

# Maria



**WHEN** she graduated from Philadelphia's Moore College of Art and Design in the spring of 2016, Maria Sweeney spoke to the assembled graduates and their families. She was given this honor as the recipient of a women's leadership award.

Maria gave an inspiring speech about her “transformative experience” at the college. She praised the guidance and encouragement she had received from her instructors. She thanked the school for the exciting opportunities it had provided. She expressed appreciation for the ways Moore had developed her confidence “in myself as a woman in the arts, and simply as a woman.”

It was a beautiful and heartfelt speech. And it was especially memorable because of what Maria did *not* mention.

“My condition is out there,” she says today. “I can’t hide it. I don’t want to be known as ‘that girl in the wheelchair.’ I just want to be known as Maria.”

And yet you can’t really understand who Maria is—her strength, her determination, her remarkable courage—without knowing what she lives with every day.

Maria’s story begins in the Eastern European country of Moldova, where she was born 22 years ago. It was clear from the beginning that Maria had physical problems. She was diagnosed with a condition in which the body’s joints don’t move normally and may even be stuck in one position. Her feet rotated inward—a birth defect known as “club feet.” Because Moldova did not have good medical care for a baby with special needs, her parents made the difficult decision to

allow Maria to be adopted. Her new parents were the Sweeneys, a couple in a small New Jersey town. As time went on, Maria was joined by two adoptive siblings: Mariah (now 23), from Russia, and Nikita (now 15), from Ukraine.

As Maria grew and became more active, a frightening pattern emerged. When she would take a tumble that would not harm an ordinary child, Maria often broke a bone—or two. As they made repeated trips to the emergency room with their child, the Sweeneys worried that doctors would suspect they were abusing her. Fortunately, the family was able to turn to one of the best children’s hospitals in the world: Nemours, the Alfred I. DuPont Hospital for Children in Wilmington, Delaware. Specialists at Nemours diagnosed Maria with a second condition known as “brittle bone disease.” Just as the name suggests, people with this condition have very fragile bones that can break easily, sometimes for no apparent reason.

When Maria was 13, doctors came to another conclusion. They realized that both of her problems—the joint abnormalities and the brittle bones—were actually part of a single condition known as Bruck syndrome. Bruck syndrome is extremely rare; in fact, Maria is the only Bruck patient being treated at Nemours.

When Maria was younger, she kept count of her broken bones. As the number climbed,

she lost interest in that game. She has been hospitalized more times than she can count. As a child, she had intravenous (IV) treatment that helped strengthen her bones. When she was 13, she had surgery to treat her scoliosis (curving of the spine). The treatment sounds like something out of a horror movie. A metal “halo” was installed around her head. (Small dents from the halo are still visible on her forehead.) Cables from the halo went up over a pulley and were attached to weights that gradually stretched Maria’s neck. Every few days, more weight was added. After six weeks of this, doctors operated, installing a series of plates and screws in her upper spine to straighten and strengthen it. Afterward, Maria had to re-learn to walk.

It would be nice to say that throughout these ordeals, Maria had the support of a group of friends who loved and encouraged her. Sadly, that wasn’t the case.

She attended a Catholic elementary school. “Academically, it was very good,” she says. “I got a solid education.” But socially, Maria struggled.

“I was different,” Maria says. “The school wasn’t at all diverse. I think there was one African-American student, and nobody but me had a disability you could see. Most of the other students were from wealthier families. My father was unemployed for a long period. We were that

weird family who had adopted kids with physical problems. I was an easy target for teasing and bullying.”

It is understandable that Maria’s classmates, especially in the early elementary years, would be curious about this girl whose body looked different, who missed school because of hospitalizations, who sometimes needed a wheelchair or a walker to get around.

It is less understandable why the adults at the school didn’t make an effort to educate the children about Maria’s condition, and about “differences” in general.

Instead, Maria was left on her own.

“It was like there was a wall between me and the other kids,” she remembers. “When I was in my wheelchair, they treated it like a toy; they wanted to play with it. They didn’t seem to realize there was a person using it.”

The idea that Maria’s bones broke easily fascinated the other children. When she was in third grade, a classmate announced that she was going to trip Maria to see if it was really true.

She broke Maria’s arm.

Maria tries to understand the mentality that was behind the girl’s action. “She was young,” Maria says today. “I know that she didn’t really understand the consequences. But she was, frankly, a mean kid and a bully. She told me she would do it, and she did.”

On another occasion, a student threw a backpack at Maria when she was sitting in the school bleachers. She fell to the ground, suffering more fractures.

Teachers were not deliberately abusive, but they could be as clueless as their students. When Maria was in fourth grade, the school had a fire drill. At that time, she was using a walker. The drill required the students to cross an uneven stretch of ground. Maria knew she couldn't keep her balance in such a situation. She told her teacher, who responded, "Well, you'll just have to." She fell, ending up with both a broken arm and a broken leg.

While such experiences were miserable, they also helped to instill in Maria a fierce desire for independence. Her physical condition was a harsh reality that she was going to have to deal with on a daily basis. But she became determined that being "the girl with that weird syndrome" was not going to define her.

Maria moved on to a Catholic high school, where her experience was a happier one and she made some good friends. But her sister Mariah, who was in the same grade, persuaded their parents to allow them to finish their high-school studies online. Maria wasn't happy about the decision at first, but she recognized that the school tuition was a hardship for her parents.

"And it turned out to be a blessing in

disguise,” Maria says now. “In the course of those years, I discovered art.”

On her own, Maria became fascinated with drawing and painting. She visited her local library again and again, checking out instructional art books. She sketched for hours, making tiny improvements with every version. In her online world, she found other people who loved art and encouraged her work.

As Maria’s confidence in her abilities grew, so did her ambition. Her parents had assumed that Maria would attend the local community college and live at home. But she had other ideas. She became determined to become a professional artist and to make her own way in the world.

“I decided I was going to go to Moore,” she said. “And I was going to live on my own, in Philadelphia.”

Maria began working hard on putting together a portfolio (a collection of her art work) for Moore. Compared to most applicants, she was at a disadvantage. She was entirely self-taught. She had started late, while other students had had years of art classes. But to her delight, she was accepted, and she received a generous scholarship for low-income students with special needs.

Maria knew she needed to prepare for life in the dorm and in the city. In the summer before her freshman year, after having tendon surgery

at Nemours, she went through “boot camp” with a physical therapist. Under the therapist’s direction, she carried a heavy backpack, prepared for fire drills, and got ready for the physical realities she would face in college.

College was a wonderful experience for Maria. She lived in a dorm, interacted with her classmates, and polished her skills. She loved the experience of being in the city, with its wealth of cultural opportunities. She threw herself into her work-study job, which involved supervising a weekly live-model drawing session. She scheduled the models, arranged lights in the studio, and cleaned up afterward.

Over Christmas break during her freshman year, a happy new chapter opened in Maria’s life. She was spending some time on Facebook when she noticed a spam folder she’d never realized was there. Most of the contents were junk, but there was also a year-old message from Eros Livieratos, a fellow New Jerseyite who had participated in Maria’s online high-school program. Eros had come across some posts of Maria’s, thought she was both interesting and cute, and sent her a friendly note—which had disappeared into the spam folder. “Naturally, I’d thought she was just ignoring me!” Eros says with a laugh.

Maria responded with an apologetic message, and the two began to talk via email and Skype. In January, Eros visited her at college. The two

hit it off. Eros, a writer, was attending William Paterson College. Gradually their friendship grew and, as Maria says, “He became my boo!”

Not only is Eros Maria’s “boo,” but the two have become partners in an artistic endeavor: a comic book titled *In a Rut*. Eros writes the copy and Maria does the artwork in what they describe as stories based on “the New Jersey scene—flawed, burned out, punk kids.” They are working on volume 2 of the series, which they sell at comic conventions and online. They have also adopted a rabbit, and Maria jokes about the two needing to save for “bunny college.”

Maria’s senior year in college was an extremely challenging one. By October of that year, she was using her wheelchair because of fractures in her femurs (the bones of the thigh). Over the holiday break, she had surgery at a Philadelphia hospital—not Nemours, where she had been seen so many times before. The surgery went very badly. She was left with an oversized metal plate in her knee, the edge of which can be felt through her skin; constant pain; and less ability to bend her knee than ever before. She was advised to take a semester off to recover, but she desperately wanted to graduate with her friends.

She wanted to walk across that stage to accept her diploma.

But as Maria has had to learn, wanting isn’t getting.

Maria did graduate with her friends, but she did so in a wheelchair.

She spoke on the topic of leadership, but she gave the topic an unusual, and very meaningful, twist.

“What I talked about, basically, was leading myself,” she says. “I’ve had to push myself to be where I am. I know a lot of college girls who’ve never even made their own doctor’s appointments. I’m not criticizing them—they haven’t had to. For me, making appointments, dealing with forms, procedures, insurance, scheduling surgeries, trying to coordinate rehab with my classes—those things are part of my life. They aren’t all of my life. But they’re things that I’ve needed to do in order to achieve the self-reliance I have always yearned for.”

A month from now, Maria will undergo another surgery, this time at Nemours, that she hopes will correct the damage done by the previous operation. She admits to being “incredibly anxious” about it, but working daily on her comics and other art keeps her busy and focused.

When asked about her future hopes, Maria grows thoughtful.

“Realistically, I can’t know where I’m going to be, health-wise. There have been doctors who say, ‘Just accept it; use a wheelchair.’ I’m

not willing to do that. I want to retain as much strength as I can for as long as I can.

“But my hope is that this next surgery goes very well, that I regain a lot of strength and stamina. I’d love to put together a comic book that a publisher would pick up. I’m excited about working on more projects with Eros.” She chuckles. “And who knows—maybe we’ll get a second bunny!” ■