We have heard of people dying prematurely after being sprayed, miscarriages, and the higher incidence of illnesses such as motor neurone disease. I heard of hedgehogs being born with no eyes.

It would be helpful if those who are detached and skeptical about the effects of the spraying listened to the complaints of those who have been more sensitive to the spray. I would like to hear some acknowledgement of the hardships experienced and the bravery of those affected. We are like a safeguard for the rest of the community. We are like an early warning system. We are like the canary down the mine-shaft, which, because of its more finely tuned system, alerted people to the presence of toxic gases before the workers were aware of them. Remember too, we still do not know what the cumulative affect of the spray will be on people with less sensitive constitutions who may not have been obviously affected this time around.

The sensible option when the pest was first discovered would have been to engender mass community involvement to do ground searching for the PAM. Also to use pheromone traps and investigate other less invasive ways of catching PAM at various stages of development. I understand there is a virus as a natural control that was investigated in Australia over 20 years ago. Spot ground spraying could have been done in targeted areas and if aerial spraying was required it could have been contained and used as a last resort.

This would not only have saved hundreds of thousands of dollars but the health risks to the population would have greatly minimized. It would also have provided a great opportunity for a co-operative community project which could have provided paid work.

I do also wonder whether the chemical company is making nice profits out of this exercise.

It is horrifying to know that MAF appears to think using aerial spraying of the population to eradicate insect pests is now the first line of defense and a normal practice. To use 'overkill' to deal with vermin is unbalanced, unsafe and not a habit to allow.

The way this exercise was conducted was irresponsible, even criminal, in the way people's health and civil rights were violated. Where else in the world have citizens been bombarded with poisonous substances over a long period? We think with horror of Agent Orange in Vietnam and the terrible gassing of the Kurds and other instances where war is being made on civilians. Let's just hope that the Auckland experience does not have such serious long term consequences for those whose environment was sprayed against their will for years.

Al l in all, the PAM risk to NZ plant life has been minimized but at the cost of ninety million dollars of our tax money, and to those badly affected particularly, our right to our life. Many have suffered from anxiety, ill health, pain, fear, frustration bordering on despair, relationships put under stress, work hours lost, disruption to daily life, expenses incurred, time wasted, and been seriously inconvenienced. All this anguish and damage to our quality of life was inflicted on us when there were alternative methods of control available and choices, when it came to managing the situation. There was the mismanagement by MAF when the pest was first discovered. Ordinary people have paid the price of this incompetence and disregard for citizen's health and wellbeing.

I was bemused to read that in Nova Scotia a few years ago, when spraying using Foray Btk was to be used there, it was quoted as having been safely used in New Zealand. This was referring to the spraying against the tussock moth in East Auckland. People in Nova Scotia were saying yes but 700 complaints of bad effects against the spray were made in East Auckland but this was ignored.

There will be other insect pests found in New Zealand. People in other areas of New Zealand have already protested against aerial spraying, such as in Hamilton when foreign fauna has been discovered there. It is a grave concern that MAF has normalized aerial spraying as an acceptable eradication method for insect pests.

People elsewhere are watching to see what happens here.

I think MAF and the Government need to take a hard look at their values and priorities over this issue. I submit that our basic human rights have been violated by the Government and its agency, the Ministry of Agriculture and Fisheries.

Last week, a Minister of the Government was forced to resign because he filled in some forms fraudulently. How much more criminal is aerial spraying of toxic material over the population month after month for some years?

I strongly urge you to call on the New Zealand Government and those responsible at MAF to be held accountable for the damage done to people's lives because of the painted apple moth aerial spraying program. Also, to demand that safeguards be put in place so that this situation will never arise again.

Grateful thanks.

I would like to thank all those who have given so much of their time and resources to organize opposition to the spraying, to researching the ingredients of the spray, to outlining alternative methods of control of PAM and for setting up the People's Inquiry. Also thanks to the Commissioners who have come to NZ to listen our concerns.

S.M. Ethell.

End

Submission to People's Inquiry – 96
Exposure: lived in Tussock Moth spray zone (hot spot)
Hana Blackmore
Oral testimony: Yes

This is personal testimony about the effects of the Foray 48B aerial spray.

I live in the Eastern Suburbs with my family in the same house that we lived in during the Tussock Moth spraying programme of 1996/97. Our road was where the moth was first discovered and was therefore in the hot zone to receive all aerial and ground sprays. The first DC6 drops were directly over our property. The east/west run of the aircraft ensured that the plane drove directly at the front of our property – climbing steeply as it passed over our house to clear the hill behind us. Spray from the plane often arrived horizontally plastering the front of the house. (We still have spray residue on the peak windows we have never been able to clean off!).

I did not expect to be affected by the spray as I am a very healthy person, rarely sick. But I was intrigued by reports of ill health that were beginning to circulate in the area after several months of aerial spraying, particularly severe atypical headaches and bleeding noses. I went along to a meeting that had been called for people to discuss their concerns with the specialist who had been contracted to investigate "any relationship between any health and the spraying of Btk".

During this meeting the Specialist, Dr Francesca Kelly (then Jenner), said that there was only one documented health effect of the spray – a corneal ulcer after spray splash. I immediately raised this with her as I had experienced this very condition. I had been caught (full face) on our front deck on my way to work. ((Due to the topography of the area we often did not hear the plane until it was on top of us).

I wear soft contact lenses and I had not noticed anything during the day, but woke the next morning in some pain with what I thought was conjunctivitis. It was so bad by the next day that I went to my optician for advice. He immediately sent me to see a consultant eye surgeon, who took photos and told me I had a corneal ulcer, but that was because I had an underlying and longstanding conjunctivitis problem.

My concerns – to be frank –were never taken seriously by public health and their contracted specialists. I had no doctor's records (I was not even registered with a doctor) .. and assumptions were made about my eye condition without even consulting my optician who knew my history. I have worn contacts for 35 years and although I had initial sensitivities with changing disinfecting fluid (the one I used in the UK was not available in NZ) – I have never had problems, never had a corneal ulcer both before or since. I had kept my lenses in saline, and offered these for testing. The offer was never taken up.

In spite of the fact that I laid an official health effect report to Public Health, I was never included or recorded in any statistics released by Public Health into the effects of the spray. Because the optician was the only 'health' professional seen – no doctor – not visit to A & E … I disappeared off the radar.
During one of my visits to the optician, I got talking with another contact lens user and she said she too had been experiencing problems with the spraying.

Apart from that incident I had no other effects from the spraying until 2002 when I was involved with the Painted Apple Moth programme. Because I was one of our group who was not affected by the spray I had offered to escort the Children's Commissioner on a fact-finding tour of West Auckland on a spray day. We spent the morning criss-crossing the spray zone visiting schools and kindergartens under the spray planes. When we returned out east at mid-day to meet some evacuated parents, both of us were suffering from headaches, and joked to each other about red wine vs spray effects.

But by the evening I had developed a slight cough. Over next few days the cough got progressively worse and worse until it was so severe I was experiencing dry spasms like whooping cough which was so bad it caused stress incontinence. After the fifth day my chest very sore and painful and I then began producing constant heavy nasal and throat mucous - but the cough was still very dry and extremely difficult to bring anything up. It felt as if I was drowning and had great difficulty breathing through it. It got progressively worse with sore eyes on 7th day - loss of appetite, dry lips - difficulty sleeping, lethargic and tired. For the first time in my life, and not since this episode, I had dozens of nosebleeds. They came out of nowhere. Sudden, painless, bright red flows. All my symptoms were still present 10 days later and I took weeks to recover. During this time I had been speaking to a friend out west when I had a coughing fit, and she immediately said *"that's the PAM cough – what have you been up to?!"*

I have never experienced anything like this before or since. I was not *ill* in any sense that I understand – I was *affected,* is the only way I can describe it. When I was about 45 years old I caught whooping cough from my youngest daughter. All I can say is what I have detailed above was far, far worse.

And no – none of this was reported to a doctor either – I was not going to waste $65 even if I had a doctor! No doubt this is another 'incident' that slips through any effect tables that public health may keep.

End

Submission to People's Inquiry – 97
Exposure: worked in spray zone
Oral testimony: No

Re: inquiry into the effects of the Painted Apple Moth Spray on the community.

Dear People

I attach a copy of a letter I sent to Waitakere City Council at the time the spraying began, which outlines the effects on me personally.

I have since moved to Whangarei and what I would add to this letter, to update, is that I have had to have medical treatment for asthma from time to time since 23 October 2002. This was never a problem to me, with or without medical treatment, prior to being caught in the spray on that day.

I have continued to experience a deep cough, continually since October 2002, which is worse at night, and again, did not exist prior to the spray.

I remain, since that date, very sensitive to a wide range of chemicals – cleaners, fly sprays, for example, which bring on asthmatic symptoms when I am exposed to them even briefly, and which had never been a problem in my life before.

From my own personal experience and because I have heard countless stories from friends and family about the effects of this spraying, I could not state strongly enough, that I feel it was an irresponsible action, carried out with disregard to the voices of the community, and that this current inquiry is well justified.

Yours sincerely.

(Copy of letter sent 12th February 2003 to Max Wilde, Manager of Field Services, Waitakere City Council, Henderson)

Dear Mr Wilde
Re: MAF spraying of West Auckland and the effects of this on myself

Background

I am a psychotherapist who has kept exceptionally good health, have no known allergies, and rarely have occasion to see my GP for health issues.

I live out of the spray area, at Muriwai Beach. On 23 October 2002, the first day of the intended three-year campaign, I had a work commitment in New Lynn, within the spray zone. I contacted the MAF information line and was told the spraying would be completed by 1.30pm that day, and had been told that it would be safe to allow a two-hour settling time for the spray.

I therefore arranged my work appointment for 3.30pm, believing I would be quite safe from any pesticides at that time.

Exposure

My client and I were in a room I rent at a medical practice in New Lynn from 3.30pm till 4.30pm. My client asked for the window to be opened, as she was feeling hot. I did so. Shortly before 4pm, I heard a plane flying very low over the building. It made four or five passes overhead. Having been told they would be finished hours previously, I wondered what was happening. Minutes later, I had a strange taste in my mouth.

When I went out to my car, at 4,30pm, I noticed a strange smell, and that there were blobs of a sticky substance over my car. I was now becoming convinced that the area had been sprayed that hour, despite the information I had previously been given.

Later that afternoon and evening, increasing into the next day, I began to experience the following symptoms.

Symptoms

Severe headache and sinus pain.
Sore, dry throat, which drinking copious amounts of water did not quench.
Nausea.
Eyes which felt greatly swollen (but were not).
Chest pains and shortness of breath.
Nose bleeding (which still happens occasionally, nearly four months later).
Deep, rasping cough (reduced in severity, but is still there nearly four months later).

Evidence

While I cannot prove the spray caused my symptoms, I can say I had felt perfectly well that day before my trip to New Lynn. I had been fit and healthy for a long period of time, being unable to recall when I had previously been ill with any kind of respiratory/intestinal illness.

Action

I phoned the MAF health line and described my symptoms. I was advised I could take Panadol for the pain. I asked were the symptoms I was experiencing typical of what people were reporting. The nurse I was speaking to said yes, she had had a lot of people phoning and reporting the same or similar symptoms. I had not been aware of the "typical" symptoms until I spoke to the nurse. I was advised it might be best if I stayed out of the spray area on spray days in future – I have certainly done my best to do so. I was also told there was no treatment as such, one could only treat the symptoms.

Second exposure

30th January 2003, was another spray day. I had little choice but to drive through the spray area to visit a client. I closed the air vent on my car and kept the windows wound up until I was more than 15 minutes past the area, despite the intense heat (I do not have air conditioning). I could see two aircraft spraying over the motorway as I drove through the area.

My measures were insufficient to keep the chemicals away from me. I smelled the familiar smell in the car, and again, later that day, I had the same symptoms as I had experienced in October last year, in particular the extreme pain in the sinuses.

When I phoned the MAF health line on this occasion, again Panadol was suggested for the pain. I said I wanted the effects recorded and passed on to MAF, so they might begin to get some true idea of the ways in which the spray is effecting people. She said to me "They don't care! They don't care – they just want to get on with the job".

Lasting health effects

I have had a shortness of breath, which gradually improved after the initial exposure but was still evident at the time of the second exposure. This has deteriorated since the second exposure. Any physical exertion has me feeling asthmatic, and even without exertion, breathing is somewhat laboured. This has never happened in my life before and started only after exposure to the spray.

Life and income effects

Because of the health effects, I am serious about avoiding any contact with the pesticide. This has meant a severe loss of income at times, as I have refused to go into the area to work on any spray day. I have had to choose my health over income.

I now find that I cannot even drive through the spray area without being effected, so my income will be reducing even further.

The next scheduled spray day is a Sunday. The spray area is widening so much that although I don't live in the area, most journeys I make will take me through the extended areas and I cannot take the risk to my health. With the spray area so expanded, it is almost certain to take more than one day to complete. Weather conditions will sometimes mean the assault is spread over three days. So now MAF is restricting my family and social life, as well as my livelihood.

With sprays taking place every 7 to 21 days, this is of serious concern to me personally and I cannot state strongly enough that I am against the aerial spray campaign. I need convincing that the PAM has to be exterminated at all. If it does, we urgently need to find workable solutions, which do not include spraying pesticide over many thousands of people in an ever-increasing area.

Given a 60% to 80% chance of success at eradication (quoting Mr Jim Sutton) and given the extent of the on-going damage to human and animal health, not to mention the outrageous financial cost, we MUST seek alternative measures.

Methods such as putting a price on the head of the moth/caterpillar have worked overseas – why can't we employ such a safe, cost-effective, environmentally friendly measure here?

A moment's research into the questions surrounding Foray 48B and Btk would stop any reasonable person in their tracks. Nobody who has any capacity to care at all for other life on the planet – human or animal – could condone or agree with the use of this poison in a widespread and **repeated** dumping on a large community.

The community will not tolerate this and neither it should.
Yours sincerely.

End

Submission to People's Inquiry – 98
Exposure: lived in spray zone
Valerie
Oral testimony transcription only

End

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Submission to People's Inquiry – 99
Exposure: lived in spray zone
Trazie Dunston
Oral testimony: Yes

These are notes Trazie used for her oral testimony – see transcription for full version

My health.
Spray Drs
Motels
Baby Eden arriving
No spray wake up phone call
Labelled & Questioned
Eden's health
No help or understanding
Breathing works
Cost.

Hi, my name is Trazie and I'm the mum to 4 beautiful kids, my only problem with that is my 3rd child was born during the spray.

It was a little into 2002 and I had seen planes fly over but I never took a lot of notice of them other than they were very close to my home and the smell that would hang around for hours but I put that down to being pregnant, along with being tired, headaches, burning eyes, rashes and a very odd taste in my mouth.

I spent the rest of that year going to my GP asking him what was wrong with me, as I just seemed to have one health problem after another and both him and I no answer.

In December of 2002 I was sent to see a AerAqua Dr and was told that because I was pregnant, myself and my son could go the (BREAKFAST) on the next spray to be done in late January, this being my son's first day at high school and was a 4am start.

From then on it just went from bad to worse. I got sicker and the more they sprayed and the more contact I had with Foray 48B the GREATER my reaction was. Then my son who had started to break out with sores, asthma, tired and blood noses was finding it all very hard, as he was ODD, ADHD, at that point. I took us both to the spray doctors to be told that they would have to put us into a motel as the stress that I was putting me under was harming my baby and maybe I should get some more sleep. (THIS WAS A BIT OF A LAUGH AS WE HAD 4AM STARTS).

This went on right up to the beginning of April when my midwife got me to ask what would happen if I went into labour in the middle of a spray as I would not be in her area???? (I WAS NEVER GOT BACK TO). The very next spray was my due date. I spent it in a motel not knowing what was going to happen.

Now overdue and only a 14 day window I was induced and on the 8th May 2003 a 5lb13oz very small overdue baby girl - considering my first two babies weights of 6lb 14oz and 7lb12oz and then my fourth at 4 weeks premature – 6lb15oz.

However, at just 84 hours old we are all packed up and went off to the motel.

We continued to do this over and over again and again, then there was a new problem. Eden was having a reaction. She was getting a lot of high temperatures and outbursts of diarrhoea sometimes up to 30 or 40 times a day and would cry for hours. We tried everything for all sorts of baby problems before a nurse and another mum at a spray breakfast noticed that this was coinciding with the spray, so we started taking Eden to Starship. Every time they had no answer but every doctor said the same thing that as there was no other signs that it could have been the spray. (Spray doctors all in my head).

Then at our next visit to the spray doctor it was because they thought I need to learn how to BREATHE, so I went to *Breathing Works* to be taught how to breathe (BIG JOKE).

Then back to the spray Doctor again to be told that I was only able to go back to a motel as I was BREASTFEEDING as he sat there watching me feed!

More sprays down the track and my 14yr old has now run away from a motel as it was all too stressful for him and he couldn't go to school for the boils he had from the spray. My family was getting sicker, my son was missing a lot of his first year at high school and the cost financially was taking its toll.

Then when we all thought that things were better and we had only one spray to go, I was at my line putting washing out to have a PLANE go over. NO WAKE UP CALL. Nothing. Eden was carried to the car in a plastic rubbish bag and I drove as fast as I could out of there. On phoning the 0800 line for AerAqua I was told to just deal with it, that I should have known that they would be spraying. At that point I made a few rather rude and threatening comments to their dr's and drove to the breakfast to find they had called in bodyguard.

Eden was 15 months not long after that and the spray stopped and funnily so did the outburst of diarrhoea and high temperatures. Eden still can't eat most foods without getting a sore tummy or in her words runny poohs. She can tell you exactly what it was that made her feel sick and with one mouthful she'll tell you that there is something in it that makes her mouth feel funny.

NO TO ALL THAT FOLLOWS!!

NUTS, macadamia, almond, hazel, peanut
FRESH OR REAL FISH
SOY
GOAT
POTATO
CREAM
UNPROCESSED CHEESE
CORN

Then there are the costs of the things that we ALL just never planned for, the things that we got told would be paid for, the things that we haven't had to use again.

A new car (160kms was a short drive on spray day)
Chilly bin
Bassinet
Baby bath
Portacot

Then the things that were damaged by the spray.
Rubber around windows on cars and homes
Trampoline mats
STRANGE veggies.

Overall, I am glad to say that it is OVER and I can only hope that it will stay this way.

Yours truly
Trazie

Submission to People's Inquiry – 100
Exposure: n/a
Sue Berman for SAS
Oral testimony: Yes

Oral testimony transcription only - See also Submission 34

End
