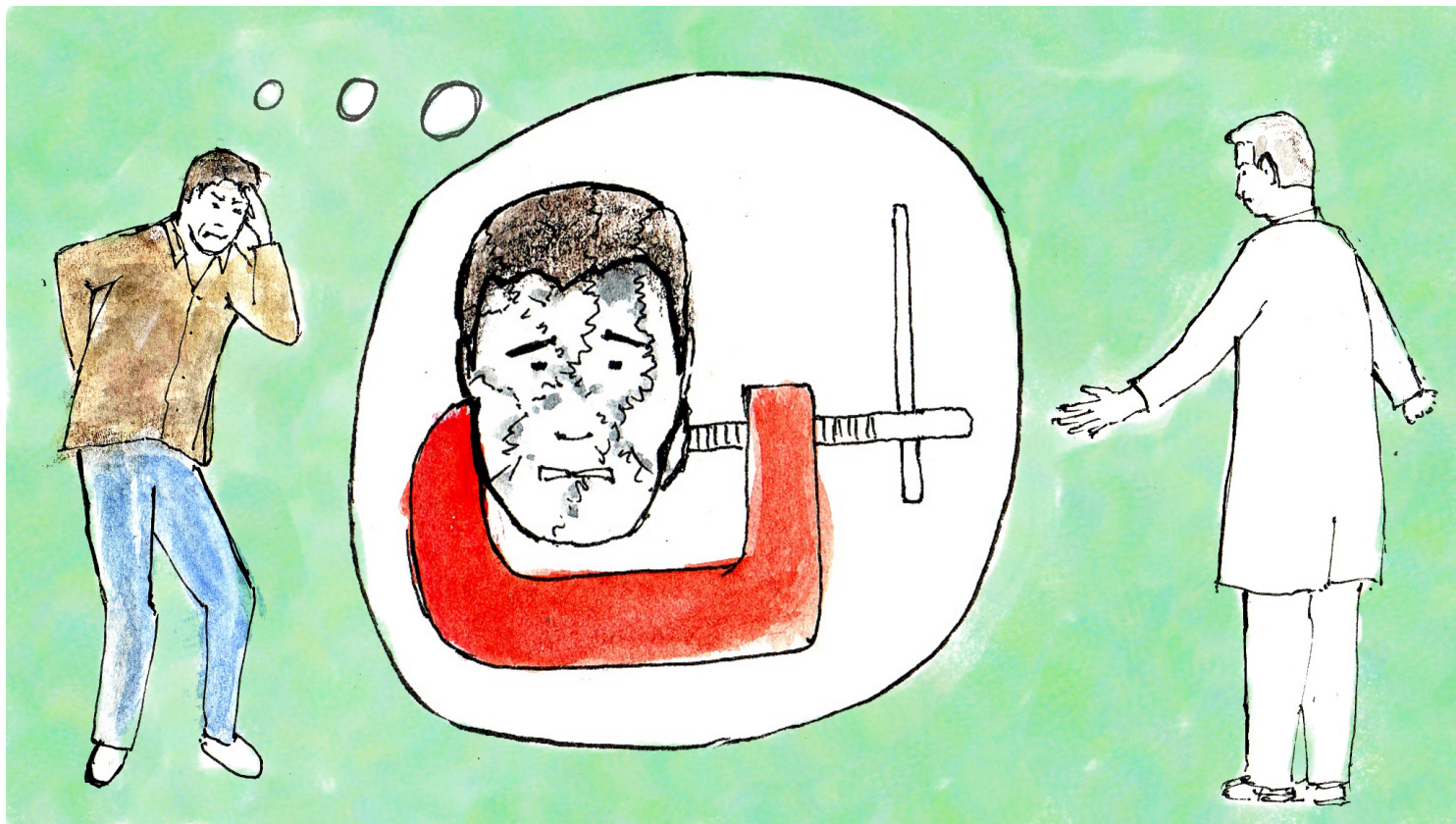


Zika Patients Are Coming Down With a Rare and Paralyzing Disorder. I Had it 13 Years Ago.

The medical community is alarmed by a surge in cases of the debilitating Guillain-Barré Syndrome. Back when I got it, no one had any idea what was wrong with me.



Story by Andrew North (<https://narratively.com/author/andrew-north/>)

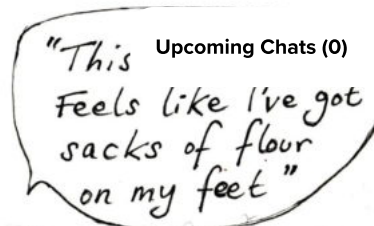
Illustrations by Andrew North (<https://narratively.com/author/andrew-north/>)

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Guillain-Barré Syndrome (GBS) is a rare autoimmune disorder that causes temporary paralysis. It's now in the news because of Zika, but I experienced it myself back in 2003, after reporting from Iraq on the U.S. invasion. When it started, I was not even sure anything was wrong with me.



I am in the newsroom just after returning from Baghdad and my legs feel weak. I also have a prickling sensation in my toes



I get home and think 'Maybe I can run it off.' But when I try I can barely lift my legs

Within a week, I would barely be able to walk or talk.

At the time, GBS (http://www.ninds.nih.gov/disorders/gbs/detail_gbs.htm) was one of those conditions you would never have heard of, unless – like me – you came down with it. On average, it affects only 1 in 100,000 people. But then the Zika virus landed in Brazil and spread across South America.

The signature symbol of the Zika outbreak has been the surge in microcephaly-afflicted babies (<http://motherboard.vice.com/read/the-little-known-virus-causing-a-panic-over-infant-brain-deformities-in-brazil>), born with abnormally small heads and brain damage. But this previously obscure virus may be akin to a missile carrying multiple warheads, which can detonate at different times both before and after impact. It turns out that Zika – which has a proclivity for brain tissue – may be causing other kinds of neurological mayhem (<http://www.bmj.com/content/353/bmj.i1901>) that only becomes apparent later in life with complications like impaired vision, hearing and development. Brazil and other South American countries worst hit by Zika have seen a seven-fold increase (<http://time.com/4209612/zika-guillain-barre-syndrome-cdc/>) in the number of GBS cases recently.

It is the birth defects that are the most worrying, but more people coming down with conditions like GBS means a significant extra health burden. One of the first challenges with GBS is actually diagnosing it:



More than 540 Zika cases – all people who were infected abroad – have now been reported in the United States, according to the Centers for Disease Control (CDC) (<https://www.cdc.gov/zika/index.html>). That is still very few compared to South America, but CDC officials say there's no room for complacency, with a surge in local Zika infections in the U.S. territory of Puerto Rico. And after changing its monitoring system, the CDC says it is now watching over 270 pregnant women – the group at highest risk – who have shown laboratory evidence (<https://www.cdc.gov/media/releases/2016/s0520-pregnant-women-zika.html>) of possible Zika infection, across the U.S. and U.S. territories.

If more people arrive in the U.S. infected with Zika and are then bitten by an *Aedes* mosquito, the virus could spread quickly. With the summer mosquito season approaching, scientists have discovered the *Aedes* variety is now breeding in at least thirty states, with one community close to the U.S. Capitol in Washington D.C. (<http://news.nd.edu/news/64004-mosquitos-capable-of-carrying-zika-virus-found-in-washington-dc/>) The building's users seem less convinced of the threat, with Congress granting the Obama Administration just over half of its \$1.9 billion request for emergency Zika-funding (<http://www.nytimes.com/2016/05/20/opinion/stealing-from-ebola-to-fight-zika.html?action=click&pgtype=Homepage&viewport=desktop&module=column-1&region=top-news&contentIndexValue=1&subIndexValue=0&feedIndexValue=4&storyKick=true&summary=true>) – and only then after a lot of cajoling and financial juggling.

Worldwide, the virus is already present in more than sixty countries, and the World Health Organization (WHO) is now predicting Zika could spread across Europe, with the greatest risk along the Black Sea coast. Earlier this year, it declared the outbreak a “public health emergency of international concern” (<http://www.who.int/emergencies/zika-virus/en/>), which the WHO last used for the Ebola epidemic in West Africa. With the full impact of Zika still emerging, it is possible that “long-term human and economic costs could be even greater than for Ebola,” Dr. Anthony Costello, head of the WHO's Department of Maternal, Newborn, Child and Adolescent Health, told me in an interview.

Part of that cost would be dealing with more GBS cases. Treating the condition is particularly expensive in its initial stages, as it is a medical emergency. The body's immune system effectively malfunctions and starts attacking its own nervous system.

When I was hit by GBS, no one was talking about Zika – and my case may have been triggered by a common stomach infection. But it put me in hospital for two weeks:

Upcoming Chats (0)



In the hospital, a neurologist takes over my care. I'm scared. With a test on the fluid in my spine he diagnoses the autoimmune disorder Guillain-Barré syndrome. My body is basically attacking itself. But it helps to know what I'm dealing with.

The danger with GBS is that it can attack your breathing, so I am hooked up to a ventilator. At least five per cent of cases are fatal. People getting GBS in South America are at much greater risk as many do not have access to good health care.

The condition gets its name from George Guillain and Jean Alexandre Barré, two French doctors, who, during WWI, first diagnosed it (https://en.wikipedia.org/wiki/Guillain%E2%80%93Barr%C3%A9_syndrome) in active soldiers. A century later, doctors still don't know exactly why it affects some people and not others – and how exactly it is triggered. But once it starts, the malfunctioning antibodies progressively shred the protective sheaths around your nerves – like the insulation on an electric wire – doing immense damage. Around five percent of GBS cases are fatal.

One common way of tackling serious cases of GBS is to give patients the expensive and potentially risky process of plasma exchange, in which all your blood is pumped out and cleansed of the “faulty” cells, allowing your body to replace them. Fortunately, I was able to avoid this treatment as I slowly stabilized:

Upcoming Chats (0)

Can the patient stand on one leg?"

After ten days in hospital, my symptoms peak. I become a research specimen instead. As GBS is so rare I am asked to appear before a weekly-hospital meeting. I feel like an exhibit as doctors ask questions. I eventually recover but it is four months before I can return to work.



Some people struck down by GBS only make a partial recovery, and need a wheelchair or walking aid. There are "troubling trends" in the spike in new GBS cases in South America, according to Candice Hoffman, a spokeswoman for the CDC. Around half the patients in one study "were still experiencing moderate to severe symptoms six months after they became ill," she said. But CDC scientists hope to learn more about how GBS works from research it is already conducting in Puerto Rico, as part of efforts to tackle the Zika outbreak there.

One of the challenges of dealing with the virus is that it effectively covers its tracks. Many people who get Zika never even realize it because the symptoms are usually mild. It is what doctors call a "silent infection," and therefore the number of cases could be massively under-reported. Some of the funding the Obama Administration has requested is for research into a vaccine. American scientists are at the forefront of what is now a global race to develop one and researchers at Johns Hopkins in Baltimore may have already made a breakthrough (<http://www.nytimes.com/2016/05/10/science/a-window-into-the-workings-of-zika.html?hp&action=click&pgtype=Homepage&clickSource=story-heading&module=second-column-region&region=top-news&WT.nav=top-news&r=0>).

Nonetheless, it could be years before a vaccine has passed all the usual F.D.A tests and is ready to be rolled out.

In the meantime, the best protection is not to get bitten – which means a good business opportunity for vendors of mosquito sprays and other critter killers (<http://adage.com/article/clios/sales-mosquito-repellent-soar-ahead-u-s-zika-outbreak/303642/>).

But how come Zika and its neurological missiles have taken the scientific community by surprise? After all, the virus was first detected (<http://www.bbc.com/news/world-africa-35431181>) back in 1947, in Uganda's "Zika" forest. The simple answer is that "viruses are always springing surprises," says Dr. Costello of the WHO. "When I first qualified as a doctor in 1981," he adds, "no one had heard of HIV/AIDS. But it [turned] out AIDS had been around a lot longer, and had been maintaining itself without being recognized." He says he hadn't heard of Zika until a year ago, because no one thought it did very much. Only when a strain of Zika showed up in French Polynesia in 2013 (<http://www.who.int/csr/don/7-march-2016-gbs-french-polynesia/en/>) was it first linked with microcephaly and Guillain-Barré.

It may then have mutated and hitched a ride on the modern globalized world to journey across the Atlantic Ocean to Brazil – possibly with soccer fans. (<http://www.theverge.com/2016/3/24/11298522/zika-virus-2014-world-cup-isnt-to-blame-brazil>) As no one had immunity to Zika, it spread rapidly. But now there is concern that Brazil could create a new vector to spread the virus, as thousands of people head there for the 2016 summer Olympics in Rio de Janeiro (http://www.nytimes.com/2016/03/05/sports/olympics/as-olympics-near-and-zika-spreads-no-talk-of-a-plan-b.html?_r=0). One hope though is that more people will develop immunity as the virus spreads.

Yet with so many unknowns, health agencies around the world are still searching for the correct response. “A lot of people have cried wolf before over previous disease outbreaks, so we have to be cautious,” admits Dr. Costello. “But we also have + ways. In the long term the impact of someone being handicapped could be worse than a death in the family **Upcoming Chats (0)**

I escaped the worst, but I’ll never forget that disturbing feeling of realizing my body is short-circuiting and malfunctioning – and then learning that it is actually attacking itself. If Zika spreads, it’s an experience that could become far more common.



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