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Resilience: my story of overcoming obstacles of bladder exstrophy to impact lives around the world

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My story

My name is Anna Artigas, and I am a 17-year-old living in Vero Beach, Florida. I was born in China with bladder exstrophy and was abandoned in a crowded train station by my Chinese family when I was about two years old. Someone found me crouched in a corner and took me to the local orphanage. For the next 28 months, I would spend most of the day tied to a chair, constantly wet from urine that seeped from my belly. My bladder looked like a little red ball sitting outside my tummy. While at the orphanage, I was taken to the hospital twice for surgery to put my bladder back into my abdomen. Both times, the surgery failed, and my bladder was back outside.

Getting another chance

In 2009, when I was four years old, my mom adopted me and brought me to Seattle Children's Hospital – where I had a 14-hour surgery that would forever change my life. The doctors turned my bladder right side in and put it back into my tummy. Because my bladder was so small, they took some of my intestines to make it bigger. They also made me a belly button from a piece of my appendix. I have a little hole in my belly button where I insert a catheter to urinate. The doctors had to break my pelvic bones and push them together to hold all my body parts in place. This keeps everything from falling out. After this surgery, I spent so long in the hospital that I forgot how to speak Chinese! After leaving the hospital, I had a body cast for another four months to heal my pelvis (Figure 1). I walked funny for a while, but now I can run, swim, and even play golf!

Figure 1: Here I am (immobilised in the body cast) about 13 years ago after my redo-bladder and pelvic surgery

My mom, Pamela Artigas, is also pictured in Figure 1. She is the president and director of the Association for the Bladder Exstrophy Community (A-BE-C).

When I was five years old, I learned how to use my catheter by myself so I could go to school. I have to catheterise every four hours, and I will have to do this for the rest of my life. When I was younger, I still leaked urine. However, as I got older, my bladder stretched enough that I no longer needed to use urinary incontinence products. I have had eight surgeries so far and need a few more.

Living with bladder exstrophy

At the beginning of each school year, I always had to explain how I was different to my teachers. We would make a plan for me to go to the bathroom and where to keep all my supplies. This arrangement was difficult because kids always asked me why it took me so long to go to the toilet or why I used the teacher's bathroom instead of the student bathroom. When I entered middle school, I could keep my catheters in my backpack. Still, I always tried to go to the toilet when other girls weren't there because I stood to empty my bladder instead of sitting down. I was very nervous that my friends would find out about my condition, so I tried to stop going to the bathroom at school. A couple of times, this made me really sick, and I had to stay in the hospital for several days and sometimes I needed surgery.

As much as I try to be "normal", having bladder exstrophy is always on my mind. What if I go somewhere and forget my catheters? What do I tell my teachers and friends about why I spend so much time in the bathroom? I'm nervous about staying at a friend's overnight, and I don't have anyone stay over at my house either. Even though I don't let my condition control me, it's always on my mind. I must always plan ahead. The hardest part for me is dealing with teachers who don't understand I need to go when I need to go. And it takes me longer to "go", so sometimes they don't believe I'm really going to the bathroom.

Figure 2: Here I am visiting a young boy after his bladder was closed at the February 2023 bladder exstrophy workshop in Kampala, Uganda

Using my experience to bring hope

Having bladder exstrophy has also given me a chance to be a better person. My mom, Pamela Artigas, is the president of the A-BE-C, so every year, my sister and I help her collect night-time clothing for kids in India so they have a change of clothes to wear after surgery. I even video chat with all the kids from India and show them how to use a catheter. At the bladder exstrophy conference every summer, I help by telling my story and also listening to what other kids are going through. Parents will call me and ask what it is like to use a catheter. Many times, after they talk to me, their kids are no longer afraid of having surgery.

Making a difference around the world

This year, I was invited to participate in a surgical workshop in Uganda with A-BE-C. Urology surgeons and dignitaries from Uganda and other African countries came to learn. As a team, we helped more than 15 bladder exstrophy and epispadias patients and their families from Uganda. Some children had long, complex surgeries, and others received simple follow-up care.

I was invited to bring hope to families and show them that their children with bladder exstrophy can live fulfilling lives. They can attend school, play sports, have friends, and even become a parent someday. The doctors had me give a formal presentation to the families to help them understand what it is like to live with this condition. I also trained children and families on the day-to-day care of bladder exstrophy and made routine visits to see the patients after their surgeries (Figure 2). I was honoured to participate in this year's workshop to help give hope to children and families in Uganda.

Table I: What I have learned about facing and overcoming obstacles presented by bladder exstrophy

1. Bladder exstrophy does not define you; it's just one part of your life.
2. Even though I had to have many surgeries, I know that they made my life better.
3. Bathroom time at school can be very challenging.
4. It's hard to balance my medical life with my daily life.
5. Having a medical team that listens to me is important in managing my care.
6. I hope by sharing my story, I can bring hope to others.

Conflict of interest

The author declares no conflict of interest.

Ethical approval

Permission was obtained to use the photographs in this manuscript. This submission follows the principles of the Responsible Research Publication Position Statements developed at the Second World Conference on Research Integrity in Singapore in 2010. This manuscript is exempt from Institutional Review Board approval. A Artigas is the sole author responsible for the written content and provides her consent for it to be widely published.