

GONE IN SEVEN DAYS

A brief story of our daughter Michelle's vaccine injury and subsequent landmark court case

By Theresa Cedillo, August 3, 2009

I close my eyes, and it seems like yesterday that I can see my beloved and blessed little baby girl Michelle so full of life, good health, and with such a beautiful spirit. I open my eyes, and before me is my 14-year-old daughter, so broken with



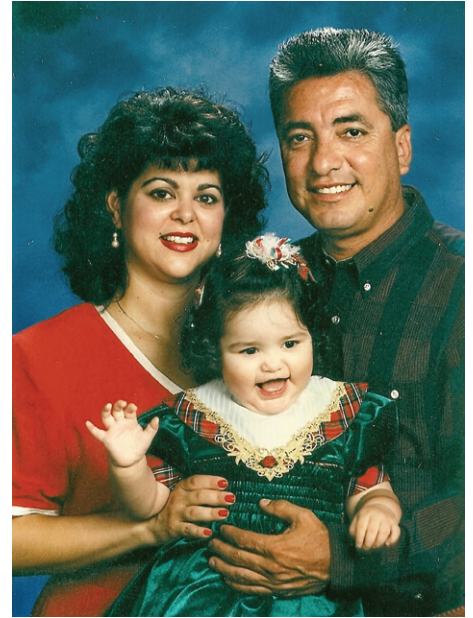
Michelle at 3 months old, very normal.



Dad with Michelle in 1995 at 8 months old, pre-MMR. She is so alert and engaged in her surroundings.

illness now and in such physical pain, but the beautiful spirit remains so strong.

In a seven-day period, Michelle's life, and ours, changed forever. On December 20, 1995, she received the measles, mumps, and rubella (MMR) vaccination. On December 27, 1995, she came down with a fever. That fever marked the beginning of a profound and dramatic decline in Michelle's health. Up until the age of 15 months, Michelle was a normal and healthy child. She talked, played, laughed, socialized, and ate normally. At the age of 14 years, she is now under the care of seven pediatric specialists, uses a feeding tube for nutrition and medication, and has been formerly diagnosed by pediatric specialists with the following: moderate-severe autism, Crohn's disease, arthritis, spondyloarthritis, osteoporosis, uveitis, open angle glaucoma, and intractable grand mal epilepsy. In addition, Michelle is legally blind in her right eye, does not speak, although she communicates with hand motions and tapping (on whatever is nearby). In addition, she hits herself when in pain or when frustrated. Just recently after she



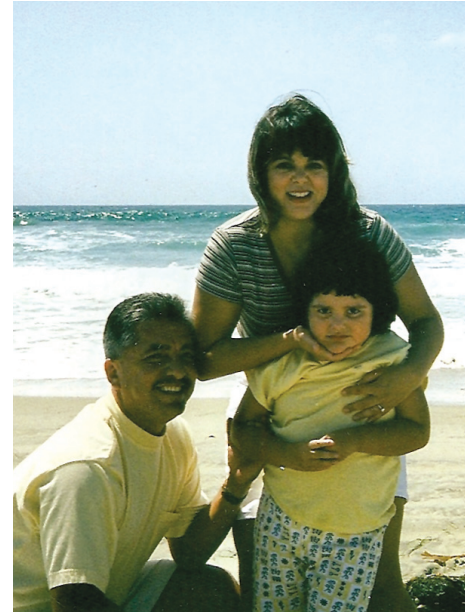
1995: One month before the MMR shot

spent five days in a children's hospital, her pediatric neurologist told us that her seizures are life threatening. Michelle is now at a high risk for SUDEP—sudden unexplained death in epilepsy. We monitor her 24 hours a day.

Sadly, the story of Michelle's period of normal development followed by regression and then a diagnosis of autism is not unique. Parents from all over the United States, the United Kingdom, Spain, Mexico, and many other countries share a remarkably similar story of normal development followed by regression and co-existing biological medical problems.

In 1997, after Michelle was diagnosed with autism, I began researching online and talking to other parents by telephone. I soon became aware of Dr. Andrew Wakefield's studies involving regression, autism, gastrointestinal disease, and the MMR. His studies, research by other scientists, and advice from parents started us on a journey to find out what had happened to Michelle and how to bring her back. We wanted to treat whatever had happened to her. We wanted her to be healthy again. Sadly, Michelle has not

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Young Michelle: “before” (approx. 8 months old) and “after” (approx. 26 months old)

Age 5 or 6 years old in San Diego, California.

regained her health. We have taken her all over the United States—Long Island, Austin, Los Angeles, San Diego, Phoenix, and Tucson—in our efforts to diagnose and treat her medical problems. We are faced with the harsh reality that her medical condition continues to worsen as she ages.

In 1998, we filed with the National Vaccine Injury Compensation Program, a program created by the United States Congress as an alternative to the traditional tort system. The purpose is to resolve vaccine injury claims and provide compensation to people found to be injured by certain vaccines.

But it was not until nearly nine years later that Michelle’s case was heard. Between the time we filed and her hearing, more than 5,000 claims were filed for vaccine injury and autism. To better process these claims, the United States Court of Federal Claims formed the Omnibus Autism Proceeding on July 3, 2002. In early 2007, Michelle’s attorneys at Conway, Homer, Chin-Caplan informed us that Michelle’s case had been chosen to be the first test case under the Omnibus Autism Proceeding in the U.S. Court of Federal Claims. The hearing was to take place in Washington D.C. My family and I were extremely honored that Michelle’s case was chosen to represent the many similar cases in the Omnibus.

We live in Arizona, clear across the country from Washington, D.C. It took us nearly a month to plan, pack, and ship everything we would need for the 3-week stay in Washington. Arrangements had to be made for a hospital bed, a feeding pump, oxygen (for seizures), a registered nurse to administer Humira injections while I attended the hearing, the enteral formula, and a wheelchair. In addition, it took the creativity of our entire family to devise a setting where Michelle would be comfortable, so she would not want to leave immediately to come home! In between planning the trip, when not busy with Michelle’s daily care, my days were consumed with preparing for her case to be heard. Michelle’s medical history to that point consisted of thousands of pages of documents. Some days I spent an entire day looking for one document or reviewing a certain time period in preparation for the hearing.

I must have done a mental walk through of the airport and flying with Michelle 100 times. We had flown when Michelle was younger to New York, but she was older now, and I did not know how she would handle the noisy, congested airport and flight. We drove three hours to the Phoenix airport and boarded the plane to Washington, D.C. Michelle did not sleep the night before and was exhausted by the time the plane took off. She slept

most of the flight. When we landed, we found transportation and began our drive to the hotel. My very first phone call in Washington came from a reporter at the *Washington Post*. Being on a tight deadline, he interviewed me on the phone with Michelle sitting next to me in the back of a taxi as we made our way through the historic city.

That night Michelle’s attorney Kevin Conway, my husband, and I did an interview with the Associated Press. Over the weekend, *People* magazine came to the hotel to photograph Michelle for an article that would appear a few weeks later.

Although the autism/vaccine injury theory had become very controversial, Michelle and my family were treated with respect by those who interviewed us. They showed concern for her and were interested in listening to how she had become so sick and what the hearing would be about.

On June 11, 2007, the hearing began. For two and a half weeks, Michelle, her father, grandfather, aunts, uncle, and I attended the hearing.

The first week was the petitioner’s (Michelle’s) week. We presented our theory and our medical evidence with six expert witnesses along with my oral testimony. We were all cross-examined by the U.S. Department of Health and Human Services (respondent) attorneys.

PARENT'S PERSPECTIVE

Our focus must always remain on the children who have been injured (some are adults now) and the quest for their help.



September 26, 2003: Michelle, 9 years old, sleeping on the plane ride back from Long Island, NY, where we took her to see Dr. Arthur Krigsman. She was recovering from a 3-week hospital admission and was still quite ill during this time.



July 25, 2003: Michelle is very sick and would be hospitalized the next day. She was severely malnourished and clinically anorexic. She was already having eye problems, was unable to eat, and had nearly stopped taking in fluids. This is when she had to get the feeding tube placed. The reasons that Michelle's legs are bruised in this picture are: 1) she was hitting herself from pain; and 2) she had developed a coagulation disorder secondary to malnutrition from vitamin K deficiency.

The very first day of the hearing, oral testimony began with Dr. Vasken Aposhian, an environmental toxicologist, who is a professor of molecular and cellular biology as well as professor of pharmacology at the University of Arizona. Next, I was sworn in and began my testimony in the afternoon. My testimony took us through the end of the day. The next morning, I resumed testifying and continued until the lunch break. Dr. Arthur Krigsman, a pediatric gastroenterologist, followed my testimony in the afternoon.

Speaking only from a mom's perspective, it was quite an experience to testify under oath and to be cross-examined about that testimony. I was nervous at the beginning, but once I began answering questions about Michelle, her decline in health, and what she has endured, it really all became about telling her story. It's what her life and our family's has been all about for the past 12 years. As I testified, I lost my nervousness, and it was replaced with a sense of justice at finally having legal documentation of what had taken place in her life. I felt the strength of every other parent I had ever talked to or e-mailed who had a story similar to my daughter's.

Although I was telling Michelle's story, I felt as though I was speaking on behalf of all the other injured children (at least partially).

The rest of the week continued with Dr. Karin Hepner, Dr. Ron Kennedy, Dr. Vera Byers and Dr. Marcel Kinsbourne, all testifying on behalf of Michelle.

The second week and into the beginning of the third week, the respondent used 17 expert witnesses, 10 of whom gave oral testimony, to testify against Michelle's case and our theory of vaccine injury.

The hearing concluded on June 26th, with closing statements by both sides.

Over the next few days we packed our things and took the long flight back home. We settled back into our normal routine and tried to keep talk of a decision to a minimum. We knew there was not a set date, and there was no way to tell how long the court would take to make a determination.

As the months passed, Michelle's medical conditions showed signs worsening. Her gastrointestinal disease began giving her problems, and her eye disease required frequent exams with specialists. Then, Michelle was diagnosed

and began treatment for osteoporosis as well as chronic pain syndrome. In addition, we began to see a slow increase in seizure activity.

On February 11, 2009, nearly 20 months after the completion of Michelle's hearing, I received a call from her attorney. We were at the hospital, and Michelle was undergoing a procedure to check her small bowel. I was told that the decision was going to be released the next day. Early the next morning, we received word that Michelle, along with the Hazelhurst and Snyder families, had lost her case.

I had waited so long for a decision that it was relief to finally know, but this was not the decision we had hoped for. With so many medical costs and intensive care in Michelle's future, we had hoped for some degree of compensation to help cover these costs.

I felt then, as I do now, that we presented a strong and solid case. I also knew that this would be only the first step of many in this long legal process. The following month Michelle's attorneys filed an appellate brief.

July 7, 2009, oral arguments were presented in Washington D.C. by Kevin



Michelle in the hospital June 2004 getting an IV infusion of Remicade as treatment for inflammatory bowel disease.



Above right, top two photos: Summer 2009, Michelle in her room.

Bottom two photos: June 2009, when Michelle was admitted to the Pediatric Epilepsy Monitoring Unit. This is why her head is wrapped and she has an IV line in her hand. You will notice that Michelle had gained a large amount of weight. This is due primarily to some of the medications she has taken in the past and also the anti-seizure medication she currently takes in very high doses.

We never give up, we defy odds, we keep searching for answers, and we keep fighting for the justice so deserved in this tragedy.

Conway on Michelle's behalf, for her appeal.

At the time that I am writing this, no date has yet been given for a decision on the appeal.

We have come such a long way, with likely an equally long way ahead of us. The continuing legal fight will not be an easy one. We stand strong in the knowledge of the factual evidence, along with increasing new research in our favor. Our focus must always remain on the children who have been injured (some are adults now) and the quest for their help. It is unfortunate that in this medical controversy, the children sometimes gets lost. Those injured must always remain the focus on all levels and by every individual involved.

I am proud to be part of an international community of parents who have banded together with very minimal resources for the sake of our injured and suffering children. I don't think there has been or ever will be a group of parents and families quite like ours ever again. We never give up, we defy odds, we keep searching for answers, and we keep fighting for the justice so deserved in this tragedy. God bless each and every one of us as we continue on.

CODA: THE INJUSTICE CONTINUES

By Kevin Conway, Esquire

Vaccines are an integral part of our nation's health policy. For this reason, federal law forbids lawsuits against vaccine manufacturers until claims are processed in the federal Vaccine Injury Compensation Program (VICP). When Congress established the Program in 1988, it intended to discourage civil lawsuits by creating a far better alternative. The Program, Congress hoped, would discourage lawsuits by providing vaccine-injured persons with quick, informal, and generous resolutions of their claims.

In many ways, the VICP has worked. Persons have received compensation for optic neuritis, acute-disseminated

PARENT'S PERSPECTIVE

encephalomyelitis (ADEM), multiple sclerosis, transverse myelitis, Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy (CIDP), intractable seizures, death, and scarring. They have been compensated for vaccine-induced brain injuries, such as attention deficit disorder, encephalopathy, learning disabilities, and behavioral problems. They have been compensated for mental retardation in a child who became autistic, for ADEM and resulting Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and for autistic-like symptoms in a child with an underlying mitochondrial disorder.

When she filed her claim in the Vaccine Injury Compensation Program on December 9, 1998, Michelle Cedillo was 4 years old. She said that vaccines caused her to suffer brain damage and autism. Her medical records showed she was healthy until the age of 15 months, received vaccines, had high fevers, and was never again the same healthy girl. Her doctors associated the change with the vaccines. The Secretary of Health and Human Services, however, disputed her claim.

In a typical VICP case, each side presents the expert testimony of a single expert. A special master then decides the case. In Michelle's case, however, the government used *seventeen* experts to refute her claim. Why? Because she claimed vaccines caused her autism. Unfortunately for Michelle, this was a problem. By the time her case went to hearing in 2007, it was clear that many vaccines had contained a toxic substance (mercury) during a time when the number of cases of autism had exploded. Due to the extraordinary publicity this issue had received, officials feared parents would refuse to immunize their children, that immunization rates would fall, and that preventable diseases would return.

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So, Michelle's highly visible and widely publicized claim had to be soundly defeated. In an extraordinary 174-page decision, the special master rejected her claim.

In her appeal, Michelle said that she had submitted sufficient evidence that her vaccines had harmed her. She claimed the special master purposely turned a blind eye on her evidence, especially the substantial concessions by the respondent's own expert witnesses. She claimed the special master had abandoned his obligation to impartially weigh the evidence. She argued that the special master had inappropriately assumed the government's role as

protector of the integrity of vaccines. She argued she had been denied fundamental fairness. On August 6, 2009, the U.S. Court of Federal Claims denied Michelle's request to overturn the special master's decision. The appeals of the Hazlehurst and Snyder families were also quickly rejected.

Michelle has options. She has until October 6, 2009 to appeal her case to the Federal Circuit Court of Appeals. She can leave the Vaccine Injury Compensation Program and file a civil action against the vaccine manufacturers. She can simply give up and accept the fact that the system has failed her. But no matter what, Michelle has inspired a generation of families with autistic children to carry on the fight – a fight that was never about "compensation." It was about finding how these children were lost – and about finding a way to bring them home again.