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The Crash and Burn of an Autism Guru

By **SUSAN DOMINUS**

As people streamed into Graceview Baptist Church in Tomball, Tex., early one Saturday morning in January, two armed guards stood prominently just inside the doorway of the sanctuary. Their eyes scanned the room and returned with some frequency to a man sitting near the aisle, whom they had been hired to protect.

The man, [Andrew Wakefield](#), dressed in a blazer and jeans and peering through reading glasses, had a mild professorial air. He tapped at a laptop as the room filled with people who came to hear him speak; he looked both industrious and remote. Broad-shouldered and fair at 54, he still has the presence of the person he once was: a conventional winner, the captain of his medical school's rugby team, the head boy at the private school he attended in England. Wakefield was a high-profile but controversial figure in gastroenterology research at the Royal Free Hospital in London when, in 1998, he upended his career path — and more significant, the best-laid plans of public-health officials — by announcing at a press conference that he had concerns about the safety of the [measles-mumps-rubella](#) vaccine (M.M.R.) and its relationship to the onset of [autism](#).

Although Wakefield did not claim to have proved that the M.M.R. vaccine (typically given to children at 12 to 15 months) caused autism, his concerns, not his caveats, ricocheted around the world. His belief, based on a paper he wrote about 12 children, is that the three vaccines, given together, can alter a child's immune system, allowing the measles virus in the vaccine to infiltrate the intestines; certain proteins, escaping from the intestines, could then reach and harm neurons in the brain. Few theories have drawn so much attention and, in turn, so much refutation: a 2003 paper in *The Archives of Pediatrics and Adolescent Medicine*, which reviewed a dozen epidemiological studies, concluded that there was no evidence of an association between autism and M.M.R., and studies in peer-reviewed journals since have come to the same conclusion. In Britain, the General Medical Council revoked Wakefield's medical license after a lengthy hearing, citing numerous ethical violations that tainted his work, like failing to disclose financing from lawyers who were mounting a case against vaccine manufacturers. The *Lancet*, which published the original Wakefield paper, retracted it. In a series that ran early this year, *The British Medical Journal* concluded that the research was not

just unethically financed but also “fraudulent” (that timelines were misrepresented, for example, to suggest direct culpability of the vaccine).

Andrew Wakefield has become one of the most reviled doctors of his generation, blamed directly and indirectly, depending on the accuser, for irresponsibly starting a panic with tragic repercussions: vaccination rates so low that childhood diseases once all but eradicated here — [whooping cough](#) and measles, among them — have re-emerged, endangering young lives.

And yet here he was in Texas, post-career-apocalypse, calmly discussing his work, and a crowd of around 250 people showed up to listen. As people walked into the lobby of the church in Tomball, they passed by a whiteboard with a message that asked attendees to express their thoughts to Wakefield. Many complied with lavish thanks: “We stand by you!” and “Thank you for the many sacrifices you have made for the cause!” When he finally took the podium, the audience members, mostly parents of autistic children, stood and applauded wildly.

In his presentation, Wakefield sounded impatient but righteous. He used enough scientific terms — “ataxic,” “histopathological review” and “vaccine excipients” — that those parents who did not feel cowed might have been flattered by his assumption of their scientific fluency. He also tried to defend himself against a few of the charges laid out in *The British Medical Journal* — offering defenses that did not hold up before the journal’s panel of editors but were perhaps enough to assure an audience of his fans that he did, in fact, have defenses. Some part of Wakefield’s cult status is surely because of his personal charisma, and he spoke with great rhetorical flair. He took off his glasses and put them back on like a gifted actor maximizing a prop. “What happens to me doesn’t matter,” he said at one point. “What happens to these children does matter.”

After the talk, a line of visitors snaked down the length of the lobby, his followers waiting to have Wakefield sign a book he wrote about his experience and convictions, “Callous Disregard.” “All right, love?” he said, handing the book back to one mother. “Of course,” he said when asked for a photo. A pregnant woman in the lobby told me she was there trying to educate herself. Another woman, with tears in her eyes, blamed herself for not working harder to obtain a separate [measles vaccine](#) for her possibly autistic child.

Michelle Guppy, the coordinator of the Houston Autism Disability Network and the organizer of the Tomball event, said she believed her own autistic son benefited greatly from one aspect of Wakefield’s work: his conviction that untreated gastrointestinal problems could be behind some of autism’s symptoms. It was Guppy, it turned out, who thought to hire the armed guards “to make the statement,” she said, “that this is neutral ground, and it’s going to be civil.” Guppy, a mother of two who was elegantly dressed for the occasion, made no pretense of neutrality herself. She narrowed her eyes when she learned that a writer from *The New York Times* was

there to write about Wakefield.

“Be nice to him,” she said, “or we will hurt you.”

During a three-hour car ride from Tomball back to Austin, where he lives, Wakefield pointed out the curiosities of the area: a roadrunner, burning bales of hay. He was a gracious host in his adopted state, which he finds far more hospitable than the country he left. Sitting beside him was a bottle of Redline, an energy drink that promises a seven-hour boost. “It’s great,” he told me. “There’s no crash.”

Wakefield moved to Austin in 2004, a few years after he was asked to leave the Royal Free Hospital, reportedly because he didn’t fulfill a request that he duplicate the findings in the Lancet paper. Supporters in Austin reached out to Wakefield after he gave a talk there, which led to his helping to found Thoughtful House Center for Children, a treatment and research center for kids with autism.

But after the General Medical Council found in January 2010 that Wakefield had committed ethical violations — subjecting developmentally disabled children to unnecessary invasive procedures, mishandling funds and failing to disclose conflicts of interest, to name a few — Wakefield resigned from Thoughtful House. The walls of his professional world have continued to close in. He no longer speaks at the popular Autism Research Institute conference, where he has prominently held court in the past. And to that segment of the American audience that may have been unfamiliar with his work until recently, he has been introduced primarily as a villain. When he was interviewed on CNN and invoked “Callous Disregard,” [Anderson Cooper](#) cut him off: “But sir, if you’re lying, then your book is also a lie.”

At the start of the drive, Wakefield spoke with the calmness of the self-certain, ready with a counterargument for every concern. How does he respond to the decline in vaccination rates that some attribute to his theory? If only officials had offered a single measles vaccine, he said, there would have been no uptick in unvaccinated children. (Immunologists argue that spacing out vaccines increases the likelihood that children will not receive all of the vaccines and that they could contract a serious illness during the interim.) Why was there no mention in his Lancet paper that initial pathology reports found little indication of bowel disease in the cases Wakefield wrote about? “You have incredibly limited space,” he told me in a subsequent conversation. As for the accusation that he received financing for the paper from lawyers intending to sue vaccine manufacturers, he insisted that the money was for a separate study. And why did the lawyer behind the litigation essentially say otherwise on tape? “He was confused,” Wakefield explained. His faith in his theory also remains intact, which he made clear when I asked him, in a separate interview, if he still believed M.M.R. caused the autism in the children in the Lancet paper. “Is that a serious question?” he said. “Yes, I do still think M.M.R.

was causing it.”

For Wakefield, the attacks have become a kind of affirmation. The more he must defend his research, the more important he seems to consider it — so important that powerful forces have conspired and aligned against him. He said he believes that “they” — public-health officials, pharmaceutical companies — pay bloggers to plant vicious comments about him on the Web. “Because it’s always the same,” he says. “Discredited doctor Andrew Wakefield, discredited doctor Andrew Wakefield.” He also “wouldn’t be surprised” if public-health officials were inflating the number of measles mortalities, just as he thinks they inflate the risks of [the flu](#) to increase uptake of that vaccine. Having been rejected by mainstream medicine, Wakefield, the son of well-regarded doctors in Britain, has apparently rejected the integrity of mainstream medicine in return.

Wakefield never seemed too perturbed by my questions; if he felt any irritation, he took it out on his GPS, which he seemed to think was out to get him, just like his critics. “There’s no left turn here, you idiot,” he said to the disembodied voice. “Turn right? Why? What’s the point?”

Finally Wakefield allowed for an error in his judgment. “I think the press conference is something we could have done without,” he acknowledged. It is no small concession. The media response might not have been so inflammatory; vaccination rates might not have taken such a hit; and on a personal level, Wakefield might have at least been spared accusations of provoking hysteria with calculated hype.

But, Wakefield clarified, he regretted the press conference only “because it inflamed the public officials.” In the long term, he said, it did not matter; eventually, they — the establishment — would have come after him anyway.

“To our community, Andrew Wakefield is [Nelson Mandela](#) and Jesus Christ rolled up into one,” says J. B. Handley, co-founder of Generation Rescue, a group that disputes vaccine safety. “He’s a symbol of how all of us feel.”

Since losing his medical license, Wakefield has depended on his followers for financing and for the emotional scaffolding that allows him to believe himself a truth-teller when the majority of his peers consider him a menace to medicine. The fact that his fans have stood by him through his denunciation may seem surprising, but they may find it easier to ignore his critics than to reject their faith in him. After all, his is a rare voice of certainty in the face of a disease that is, at its core, mysterious.

The diagnosis of autism can be devastating. In some cases, a child regresses between 12 and 24 months, baffling parents who do not recognize the child who has replaced the one they knew

and has no words to explain. In other instances, they watch their friends' children sit up, babble and reach out for hugs, when their own do not. Unable to communicate, a small percentage of autistic children bite their own arms raw or bang their heads against the wall, for reasons poorly understood.

"We still do not have an explanation for the vast majority of autism cases," says Thomas Insel, the director of the National Institute of Mental Health, who is in charge of coordinating the \$120 million worth of research being conducted on autism there. With regard to autism, Insel calls himself a "prophet of humility."

Most researchers say that there is a rise in the number of children who are landing somewhere on the autism spectrum and that only some portion of that increase can be explained by raised awareness of the disorder. In this decade alone, Insel says, diagnoses of autism spectrum disorder (which includes mild cases) have jumped to 1 in 110, from 1 in 150; in boys, it's now 1 in 70. He worries that the rate is accelerating. "I would say I am losing sleep over this," Insel says.

What has become increasingly clear to Insel is that something is to blame. Some environmental factor is, or many environmental factors are, interacting with certain gene types, yielding who knows how many different pathways to the same disease. And although many parents think they know with instinctual certainty what that factor was in their own child, researchers "haven't found anything that looks like a smoking gun," Insel says. To him, the M.M.R. vaccine, so aggressively studied since the media splash following Wakefield's 1998 paper, is one of the few factors that can be ruled out. But could it be aspartame? UV rays? Elmo? No one knows.

"With autism, people have done this all along — grasped onto various explanations and reached premature closure on each of them," Insel says of Wakefield's work. "What I take from the Wakefield story is that everyone is desperate to find answers to what we see as an urgent problem. And if I'm really brutally honest about this, we still don't have an answer."

To parents who have run up against unsatisfying answers from the scientific community, Wakefield offers a combination of celebrity and empathy that leaves strong impressions. Michelle Guppy, the mother from the Houston Autism Disability Network who brought Wakefield to speak in Tomball, subsequently spoke to me on the phone about the experience she had at Thoughtful House. She had taken her adolescent son there after a series of mainstream doctors failed to help his constant [diarrhea](#), which required her to change his diaper as many as 10 times a day.

"I mean, I remember, Dr. Wakefield was there," Guppy said, her voice starting to quaver. "And

you know, it was just the validation. I don't care if my son was overtreated or cured — just the validation that we as parents who knew something was wrong got an answer. Just the fact that someone listened and someone tried to do something — someone said, 'Yeah, this is not just autism; your son has a real medical issue that we can treat.' I think that validation is all that parents want — just that someone is taking the symptoms we report and looking at them to see what can we do about it."

At Thoughtful House, her son was given an [endoscopy](#), which is considered an invasive procedure. Following the diagnosis, a doctor there (who has also left Thoughtful House and has also come under a cloud of criticism) put him on anti-inflammatories and a gluten-free, casein-free diet. Perhaps her son's system was maturing anyway, but Guppy credits the treatment, and Wakefield, for vastly improving both their lives.

Wakefield's big theory — that M.M.R. causes a bowel disorder, which he calls autistic enterocolitis, that then causes autism — has been dismissed by mainstream medicine. And a position paper published last year in Pediatrics also stated that available research did not support the use of casein- and gluten-free diets in the general autistic population (the diets, adapted in extreme measures, can cause health complications of their own). But Timothy Buie, a pediatric gastroenterologist at Harvard Medical School and one of the paper's authors, felt that the press ignored other key implications in their findings: that there might be a subsection of autistic patients who would benefit from dietary interventions and that the role of the immune system in gastrointestinal dysfunction in children with autism "warrants additional investigation."

Buie makes it clear that he is no fan of Wakefield's; but he does say that Wakefield was a kind of pioneer in disseminating certain useful ideas about autism. Wakefield's least controversial conviction may be the belief that some symptoms of autism — repetitive body movements, leaning over furniture, self-injury — might be symptoms of gastrointestinal distress in an autistic population unable to verbalize that discomfort.

Pat Levitt, a neuroscientist at the Keck School of Medicine at the [University of Southern California](#) and an autism researcher in whom the National Institute of Mental Health has invested heavily, is also now interested in the role of gastrointestinal dysfunction in patients with autism. He has found a gene variant that is more prevalent in children who have autism and gastrointestinal problems than it is in children who have autism but no digestive irregularities. Levitt does not believe that a faulty gut is the cause of autism, as Wakefield theorized, but that the two problems might develop, in some subset of people on the autism spectrum, in tandem, each a result of a flawed interaction of genes and environment. He does not believe — as some of Wakefield's followers hoped — that by treating an intestinal malady,

he will cure the underlying autism. “But is it the case that if you have GI problems, *that* can exacerbate your child’s behavioral issues?” says Levitt, whose recent work has not yet been replicated. “The answer is absolutely yes.”

Levitt and Buie said they believed that for years parents’ concerns about their autistic children’s gastrointestinal problems were too often dismissed, partly because doctors associated those concerns with quackery and vaccine fears and the false hope that a diet could cure the autism itself. When Levitt gives talks, he sometimes puts a picture of Wakefield up on the screen. “Bad science,” he then says, “set us back 10 years.”

The slow course of gastrointestinal research in autism — still a controversial subject — has fewer public-health implications than dropping vaccine rates do, but it is an interesting footnote, one of the odd legacies of Wakefield’s work. He was adored by parents because he validated some of their most agonizing concerns when they felt few others would. But he was also one main reason that those medical symptoms were being dismissed in the first place.

If Andrew Wakefield’s followers see him as a martyr, then his chief persecutor, in their eyes, is a British journalist named Brian Deer. Wakefield calls Deer a “hit man,” though Deer claims no such agenda (he has been as critical of the medical establishment that allowed Wakefield to get as far as he did as he has been of Wakefield himself). Were it not for Deer, Wakefield might have been nothing more than a scientist who was proved wrong. But Deer, who has been investigating Wakefield since 2004 and who this April won the Specialist Journalist of the Year award from England’s Society of Editors for his work, has presented a far more damning view of Wakefield to the world.

In his British Medical Journal series, Deer made the case that Wakefield was not just wrong but also unethical. He said that the doctor misrepresented at least one aspect of the medical condition of every child he wrote about in the study. Wakefield contests virtually every one of those charges, and it would take a book to encompass Deer’s allegations, Wakefield’s parries and Deer’s counterproof. But one charge that Deer argues convincingly is that several children in the Lancet paper had records showing concerns about developmental delays before getting the M.M.R. shot. Deer points out that another child, whose record was more ambiguous, was seen by a doctor before receiving the M.M.R. vaccine, because his mother was concerned that his hearing was imperfect, “which might sound like a hallmark presentation of classical autism,” Deer wrote.

In Wakefield’s presentation at the church in Tomball, he seized upon this detail as evidence of Deer’s overreaching. He pointed out that Deer neglected to mention that the mother also reported to that same doctor that there was discharge from the child’s ear. “What does that suggest to you?” he asked the audience. Some parents called out with confidence, “**Ear**

infection,” which — those parents were very likely to know — can impair a child’s hearing. With that one example, Wakefield did what he does so skillfully: empowered parents as medical experts as he tried to undermine the credibility of his accusers, just enough to convince those who already support him that they are justified in doing so.

You could read Deer’s collected body of research on Wakefield and come away with the conviction that Wakefield was an underhanded profiteer who exploited parents and abused their disabled children with invasive tests for the sole purpose of capitalizing on parents’ fears about the M.M.R. vaccine. (He applied, for example, for a patent for a diagnostic kit that could test for measles virus in the intestines.) But Deer does not think Wakefield was solely motivated by profit. He compares him to the kind of religious leader who is a true believer but relies on the occasional use of smoke and mirrors to goose the faith of his followers. “He believed it was true,” Deer says of Wakefield’s theory of M.M.R., but he was also willing to stretch the truth to get more financing for more research. Deer theorizes that Wakefield’s maneuverings were all rationalized by his conviction that he was right: “He would prove it next time.”

Wakefield now lives in a high-end Austin neighborhood, a private enclave where most homes, including his, enjoy generous acreage and bucolic views of the hills. “You can almost believe you’re in Tuscany,” he says of the view from his back deck.

A large dog roamed about the house; a very tall son watched an English soccer match; and Wakefield, while making coffee and emptying the dishwasher, continued to bat away charges. He claimed, for example, that a “safer” measles vaccine for which he filed a patent was not, in fact, a rival to M.M.R., which would have been a clear conflict of interest; it was instead an immune-boosting vaccine for those with compromised immune systems, an unfortunate semantic mix-up. (“He is very good at what I call whack-a-**mole** arguments,” says Seth Mnookin, author of “The Panic Virus,” a history of the controversy over autism and vaccines.)

Wakefield is a persuasive speaker, even when the listener knows better. As we talked, I couldn’t help thinking of a clip of Wakefield I saw on YouTube. The video showed him at a conference in 1999, telling the audience about the time he lined up kids to give blood samples at the birthday party of one of his children: he needed a control group of children who did not have autism, and this was convenient. “Two children fainted,” he said. “Another threw up over his mother.” For their service, they were rewarded with £5. “People said to me, ‘Andrew, you know you can’t do this to people; children won’t come back,’ ” he recounted. “I said, ‘You’re wrong — listen, we live in a free-market economy; next year, they’ll want £10.’ ”

Clearly, drawing blood in that setting was part of no medical protocol that an ethics committee would ever approve. The General Medical Council, in its ruling against Wakefield, said that by engaging in this behavior, he displayed conduct that “fell seriously short of the standards

expected of a doctor and was a breach of the trust that the public is entitled to have in members of the medical profession” and deemed the episode “serious professional misconduct.”

Wakefield was either naïve or arrogant to think that he could joke on camera about the lengths to which he had gone in the pursuit of proving his theories right. But what is also striking about that video is the sound of the audience laughing. He had won over a room full of parents, who were caught up in the charm of a maverick. It was hard to imagine Wakefield making such a joke now; he has not retreated from his position, but he has shifted his sense of identity from that of a renegade to that of a martyr. He often says that he has stuck by a theory that “has cost me my job, my livelihood and my country.” The more he has sacrificed, the more he must believe in his theory — or else what was it all for? A quote from Peter Medawar, a British scientist who wrote a famous critique of a book of specious ideas about evolution, comes to mind: “Its author can be excused of dishonesty only on the grounds that before deceiving others he has taken great pains to deceive himself.”

Wakefield continues to work with a sense of mission and an entrepreneurial savvy. Since leaving Thoughtful House, he has been working on a book about parents who have been falsely accused of [Munchausen syndrome by proxy](#): the world of false accusations, of unheard parents in pain — familiar territory, all of it. He is also trying to raise money for a center for autistic adults. It is a shrewd business move with explosive potential for growth: 80 percent of the autistic population in the U.S. is currently under 18.

That morning in Austin, Wakefield was on his way to yet another contentious interview in New York, this one with [George Stephanopoulos](#). His son, who drove Wakefield and me to the airport, had no plans to follow in the footsteps of his parents and his paternal grandparents, all of whom were doctors: he was majoring in public relations and marketing instead. Perhaps his father’s experience had taught him something about the perils of science and about the power of messaging.

It seems very unlikely that any study, no matter how carefully conducted, will assure Wakefield of the safety of M.M.R. at this point: numbers can lie, or be manipulated, and even paranoids have enemies. Didn’t they laugh at the researcher who said bacteria caused [ulcers](#)? Doesn’t he owe it to the children to continue on?

Before leaving for the airport with Wakefield and his son, I took in the view from the deck. The hills looked lofty, peaceful, a little bit blurred in the distance — you could believe, as Wakefield had promised, you were in Tuscany. With a little effort, you can believe almost anything.

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