

Faces of  
**ANTIMICROBIAL  
RESISTANCE**



**IDSA**

Infectious Diseases Society of America

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# FOREWORD



Antimicrobial resistance (AMR) is a growing threat to the United States health care system. As an infectious diseases physician I am devastated each time I have to tell a patient that they have run out of options to treat an infection caused by a resistant pathogen. No individual in the 21st century should have to worry about losing his or her life to an infection that was once easy to treat with antimicrobial drugs. Unfortunately, this nightmare scenario is increasingly common. Patients are battling life-threatening illnesses contracted during routine surgeries, cancer treatments, or therapies for chronic diseases.

From the 2016 discovery of the highly resistant *mcr-1* gene in the US to the 2017 death of a Nevada woman due to an infection resistant to all available antibiotics, the AMR crisis is receiving increasing public attention, and for good reason. We've all seen the numbers: antibiotic resistance alone accounts for at least 23,000 deaths, over 2 million illnesses, and over \$20 billion in unnecessary health care costs each year. But press reports and statistics only tell part of the story. Patients like mine—real people, grandparents, parents, children, neighbors, and friends—are the reason we must address the problem of antimicrobial resistance.

This *Faces of Antimicrobial Resistance* report highlights some of these individuals, whose stories demonstrate the urgent need to combat AMR. There is no silver bullet for AMR; we need a robust, multi-faceted approach that includes infection prevention, antimicrobial stewardship, surveillance, research, innovation and an expert workforce. A combination of well-coordinated strategies will be necessary to protect patient safety and the public health and turn the tide of this crisis.

William Powderly, MD, FIDSA  
President, Infectious Diseases Society of America  
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My son Braxe Ruesch was 2-½ when he had what seemed like a recurring ear infection that we believe he contracted at day care. It would be treated, clear and then return. Finally, a doctor took a culture of the stuff leaking from his ear. I still remember the phone call telling us it was methicillin-resistant *Staphylococcus aureus*, or MRSA. I had suffered from many staph infections, so I was familiar with MRSA and was terrified when I heard the news.

The doctor prescribed several antibiotics in an attempt to treat the infection. Braxe wasn't in any real pain, and the only symptom was thick oozing fluid in his ear. But my wife and I were fearful, knowing that with every failed attempt to cure the infection the situation became more critical.

We ultimately took Braxe to Duke University Hospital's infectious disease team and he was seen by Dr. Michael Cohen-Wolkowicz, who saved Braxe and changed our lives. Dr. Cohen-Wolkowicz said Braxe had to be admitted to the hospital, which was frightening. I believe the first course of medicine was vancomycin administered through an IV, not an easy thing for a 2-½-year-old. Braxe was not allowed to leave the hospital room for the week he was there, which was difficult in itself. It was Halloween, and he had to dress up in the room and watch from the doorway while the other sick kids marched by in their outfits, which was heartbreaking. The next day was his older brother's birthday, and we celebrated in the confines of the hospital room.

**“But my wife and I were fearful, knowing that with every failed attempt to cure the infection the situation became more critical.”**



# BRAXE RUESCH

Durham, NC

*As told by his father, Kurt*

I had to sit with Braxe while he was placed on a machine for a CT scan. I will never forget his look of fear and confusion. I also remember feeling helpless and fearful as he was placed under anesthesia for a procedure.

After a week, we were able to take Braxe home, but three times a day for three hours at a time we had to hook him up to the IV to administer the medication. Just hooking him up to the IV was extremely stressful. There was an intense process of sterilization, and we were terrified that we would do something wrong that would make the situation worse. It was challenging having an active 2-½-year old running around while being hooked up to an IV – similar to chasing a puppy on a leash.

After two weeks of that, Braxe was tested to see if the MRSA was gone. It wasn't, which was crushing.

We tried to be hopeful and positive, but we felt as though we were out of options. Doctors told us they wanted to try a new drug that could help, but noted it could damage Braxe's internal organs because it wasn't made for small children. We were not overly optimistic that it would work, but thankfully, it did. The MRSA was finally gone.

We believe Braxe's inability to hear out of one ear at a time when his speech was forming caused him to develop speech problems. He still has issues with certain sounds. My wife and I both struggled emotionally during this time and the fear made a lasting impression on us.

We're thankful we have had a happy ending. But the next child may not be so lucky.

# PEGGY LILLIS

Brooklyn, NY




*As told by her son, Liam*

On Tuesday, April 13, my mom had a root canal, and the dentist prescribed the antibiotic clindamycin to treat an abscess. The next day, she felt fine. On Thursday, mom came home from work and said she didn't feel well. Thinking she caught a bug from one of her students, she still went to her class that night.

The following day, though, my mom stayed home from work, which is something she almost never did. She ended up in bed all weekend with what she thought was a stomach virus. On Saturday, she spoke to her doctor by phone. He prescribed, by phone, a prescription strength anti-diarrheal medicine and told her she should see a GI doctor on Monday. She began taking the medication later that day. We came to find out later that an anti-diarrheal medicine is one of the worst things you can take when you have *Clostridium difficile*, or *C. diff*.

That Saturday, my fiancée Melissa's grandfather suddenly passed away, and my mom told me to go take care of Melissa. We continued to check in on my mom – as did my brother, Christian, by phone – bringing her soup, tea and other liquids. She still had difficulty keeping anything down, and seemed to be getting worse. Worried that she had been sick for several days, on Monday, Christian spoke to mom; they agreed that he would take her to the doctor the next day.

On Tuesday, April 20th, my brother came over to take my mom to her doctor's appointment. But she was very pale, somewhat weak and dizzy. Worried about dehydration, we decided that she should be taken to the hospital instead, and we called 911. The medics arrived to take her to the hospital and discovered that, despite her still being up walking and talking, her blood pressure was dangerously low. This is the first sign that something was seriously wrong.



Christian called me at the wake and told me to come to the hospital. Upon arrival at the hospital, the emergency room physicians had determined that my mom had a massive infection, later determined to be caused by *Clostridium difficile*, which was brought on by antibiotic use. Despite being lucid, and telling us she was fine, my mom was in septic shock. They began fluid and antibiotic therapy. Christian and I called our family to tell them that my mom was really sick. Because she was in shock, the doctors said she was unable to make her own medical decisions. So we decided that Christian would, with me and our Aunt Helen, who is a nurse.

The doctors started a central line for fluids and antibiotics, performed additional blood tests, scheduled my mom for a CT scan and performed a colonoscopy to determine if she had an obstruction. She was sedated and intubated to make sure her airway wasn't compromised during the procedures. The doctors continue treating my mom with IV antibiotics and other drugs, and told us that if she didn't respond by morning they would do surgery to remove her colon "in an attempt to save her life." It was at this point that we realized that what we initially thought was the flu only four days ago could ultimately cost my mom her life. Even though the doctor told us to go home and get some rest, that he would call us if surgery was necessary, we stayed as long as we could, surrounded by mom's brothers, sisters, cousins and close friends. Even some of Christian and my friends. Eventually, we all went back to our house to try and sleep, and pray.

**"...They would remove her colon 'in an attempt to save her life'."**

At six o'clock the next morning, the doctor called Christian and told us to get to the hospital. My mom had not improved overnight and surgery was necessary. The doctor told us that she was so ill he was afraid she wouldn't survive surgery, but that she would very likely die from sepsis without it. We consented to the surgery, which my mom survived.

From late morning until the afternoon, it seemed that she was improving. But around 4 pm, her vital signs started to deteriorate. The doctors put her on 100% oxygen and provided additional drugs to support her blood pressure. She continued to decline throughout the afternoon.

At 7:20 pm, the ICU doctor informed us that my mom had passed. She had gone into cardiac arrest. They had tried to revive her several times to no avail.



# TIMOTHY MOK

Lexington, KY

During his second year of hematology and oncology pharmacy residency at the University of Kentucky, Timothy “Timmy” Mok traveled to Maryland for one of his rotations to learn to practice in a real-world environment. A month into the rotation, he began to feel extreme stomach pain. He went to a hospital in Virginia, where he was diagnosed with a perforated appendix and was told he would need surgery.

Before the surgery could occur, however, doctors discovered an abdominal abscess and said it would need to be treated first. Doctors placed a drain over the site of the abscess and fluid was collected and tested. The culture showed he had an infection caused by extended spectrum beta-lactamase (ESBL) positive *Escherichia coli*, or *E. coli*, as well as resistant strains of two other bacteria. This particular strain of *E. coli* is highly resistant to a wide variety of antibiotics, making these infections especially difficult to treat.

Due to the resistant nature of the bacteria, Timmy was placed in isolation in the hospital, and had to stay in Virginia longer than originally planned which was emotionally tough as he had no family in the area. Family members had to take vacation time to stay with him during his ordeal. Timmy was grateful to have visits from new friends he met during his rotation.

**“Timmy  
was placed  
in isolation.”**

After many weeks, he was finally cleared to go home. His discharge was delayed because the resistant nature of the bacteria would require insurance approval of home IV antibiotics. He was not able to return to work until a month after he was hospitalized. This greatly impacted his residency training and added a large financial burden. He is still not sure where he may have been exposed to the resistant bacteria as he does not have any prior medical conditions; he believes it may have happened while he was working in a hospital. Nevertheless, Timmy is very thankful and feels lucky the infection resolved.



# MARCUS GLOVER

Middletown, NY



One week after shoulder surgery, Marcus began having bad stomach pains and severe diarrhea. At first he ignored it, but eventually he began to worry when he had trouble staying hydrated and felt cold all of the time. He saw a doctor who thought he may have caught a virus from his mother, and was told he could get a colonoscopy or go home. He chose to go home.

**“...Eventually he began to worry when he had trouble staying hydrated and felt cold all of the time.”**

Soon after Marcus returned home, his dog stepped on his stomach, causing shooting pain in his abdomen, so he went to the emergency room (ER). The ER doctor gave him antibiotics and told him to rest. Marcus remembers being very sweaty and having very dark urine. He was suffering from extreme dehydration and the doctors ordered tests to identify the cause. Marcus lost 20 lbs. due to dehydration.

Doctors determined that during his shoulder surgery Marcus became infected with *Clostridium difficile*, an intestinal bacterium that seriously disrupts the digestive system, causing diarrhea and fatal dehydration if not identified quickly. Doctors tried several antibiotics before they found one that worked, and it took several weeks before Marcus was back to normal. He missed a month of work due to his illness, and he had to undergo special procedures the next time he had surgery for fear of re-infection. Prior to the infection he had few digestion and stomach issues but he now has had recurring problems that have sent him to the doctor several times.



Meredith Littlejohn’s parents, Steve and Stefanie, remember their daughter’s hope-filled optimism and amazing courage throughout her treatment for acute myeloid leukemia (AML). She was first diagnosed in mid-November 2012, when she was a high school senior at the top of her class. Meredith, or “Mert,” had an exciting life ahead of her, and would soon be accepted early to Emory University.

There were four rounds of chemotherapy over the next months, with brief home respites between rounds until April when she went into remission. Meredith and her family and friends were thrilled she was able to attend her senior prom and graduation. But, in June of 2013, she suffered a relapse. She resumed treatment, and did well until August, when she contracted *Candida*, a fungal infection that is not uncommon in AML patients. Her infection did not respond to traditional treatments and her infectious diseases doctors called colleagues across the country to find an effective treatment. Fortunately, they found an effective combination of therapies and her infection cleared.

**“During the procedure her blood oxygen levels dropped significantly and she went into septic shock.”**

Meredith spent her 19th birthday in the intensive care unit (ICU), where she still managed to throw quite the party with her friends. She was thrilled when a few of the hospital residents she thought were cute dropped by to wish her happy birthday, and she also received a tweet from an actress on her favorite TV show “Gossip Girl.”

# MEREDITH LITTLEJOHN

## St. Louis, MO

In September, Meredith left the ICU and returned to the children's oncology floor, but then she was diagnosed with a *Pseudomonas* infection under her arm. Her doctors monitored the infection as she had more cancer treatment.

Because the infection was resistant to newer antibiotics, doctors prepared to use colistin in case it spread to her blood stream. Colistin is considered an antibiotic of last resort due to its extremely toxic effect on kidneys, which are already compromised in someone undergoing chemotherapy.

In early October, Meredith had a bone marrow transplant, which was successful. Her blood was 100% replaced by the donor's blood, changing her blood type. However, infection still plagued her and she began receiving colistin. As mucus plugs accumulated in her lungs, intubation helped her breathe and her doctors performed several plug removal surgeries. Meanwhile, although the infection spread to her lungs, her body responded extremely well to the surgeries, and her family and friends looked forward to rehabilitation.

To begin rehab, she had a tracheotomy – an incision in her windpipe – so she could get rid of her breathing tube and function during physical therapy. During the tracheotomy procedure her blood oxygen levels dropped significantly and she went into septic shock because the *Pseudomonas* had reached her bloodstream. Although the doctors resuscitated her, and did so again when she went into shock the following day, on the next day, the infection prevailed despite the team's best efforts. Meredith died a year after her AML diagnosis – not of the cancer, but of an antibiotic-resistant infection.

# TATIANA CHIPREZ VARGAS

Stockton, CA

“June 7, 2014 was the best day of my life,” said Tatiana Chiprez Vargas of Stockton, California. “It was our special day, our wedding day. It was the most amazing day ever.”

Just a few weeks later, Chiprez Vargas was lying in a Northern California hospital’s Intensive Care Unit (ICU) fighting off a deadly bacterial infection.

In late-June 2014, Chiprez Vargas, then 25 years old, had just returned from her honeymoon. She and her husband had tied the knot after dating for seven years and were both excited about their future together.

While at work one day, Chiprez Vargas began feeling ill. As the day went on, she felt more and more tired and finally decided to leave early. After trying over-the-counter cold and flu medicine, her symptoms did not improve and actually began to get worse. Her chest and back began to hurt and she could not lie on her back.

Not able to handle the pain any longer, Chiprez Vargas went to the ER where she was diagnosed with strep throat, treated with antibiotics and released. She couldn’t keep the medication down and with her health declining further, she went back to the hospital.

Chiprez Vargas was admitted to the ICU with a 103 degree fever, nausea, shortness of breath and chest pain. She began coughing up blood and her lungs began shutting down. Following blood tests and a consultation with several doctors, including an infectious diseases specialist, she was diagnosed with something commonly known as a staph infection. In her case, a difficult to treat infection called methicillin-resistant *Staphylococcus aureus* (MRSA).



MRSA refers to a bacterium commonly found in humans, *Staphylococcus aureus*, which has mutated so that methicillin, the antibiotic that once could control it, is no longer effective. It can cause a variety of complications, including skin infections, pneumonia and bloodstream infections.

In the hospital, Chiprez Vargas was quarantined as doctors worked to treat her. She was given an antibiotic that is active against MRSA and she began showing improvement. She was released on the Fourth of July, but was readmitted shortly after with the infection still in her lungs. She also had contracted a secondary infection. Following a second round of treatment and testing, she was finally released.

**“A lot of people don’t know what MRSA is until something happens.”**

How Chiprez Vargas contracted MRSA remains a mystery.

Today, Chiprez Vargas is doing well, but has a chronic cough. She doesn’t remember much of her time spent in the hospital, but the ordeal has left a lasting impression. Any sign of a cold makes her feel like MRSA might strike again.

Looking back on her experience, she hopes that her story helps raise awareness around antibiotic resistance.

“A lot of people don’t know what MRSA is until something happens. I think a lot of people still need to know what’s out there.”



Born with Cystic Fibrosis (CF), Brianna Strand was used to being treated for the routine lung infections associated with the disease. Beginning her junior year at Washington State University, however, something changed. She had been getting ongoing CF treatment at the university facility, but after several extended courses of antibiotics, her lungs still did not feel normal. Because she had experienced a year-long decline in lung function, her doctor suggested she visit a specialist at the University of Washington.

The summer after her graduation in 2012, Brianna began receiving treatment at the UW health center, where infectious diseases physician Dr. Paul Pottinger took a culture from her lungs and found *Mycobacterium abscessus*. *M. abscessus* is a hospital-acquired infection (HAI) that usually causes minor skin infections, but in patients with chronic lung diseases, it can cause significant problems. Due to the infection and CF, Brianna began a combination of 2-3 antibiotics a day that though cumbersome, was manageable.

**“Her health problems disqualify her from having a lung transplant because the risk of infection is too high.”**



# BRIANNA STRAND

Port Orchard, WA

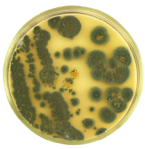
In 2014, Brianna went back to UW after an infection flare-up. She had a high fever and could not keep food down for more than a month. Doctors constantly switched and adjusted her medications and dosages to try to get the infection under control without making her ill. Eventually her doctor hit upon a combination that seemed to work. It took several months to get it under control, and her new drug regimen involves taking 2 intravenous antibiotics around the clock, as well as 2 orally each day.

Brianna must now have her lungs tested for infection every three months, and a nurse visits weekly to ensure the infection is not flaring up. Her health problems disqualify her from having a lung transplant because the risk of infection spreading to the new lung is too high. Equally devastating is that she and her husband cannot have children while she remains on the high doses of the antibiotics she is taking. She hopes a new antibiotic will be approved that will clear her infection, and allow her to have children and undergo a lung transplant.

# The Development of ANTIMICROBIAL RESISTANCE

● **1943**

Penicillin introduced as first commercially available antibiotic.



● **1946**

Streptomycin introduced commercially as first drug effective against tuberculosis.



**1950's-70's**

more than 20 new classes of antibiotics are introduced commercially in this thirty year period often referred to as the "Golden Age of Antibiotics."

● **1950**

Tetracycline introduced commercially as a new class of antibiotic.



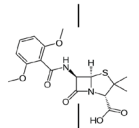
● **1959**

Strains of *Shigella* bacteria begin to show resistance to tetracycline.



● **1960**

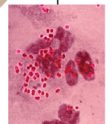
Methicillin is introduced as a next generation penicillin.



1940  
2020

1950

2010



● **2017**

A Nevada woman dies from a bacterial infection resistant to all 26 antibiotics available in the United States.

● **2016**

A new resistance gene, *mcr-1*, which conveys resistance to several last line antibiotics is found circulating in several US states for the first time.

● **2015**

The National Action Plan to Combat Antibiotic Resistant Bacteria is unveiled as a multipronged approach to addressing the increasingly dire threat of antimicrobial resistance.

● **2013**

The Centers for Disease Control and Prevention release their "Antibiotic Resistant Threats in the United States" report which lists 3 "urgent" threats, 12 "serious" threats, and 3 "concerning" threats.

● **2012**

Several hospitals report outbreaks of carbapenem resistant Enterobacteriaceae (CRE) due to improperly cleaned duodenoscopes.

● **2009**

Strains of *Neisseria gonorrhoeae* are found that are resistant to all known treatments are discovered.



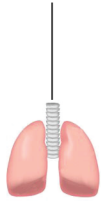
● **1964**

IDSA's first President Maxwell Finland warns of the dangers of antibiotic resistance in bacteria and champions some of the early work in the field.



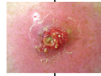
● **1965**

Penicillin resistant pneumonia begins to spread.



● **1968**

First US case of methicillin resistant *Staphylococcus aureus* (MRSA) in a Boston hospital.



● **1970's-80's**

over 60 antibiotics are discovered in this twenty year period, mostly variations on already discovered classes.

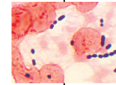
● **1972**

Vancomycin is introduced in the US.



● **1988**

Vancomycin resistant *Enterococcus* (VRE) are discovered.



● **1990's-2000's**

The number of companies conducting antimicrobial research plummets from several dozens to single digits as 'low hanging fruit' already has been discovered and commercial returns on new antibiotics become inadequate.

1970

1980

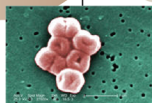
1990

2000

● **NDM-1**

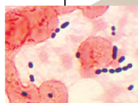
● **2008**

A new gene called New Delhi metallo-beta-lactamase (NDM-1) is discovered that gives bacteria complete resistant to two of the largest and most used classes of antibiotics.



● **2004/5**

Strains of *Acinetobacter* and *Pseudomonas* are discovered that have become resistant to virtually all known antibiotics.



● **2000**

The first case of extremely drug resistant tuberculosis is diagnosed (XDR TB).

● **1996**

Levofloxacin introduced as a second line antibiotic to combat pneumonia resistant to more common antibiotics, but some strains develop resistance to this new treatment within the year.



● **1990's-2010's**

Only 2 new classes of antibiotics are commercially introduced in this thirty year period.

**Legend**



Progressive Steps



Events of Resistance

# CATHERINE DUFF

Carmel, IN

I was already very sick when I had my first *Clostridium difficile* (*C. diff.*) infection. It was the fall of 2005, I was driving home from a dinner and started having intense pain in my abdomen. I drove to the emergency room, had a CT scan, was diagnosed with severe diverticulitis, put on antibiotics and had surgery to remove one-third of my colon. My pain became worse. I collapsed and was taken back into surgery because an abscess had burst, and I developed a serious blood infection. I was put on intravenous (IV) antibiotics, diagnosed with MRSA (methicillin-resistant *Staphylococcus aureus*) and developed *C. diff.* from the antibiotics.

I woke up from the second surgery with a colostomy bag to collect waste products. It took five months of IV antibiotics before I got better. In May 2006, I had another surgery to reverse my colostomy, and was given antibiotics. I developed *C. diff.* again. It took five months of antibiotics to get better and allow me to return to work. I missed an entire year. During the next six years, I developed *C. diff.* six more times. Each time it was worse, and took longer to recover. Eventually I couldn't work. For months at a time I had diarrhea up to 30 times a day. I was bedridden and lost almost 70 pounds. I developed a fast heart rate and my kidneys started failing.

The seventh *C. diff.* infection in April 2012 was resistant to antibiotics. After several months of trying different antibiotics, my doctors told me they had nothing left to offer, and that I should say my goodbyes to my family. Knowing modern medicine could not save my life was surreal. My family learned of an experimental treatment called fecal microbiota transplant (FMT). The treatment involves the donation of stool from a healthy, tested donor to the patient.



Because the doctors wouldn't perform it, we did it at home, with my husband as the donor. Within four hours I felt almost normal. If I hadn't experience it myself, I wouldn't have believed it.

**“My doctors told me they had nothing left to offer and that I should say my goodbyes to my family.”**

I completely recovered, but within months had to undergo emergency spinal fusion. I was given IV antibiotics (against orders) and developed *C. diff.* again. It was antibiotic-resistant. After several months, one of my doctors agreed to perform FMT by colonoscopy. It worked just as it had before and right away I felt almost fine.

While I recovered, I couldn't stop thinking of the 30,000 Americans a year who die from *C. diff.* who never had the chance of receiving the life-saving treatment. So early in 2014 I started The Fecal Transplant Foundation to provide education, raise awareness and advocate for patients and for the science of FMT. Since then I've become involved with several groups working on the world-wide epidemic of antibiotic-resistant bacteria. Giving antibiotics needlessly contributes to the problem, whether for *C. diff.*, infections that are viral, not bacterial, or for infections that would clear up on their own. Another problem is the use of antibiotics in our food and water supplies and the increasing speed with which quickly evolving bacteria are developing resistance to even antibiotics of last resort. Please think twice the next time you are prescribed (or prescribing) antibiotics. Do you really need them? Maybe, if your life is at risk. Otherwise, probably not.



Otherwise very healthy, Mary Millard was diagnosed with an aortic aneurism, a ballooning of the body's main artery that is deadly if it bursts. Mary had surgery to correct the problem, but prior to the procedure suffered cardiac arrest and was put on a form of life support called extracorporeal membrane oxygenation (ECMO), which bypasses the heart and lungs by using tubes and external machinery to oxygenate the blood. She spent three weeks in the hospital and was about to be discharged when she developed a fever and doctors discovered she had contracted a *Pseudomonas aeruginosa* (*P. aeruginosa*) infection that caused her to go into septic shock.

Doctors explained that the bacterium had attached itself to the artificial parts put into her body during the surgery and formed a biofilm, a very difficult infection to treat. Additionally, the *P. aeruginosa* is resistant to many standard antibiotics.

Ciprofloxacin was the only oral antibiotic that worked. Mary spent about two months in the hospital recovering.

Mary's life has changed drastically in the two years since she was infected. She remains on ciprofloxacin and the dosage has been increased several times as the bacteria has grown more resistant, resulting in muscle and joint pain as well as cognitive issues. Ciprofloxacin also causes tendon problems, restricting some of her activities, and has seriously disrupted her digestive system, which has limited what she can eat. The cost of her medicine is prohibitively high and she has applied for disability because she is unable to work due to frequent hospitalizations and physician visits.

# MARY MILLARD

Bennett, NC

**“Mary is currently on the maximum dosage... and if it stops working, her last resort will be to have surgery.”**

The worst part is that her antibiotics are merely containing her infection, not curing it. She visits the doctor about every three to six months when she gets a secondary infection resulting from the problems with her digestive system. She also gets her blood cultured once a month to check for signs of the infection flaring up.

Mary currently takes the maximum dosage of ciprofloxacin and if it stops working, her last resort will be to have surgery. Her doctors say surgery would have 50/50 chance of working due to complexity, after which she will be out of treatment options and would likely die.

# NATALIE\*

\*Pseudonym

Winston-Salem, NC




## “Natalie had skin reactions to every IV antibiotic doctors tried.”

While recovering from a car accident in 1999, Natalie became ill with a hospital acquired, multi-drug-resistant *Staphylococcus aureus* (MRSA) infection and has been battling it ever since. She was treated with a powerful antibiotic called vancomycin. During the course of the vancomycin treatment she had a reaction to it known as “red man syndrome” which causes extreme skin itching and a large red rash across the upper torso. When she was transferred to rehabilitation, she began running a fever again and displaying a rash in other parts of her body. Doctors determined that she was having an allergic reaction to the vancomycin itself and therefore, ended the antibiotic treatment. She made a strong recovery and returned to her life.

In 2006, Natalie was diagnosed with lymphoma, a cancer of the immune system. She was treated for the lymphoma and determined to be in remission. Eighteen months after that she had symptoms and blood work that indicated that the cancer was recurring, however doctors discovered she had an encapsulated infection that was treated through surgery. Two years later, the MRSA re-emerged in an arthritic knee, but Natalie had skin reactions to every IV antibiotic doctors tried. Eventually her infection subsided after several antibiotics were used.

In 2011, doctors found the encapsulated MRSA in a psoas (lower back) muscle, and she had it drained. She began a regimen of IV antibiotics to prevent the infection from returning and repeatedly had rash reactions to a range of different antibiotics doctors tried. Less than one year later doctors found another encapsulated infection in the psoas muscle on the other side of her back, drained it, and again treated with IV antibiotics. This time she had a life threatening allergic reaction requiring hospitalization.

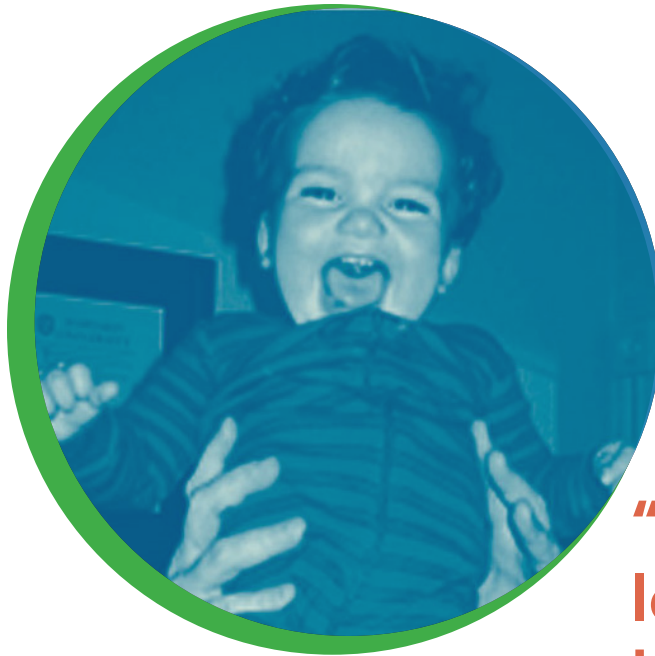


After suffering from the various strange and recurring infections, Natalie asked the oncologist to consult with an infectious diseases doctor, who diagnosed her with common variable immunodeficiency. This condition makes her much more susceptible to bacterial infections than the average person.

Doctors have been unable to permanently cure Natalie's chronic MRSA infections, and she has had at least 10 to date. Blood work monitoring steep spikes in inflammation markers and the symptoms of a recurrence, now all too familiar to Natalie, allow for quick communication with her doctor to report when the infection has returned. Her antibiotic regimen over the past couple of years is oral linezolid which she has taken for one week each month to keep the infection at bay, and then for a 5 or 6 week course each time there is a recurrence. Linezolid is the only antibiotic that does not cause her to experience an allergic reaction, although its side effects on one's bone marrow contribute to anemia, lowered platelets, and intense GI upset contributing to extreme fatigue. Every time Natalie gets an infection it takes 12-16 weeks for her to fully recover from the infection itself and then from the burdensome side effects of the antibiotics.

Her current infectious diseases physician believes the infection is in a bone in her pelvic area that continually causes the MRSA to re-inflame. Natalie has recently stopped the monthly antibiotic (linezolid) treatment because her doctor is concerned that the bacteria may develop a resistance to the linezolid or that she may develop a reaction to it as she has with her other antibiotics. Therefore, he is "saving" the linezolid to use when she experiences her next MRSA. Meanwhile, her doctor is exploring use of an antibiotic currently unavailable for commercial use in the US, but used in Europe to treat MRSA (fusidic acid). It may be possible for Natalie to use this drug as part of a "compassionate use" arrangement via a pharmaceutical company. This regimen would require daily antibiotics. In addition, Natalie uses drug infusion therapy every three weeks for her immunodeficiency. Risky surgery to remove the infected bone in her spine will likely be her last resort and she does not want to risk the loss of mobility and likely pain that would follow.

Natalie's unpredictable recurrences of her chronic MRSA and extremely burdensome regimen forced a revamping of her and her high school daughter's lives. Three years ago she was unable to continue her non-profit consulting work and had to close her 25-year-old business. Her income has been drastically reduced and she now lives on disability and uses Medicare for health insurance. Because of another recurrence, she was unable to take her daughter on a long-planned summer vacation this year and because she was so ill, she had to rely on others to provide care for her daughter for about five weeks this summer.



**“Simon kept looking at me with his chocolatey-brown eyes and long eyelashes, repeating, ‘Agua’.”**

My son Simon was a tranquil baby until he was 15 months old, when he started getting sick with various illnesses, such as ear infections and asthma. In April 2004, doctors prescribed antibiotics and steroids so Simon could breathe better after a throat infection. He seemed to be recovering fine until one morning he awoke with a terrified shriek and fever and my husband, Jim, took him to the emergency room.

Doctors ran the standard battery of tests and decided Simon was asthmatic. When I joined Jim and Simon at the ER an hour later, Simon was sleeping on my husband’s lap looking angelic. But given how irritable he was, I knew something was wrong. Jim noticed Simon’s lips were blue as we left the ER. The doctors measured his oxygen level but said it was normal. We gave Simon albuterol via an inhaler. His eyes rolled back into his head, but we told ourselves, “He’s sick like any other kid his age. He’ll be fine.”

That afternoon Simon vomited the little milk he had had that morning and lay limply in my arms. He kept asking for “agua” (water in Spanish) and drank about four cups, only to vomit all of it. His cheeks and forehead were cold and his lips were turning blue. His nostrils were flaring, and he was breathing heavily. I called the doctor and she told me to call 911. The EMTs applied an oxygen mask and said his oxygen level was fine. His eyes were wide open, and he was looking around, but was not moving. I tried to convince myself that Simon was okay, but as soon as he was wheeled into the ER, I kept hearing, “Your child is very, very sick.” I became hysterical. Simon kept looking at me with his chocolatey-brown eyes and long eyelashes, repeating, “Agua.”



# SIMON SPARROW

Chicago, IL

*As told by his mom, Everly Macario*

Simon was brought to the ICU to be intubated to help him breathe and connected to what seemed like 100 tubes, in addition to being given broad-spectrum antibiotics. I noted his eyes were open and asked the doctors if that was a good sign. I knew something was seriously wrong because the doctors seemed confused, scared, frantic, and helpless. They took me to a room where one of the doctors told me Simon had an infection, but they didn't know the cause. Simon's blood pressure was dropping and then went into septic shock. One doctor encouragingly said, "Most kids leave the ICU." Later she admitted Simon was going downhill.

By the time Jim returned to the ER, I knew Simon was dead. We gathered around his bed with many doctors. One said putting Simon on ECMO (the "heart-lung machine") was "his only chance." Jim and I desperately prayed for Simon to come out of his septic state. Doctors told us, "We're not sure if your son is going to make it." Simon became bloated, and his skin turned purplish and scab-like. He did not look like himself. Late the next morning, Jim and I decided to take Simon off of the ECMO machine, as he was not responding at all, and he was pronounced dead at 12:45 p.m., without a precise cause of death. The autopsy later confirmed that Simon died from community-associated methicillin-resistant *Staphylococcus aureus* (CA-MRSA). Neither my husband nor I had ever heard of it. MRSA is a virulent antibiotic-resistant bacterium. MRSA is only treatable with vancomycin – but first you must have a diagnosis of MRSA.

It seems unfathomable that a healthy, hearty and beautiful little boy could have been infected with a deadly bug and be gone in less than 24 hours. MRSA took my son swiftly. Now I have a window into what so many families experienced 50+ years ago: the death of a child caused by a bacterium or virus. It is ironic that the same advances in science that helped us live healthier and longer lives led to the creation of bacteria that no longer respond to antibiotics. As long as we do not treat antibiotics as a precious resource only to be used in the most extreme cases we will continue to have a false sense of security in medicine.



# TENZIN LOBSANG KUNOR

**Madison, WI**

Tenzin Lobsang Kunor was in the last semester of college, had just been admitted to graduate school, and offered an assistantship connected to the program. Best of all, he recently started dating the love of his life. He felt happy, carefree, and enthusiastic about the future.

On Thursday, April 25, 2013, however, the carefree feeling changed with an unexpected phone call. During a routine meeting with his supervisor at his college job, she received a phone call from her supervisor. The health center was trying to reach Tenzin to inform him that he was diagnosed with tuberculosis (TB). He had been tested for TB because he had severe chest pains and a sore throat for a several months, but he did not expect the diagnosis. What happened immediately after the phone call was a blur to him, but Tenzin distinctly remembers the car ride with his supervisor to the hospital in La Crosse. She did everything possible to make Tenzin feel more comfortable and continuously encouraged him that it was all going to be okay.

Tenzin spent a few days in the hospital in quarantine and ultimately was diagnosed with multi-drug resistant TB (MDR TB). During his time in the hospital, his partner and friends could not visit without wearing a mask. Many others sent words of encouragement, small acts of kindness that helped Tenzin to stay optimistic.

TB, or *Mycobacterium tuberculosis*, is an airborne infectious disease that is now the leading infectious disease killer in the world claiming 1.8 million lives each year. Multi-drug resistant TB (MDR TB) occurs when the bacterium is resistant to at least isoniazid and rifampin, the two most potent TB drugs. Nearly 30 percent of global annual deaths from antibiotic-resistant bacteria are due to drug-resistant TB.

After being in isolation in the hospital, he was sent home to Madison, Wisconsin, to live at home with his family where he finished the rest of his undergraduate courses, although he was not able to participate in any graduation ceremonies. While at home, he was still in isolation and had to live in his parents' bedroom since it was connected to a bathroom. Anytime he left his room, he had to wear a mask. The first few months he had a peripherally inserted central catheter, or "PICC" line, in his arm through which he self-administered medicine. The rigorous treatment regimen of many drugs caused a host of side effects, from nausea, loss of appetite, fatigue, restlessness, and anxiety to loss of hearing, temporary impairment of vision, and peripheral neuropathy, a type of painful nerve damage, in his feet.

On September 2, 2013, 139 days after his initial diagnosis and confinement for isolation, Tenzin was officially deemed non-communicable. That felt like such a glorious day to him, and he felt so free being able to leave his house without a mask. At the same time, he felt uncomfortable around others because he had grown accustomed to feeling that his existence was contaminating the air.

**"...After 28 months and over 8,000 pills, Tenzin officially completed the treatment."**

After isolation ended, and he was no longer able to infect others with TB, Tenzin continued his treatment for MDR TB. In January 2014, he also started graduate school which he found to be incredibly exhausting, especially with the side effects of TB medications. Despite these challenges, he was able to complete his graduate degree while simultaneously enduring TB treatment--one of the things he is most proud of. On August 7th, 2015, after 28 months of treatment and over 8,000 pills, Tenzin officially completed the treatment for MDR TB.

To this day, Tenzin still feels stigmatized by his experience with MDR TB and does not always feel comfortable disclosing his experience. Nevertheless, he has since written several blogs – one featured in *The Huffington Post*, served as a Consumer Reviewer for the Department of Defense's Congressionally Directed Medical Research Programs, presented at various trainings and conferences including the International Lung Health Conference in Liverpool, and has been an active member in We Are TB, a TB survivor group dedicated to advocacy and support. Tenzin is passionate about health equity, interactions of TB and race and class, advocating for better prevention, diagnostics, treatment, and continuing to share his experience in the efforts to bring more awareness of TB and to eliminate the stigma that affects patients and survivors.



In July 2015, Roger had successful surgery for his lung cancer. His wife, Marsha, recalls that a week after surgery, doctors mentioned that Roger's white blood cell count (a marker of infection) was rising slightly, but they weren't worried. Roger felt fine and was looking forward to going home. He'd had the same procedure on his other lung the year before and recovered without problems.

Before he left the hospital, the infectious diseases team took a sample from his lung to check for infection, and the culture was positive for the *Pseudomonas* bacterium. He had trouble breathing, and his white blood cell count rose, a sign he was fighting infection. He was started on broad-spectrum antibiotics, but worsened, went into respiratory failure and was moved to the intensive care unit (ICU).

**"...He was infected with an extremely antibiotic-resistant strain of *Pseudomonas*."**

Roger was too ill to undergo tests to determine the cause of his respiratory distress. Doctors told Marsha he was unlikely to survive. While in the ICU he went into cardiac arrest, and was rushed into surgery. His white blood cell count continued to rise as the infection spread. Roger had a CT scan that revealed a large amount of bleeding near the bottom of Roger's lung due to the *Pseudomonas* infection, which also was hindering his heart and lung function.

Doctors kept him stable overnight and the area was sprayed with antibiotics to prevent re-infection.

# ROGER POSER

## Houston, TX

Three weeks after surgery, Roger's white cell count remained unstable. Doctors determined some stitches from his lung surgery had loosened. His lungs continued to lose function, so he was placed on a respirator. Doctors suspected the bacteria were following the tubes in his lungs. Roger moved to another hospital and had an experimental procedure to place valves in his lungs.

After two months in the hospital, Roger was taken off the respirator and doctors focused on curing the infection. Infectious diseases physician Dr. Clare Gentry – who Roger and Marsha credit with saving his life – determined he was infected with an extremely antibiotic-resistant strain of *Pseudomonas*. Doctors began to fear they would not find a combination of antibiotics that could control the infection, and they would have to do extremely risky surgery to remove all of the infected tissue from inside his chest.

Dr. Gentry prescribed ciprofloxacin, which was temporarily holding the infection at bay. Dr. Gentry suggested Zerbaxa®, a combination antibiotic therapy that was not FDA-approved to treat pseudomonas but had shown promising test results. Because Zerbaxa® is very difficult to obtain, Roger was put on a waiting list. Several weeks passed, and his infection became increasingly resistant to the ciprofloxacin. Finally, doctors obtained the Zerbaxa®. Within one day of treatment, Roger's white blood cell count dropped dramatically and approached the normal range. Doctors remained skeptical about Roger's recovery as his infection could develop a resistance to Zerbaxa® as well. But his white blood cell count continued to improve, so Dr. Gentry tapered him off the Zerbaxa® to see if the infection would return. It did not, and Roger was able to go home, nearly four months after his initial surgery. He has recovered, with no signs of re-infection. Roger's immune system was severely weakened after extended courses of antibiotics, and he has been briefly readmitted to the hospital several times for minor illnesses. But he recently overcame a cold on his own without being hospitalized.

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