In 2008, paediatrician Paul Offit had a book published—not exactly uncommon for a doctor near the top of his specialty. But the situation was complicated for Dr Offit. As chief of the division of infectious diseases at the Children’s Hospital of Philadelphia, he is the most prominent—and some would say most fearless—spokesperson for vaccine science and safety in the United States today. His book *Autism’s False Prophets,* deals with the false alarm that vaccines cause autism and how antivaccine activists, and an easily duped media, are sowing the seeds of a health scare similar to, if not worse than, the one that the UK is just recovering from. So inflammatory is this issue that Dr Offit opted out of the big city publicity tour that is usual for most authors.

“I do radio and television but not appearances in book stores. I’ve had a few incidences where I get heckled by people who disagree with me strongly, almost religiously, and disrupt my capacity to express my point of view,” he explains. He also receives a lot of hate mail—after one credible death threat, he was accompanied at official meetings by an armed guard.

The health scare linking the combined measles, mumps, and rubella (MMR) vaccine to autism is more than a decade old. A large body of evidence has built up to discredit the decade old *Lancet* paper that linked the measles virus with irritable bowel syndrome and autism. This includes a 2005 Cochrane systematic review of 139 studies to assess the effects of the MMR vaccine in children, and a 14 year long Finnish study that concluded that the vaccine was not dangerous. The study, which followed 1.8 million people, found that serious adverse events were rare and greatly outweighed by the risks of disease. The author of the *Lancet* study, Andrew Wakefield, is still embroiled in a General Medical Council case over research misconduct.

In the UK, experts are signalling what they call a “burning off” of the health scare, as the protest base diminishes, press interest drops back, and immunisation rates recover, albeit slowly. An unpublished Department of Health survey of over 1000 parents in 2008 assessing the effect of the childhood immunisation programme found that 73% had their child immunised without seeking advice. The survey concluded: “It’s possible that, as fewer scare stories appear in the press, the decision over whether to immunise has become easier.” In the second half of 2008, the UK provided 350 000 more doses of MMR than over the same period the year before. MMR coverage fell from 91% to 80.7% in 2003-4 and is now creeping up to 85.5%, according to the Department of Health.

At the end of June, the BMA will debate mandatory vaccination at its annual conference. Former BMA chair Sandy Macara, who has proposed the motion, said he didn’t mind being called draconian “as long as this issue is taken seriously.” The Welsh health minister Edwina Hart last week ruled out introducing compulsory MMR vaccinations. “It would, on the advice I have received, make matters worse, not better,” she said. Measles cases in Wales are at their highest for 20 years, with 302 current cases.
But while data from the UK suggest a renewal of public confidence in the MMR vaccine, doctors in the US fear a slide in the opposite direction. Figures from the Centers for Disease Control and Prevention report that the number of measles cases in early 2008 was at a 10 year high. During 2000-7, the mean number of measles cases each year in the US was 62. In 2008, 131 cases had been confirmed by 31 July, including outbreaks in San Diego (11 children), New York (27 cases), and Illinois (32 cases). This spike was not the result of an increase in imported cases but higher numbers of unvaccinated school age children. Sixty one of the 83 US citizens aged 1-19 years who caught measles during this period had not been vaccinated because their parents claimed exemption for religious or personal reasons.

**Campaigners against vaccines**

One of the main drivers of the safety fears are antivaccination groups. Prominent among the UK groups is Warrington based JABS, whose website still maintains that “some children have and will continue to be damaged by combined and single dose vaccines.” Founder Jackie Fletcher has a son with epilepsy and brain damage, which she blames on the MMR vaccine. Her views are widely quoted by the mainstream media.

Another group is the One Click Group, whose tactic is to circulate by email a digest of antivaccination press cuttings, “Mother wants answers as baby dies from vaccine,” is one recent headline taken from a local paper in Trinidad and Tobago. The group has emailed several members of BMJ staff, all of whom found themselves unable to unsubscribe from the unsolicited email. The group, run by a former public relations worker, Jane Bryant, is especially uncompromising in its message. Ms Bryant first came to prominence campaigning to get chronic fatigue syndrome treated as a medical condition.

The US has also witnessed a growth in antivaccination organisations since the late 1990s, including the high profile Generation Rescue, whose slogan is “Autism is reversible.” The organisation is fronted by former Playboy model Jenny McCarthy, who has an autistic son and is the girlfriend of Hollywood actor Jim Carrey. Some of these groups have noticeably deeper pockets than their British counterparts. Generation Rescue, for example, was founded by a wealthy financier from northern California called J B Handley, whose son has autism. Mr Handley and his wife are convinced that mercury chelation therapy has successfully treated their son. In February, Generation Rescue took out a one page advertisement in USA Today costing a six figure sum. Activist and blogger Gary Kompothecras, a millionaire and political donor, calls himself “warrior dad.” Doctors who disagree that vaccines are responsible for regression in children are called “dirtbags,” he says. The message is typically hard edged and uncompromising.

Generation Rescue’s position is that autism is caused by “environmental illnesses caused by an overload of heavy metals, live viruses, and bacteria.” Ms McCarthy also implicates the tripling of vaccines given to children in the past 15 years (with unstudied ingredients like mercury, aluminium, and live viruses).

The website recommends “biomedical intervention,” saying it “is leading to recovery for thousands.” To this end, the website’s online shop sells suppositories for children at $109 (£56; €78) for 15, “to remove excessive levels of toxic metals from the body.” Ms McCarthy regularly appears on top rated US shows such as Oprah and Good Morning America to air her views. Founder J B Handley has a blog on CNN.com.

In June last year, Ms McCarthy led a “green our vaccines” rally of a reported 8500 families in Washington, DC. The rally demanded that congress re-enact legislation eliminating mercury and other “toxins” from children’s vaccines, study the incidence of autism in vaccinated versus unvaccinated children, and allow more families to file for compensation for “vaccine induced autism.”

Less new age is the long established National Vaccine Information Center (NVIC), set up in 1982, which has its roots in the pertussis vaccination health scare of the 1970s. A key function of the NVIC, run by Barbara Loe Fisher, is its vaccine reaction registry: “When parents report a death or regression into chronic poor health after vaccination to NVIC, we document the report and advise parents to also make a report to the federal Vaccine Adverse Event Reporting System,” says Mrs Loe Fisher.

Dr Offit dislikes the NVIC (“the national vaccine mis-information centre more like,” he says) but says at least the website has links to federal agencies such as the Centers for Disease Control (CDC) vaccine information site. But he’s very concerned about the vaccine registry.

“Barbara is a very powerful parent advocate. But if a parent contacts her to say that their child has had an adverse reaction to vaccines, she simply believes them. If the data show the problem was not vaccine related she tends to say the data were manufactured by those [who gain from vaccines].”
PUBLIC HEALTH

“Influence
But are these campaign groups really a risk to mass childhood vaccination? And how far has it threatened vaccination programmes?

Julie Leask is from the National Centre for Immunisation Research and Surveillance, Australia. She is an expert on the antivaccination movement in Australia and identifies themes in the rhetoric used by these groups: “The subtext to messages is always the same, there are the universal themes of cover-up; vaccines as poisonous chemical cocktails; an unholy alliance for profit; the threat of excessive government control; and the back to nature idyll.”

Says Ms Leask: “Antivaccine groups have always consisted of people who refuse to support medicine’s dominance and are also anti-establishment, anti-government. Alternative therapies give them a convenient and more appealing strategy for preventing and managing the vaccine preventable diseases in children.”

Pru Hobson-West, a senior research fellow at the Centre for Applied Bioethics, University of Nottingham, has identified and studied 19 groups in the UK that are critical of vaccinations. They included Action against Autism in Glasgow and the London based vaccination.co.uk. She found the groups were all relatively small and led by one or two parents, with a membership base ranging from 60 to 2000.

Ms Hobson-West discovered the more radical groups didn’t necessarily have personal experience of vaccine damage but were often seasoned campaigners for causes such as alternative health and animal testing. Importantly she found the groups “did not make their case by arguing that the risks of vaccination outweighed the benefits. Instead they talked about risks as unknowns. Lack of knowledge is used by the groups to explain their wariness in advising vaccination.” The leader of autism group the Informed Parent told Ms Hobson-West: “The more you read on it, the more you realise what little we know about the body and health. There’s so much we don’t understand.”

The vigour with which some of these groups pursue their message can dissuade doctors from challenging unscientific and incorrect views in public. As mentioned, Dr Offit has given up appearing opposite vaccine dissenters. “I get emails which liken me to the devil. It is unsettling. Parents have a perfectly legitimate right to ask questions; to ask a scientific question and to be answered in a scientific venue. We certainly have the answers. But there are a core group of people that simply don’t want to believe it.”

“I get emails which liken me to the devil. It is unsettling”

Dr Paul Offit, Philadelphia

“I’ve been asked three times to be on the Larry King show, with Jenny McCarthy and then with Andrew Wakefield. McCarthy is very angry, mean spirited on Larry King Live. She is rude, cuts across people, curses, and has no respect for authority. But she is still a mother of a child with autism and she is therefore a sympathetic character. That leaves only one role for me—that of the villain. You are there to tell her she is wrong. She’s got all these ways of making her son better and what can I offer? There is no cure. It is sad that it’s come to this, that we have to look to celebrities to give us our healthcare advocacy.”

David Salisbury, director of immunisation at the Department of Health, says he has received threats at home and at work from activists. He says the “degree of anger” seems similar to that of animal rights activists. “One GP who used to be connected to JABS recommended that capital punishment was appropriate for me. Why should I accept it? This degree of personalisation.”

Neither Generation Rescue nor JABS replied to my questions. The One Click Group was hostile when I approached them with some straightforward questions. I was directed to another charity and, bizarrely, Peter Fletcher, former chief scientific officer at the Department of Health. When I asked to be taken off its mailing list I was told: “Unsubscribing from the One Click News Alerts requires one mouse click. If this is beyond you, never mind eh?”

Barbara Loe Fisher of the National Vaccine Information Center said her organisation did not “advocate or condone” threats against anyone. But, she added: “Every week we receive reports from parents, who are being demonised, harassed, threatened, and even reported to health authorities for making informed, independent vaccination choices for their children.”

The situation is not helped by a media often happy to engage with groups without regard to scientific knowledge. Dr Offit and colleagues opened the Vaccine Education Center in 2000, in response to scientific misinformation. “The media likes controversy. It’s not a controversy—only one side is supported by the science. It’s like screaming into the wind on some level. The trouble is that people still get their information from entertainment media.”

Professor Salisbury says: “There is no doubt that the media give disproportionate weight to the [antivaccine position]. Look at the frequency that journalists writing articles about immunisation go to Jackie Fletcher for a comment.”

“For some campaigners no study is acceptable if it continues to show no link—you get answers by rote: the study was weak, didn’t look at the right children, didn’t use the right method. It’s like AIDS denialists, and there are evidence denialists. The constituency base [of these groups] has got narrower and narrower. There are a diminishing number of people who think [there is a link]. Look at the number of people who contribute to the JABS website; it’s down to a tiny number.”

But what can doctors do? These groups can be tough opponents for doctors—they are web literate, with some offering hard and fast answers to concerned parents, others adding to existing doubts so carers opt to delay or do nothing about vaccination. Professor Salisbury agrees that it can be very hard for doctors to challenge antivaccine campaigners, especially those who are parents of autistic children.

“Stories are very powerful and persuasive. It is very hard to dislodge these stories with cold scientific studies. If a parent says, ‘I know that x did y,’ it’s hard to say no to their face,” he says.

Another doctor, who asked to remain anonymous after a bruising battle with a radical antivaccine group, says it’s important that medics don’t engage with certain groups. “You must never care about this as much as they do. What is vital to them is the existence of a heretic—the doctor—because you are dealing with a faith here. They do nothing but trouble. I would not take legal action, for example, it would be a pyrrhic victory.”

Harm to health
There is evidence of the harm that false claims against vaccines can do. Although the UK has semi-recovered from the MMR scare, the damage continues: herd immunity has been lost and there has been an increasing number of outbreaks, including one death. Despite the recent increase in the proportion of children vaccinated, measles cases in England and Wales rose sharply in 2008 compared with the previous year—a total of 1348 cases, according to the Health Protection Agency. The UK has no hope of reaching the World Health
Organization’s goal of eliminating measles in Europe by 2010, said Professor Salisbury.

Across Europe, national surveillance organisations reported 12,132 cases of measles in 2006 and 2007, 26% of them in the UK.

In the US, vaccination rates are still relatively high but there are clusters of anti-vaccine communities across the country. Vaccination is compulsory for school entry, although Dr Offit points to an erosion of mandate: “In 48 of 50 states you can get a religious exemption and 21 out of 50 states allow philosophical or personal exemptions. If you look at outbreak states, they are where philosophical exemption is easier to obtain.

Key parts of the country are relatively unvaccinated: Oregon, south California, New York State, Minnesota. I think it is getting worse, yes. Is it a growing trend? Yes.”

There is evidence of a link between clusters of non-medical exemption to school immunisation and clusters of diseases in the US. The Centers for Disease Control has warned: “Increases in the proportion of persons declining vaccination for themselves or their children might lead to large-scale outbreaks in the United States.” And this is exactly what happened in San Diego last year. An unvaccinated child contracted measles on holiday in Switzerland and back home, the virus spread to his sibling, school friends, and children who had been at his paediatrician’s office at the same time as his visit. At the San Diego school almost 10% of the pupils had an exemption to vaccination on their file.

Bruce Gellin, deputy assistant secretary for health and director of the National Vaccine Program Office in Washington, DC, is concerned: “San Diego is an opportunity to show people what happens when a significant number of people are not vaccinated,” he says. “We were lucky here. There was a large vaccinated population but it could have turned into a massive outbreak but fortunately sooner or later this virus had nowhere to go. It’s a teaching moment. Parents today forget this is a real disease where some people do OK, but some don’t.

“People get further and further away from what these diseases are; they forget the importance of vaccines. They look at these black and white photographs of children [with tuberculosis] in an iron lung, and think ‘not relevant to me.’

“Nationally about 2% of children in the USA have a non-medical exemption. In Washington State that figures goes up to 5.7% in 2007-8, and some counties of Washington as high as 1.5%.”

A note of caution is provided by Howard Bauchner, professor of paediatrics and public health at Boston University School of Medicine and Boston Medical Center, editor of the BMJ Group journal Archives of Diseases in Childhood. He wonders if parents are being put off by the sheer number of vaccinations children are expected to have. “Over the past 10 years, new immunisations have been introduced at a dizzying pace. Is vaccine fatigue—among parents and physicians—impacting immunisation rates? The immunisation schedule used to be relatively easy to follow—now there are three separate schedules, followed by detailed notes.”

This migration of the MMR autism scare to the US has worrying characteristics, ones which will make it harder for doctors to reassure concerned parents, says Professor Salisbury. “Here in the UK, vaccine was an individual, narrow problem; when the science unpicked it, and Andrew Wakefield was in turn unpicked by the press, it became very difficult to advance the argument that MMR causes autism.

“But it is more diffuse in the US. First there was the concern about the mercury preservative thiomersal in vaccines, then MMR and autism, and then about the dangers of multiple vaccines—it makes it much harder to pick off what parents’ concerns are.”

Professor Salisbury says the Department of Health’s fight back was in part helped by the uncompromising position it took on the combined MMR vaccination, refusing to fund single vaccines. “The government did not appease—we didn’t change policies. We did not offer a choice, despite the existence of single vaccines. [With whooping cough, patients were offered vaccine without pertussis.] We had no close links with dissenters.”

What are US public health officials doing to fight back? The federal response was recently damned in the New York Times as “muted and couched in dull scientific jargon.”

At the Centers for Disease Control, officials say its efforts are targeted on supporting family doctors on the ground.

According to Melinda Wharton, acting director of immunisation safety office, CDC, “when push comes to shove it is about individual families in the doctor’s office and they have to say yes or no to immunisation.” She says it is difficult for people like her to understand why parents would say no, “It’s why I went to medical school—I have a certain approach to the world, [an evidence based approach] to looking at information and evidence.”

Bruce Gellin agrees: “Some of these conversations [between patients and doctor] can be quite detailed and not all physicians have adequate time to do that. We have developed a toolkit with the American Academy of Pediatrics.” He also praises tear sheets designed by Dr Offit—pre-printed information that paediatricians can tear off and hand to parents. “Patients feel that there is an ‘us and them’ barrier, that a lot of stuff goes on behind closed doors. We need to open the doors, and we are doing lots of outreach work, regular interviews with thousands of parents.”

There are reasons to be cheerful. In February, the two year Autism Omnibus hearing in the US ruled there was no evidence for either MMR or thiomersal causing autism. The case involved 5000 children.

Professor Salisbury agrees the autism ruling was “absolutely damning” for anti-vaccination campaigners but adds “It’s like holding mercury in your hand: just when you think you have it, it metamorphoses into something else.”

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See also the discussion on doc2doc “Bad Science” columnist Ben Goldacre talks about MMR at bmj.com/video

References are on bmj.com Cite this as: BMJ 2009;338:b2435

See REVIEW OF THE WEEK, p 1568