THE SPRINGFIELD STUDENT
1910

Smiles, Scrunchies, Courage: Arielle Johnson fights Addison’s Disease

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Her long, blond braided hair was always pulled back with a colorful scrunchie. She wore a smile so contagious that it lit up any room she was in. But soon enough, her smile started to disappear. The spark in her eyes vanished. The sun would rise every morning, yet she found it impossible to find the energy to get out of bed and go to school or practice.

Meet Arielle Johnson – a first year student at Springfield College studying Occupational Therapy and a member of the women’s lacrosse team.

At age fifteen, life threw Johnson her toughest challenge yet, however, the way she attacked the situation through her perseverance, determination and hard work guided her through the most difficult time of her life.

Born and raised in Pomfret, Connecticut, a small town near the border of Rhode Island, Johnson was a very happy and active child. She pretty much played every recreational sport there was, from basketball, to soccer, to softball.

She even rode horses as a side hobby. Going into high school at Woodstock Academy, the regional school in her area, Johnson continued her love for sports by being a part of the lacrosse and field hockey programs.

Freshman year of high school is already hard enough, from trying to make new friends, to a tough new load of classes, and the pressures of joining every club or organization there is offered. On top of all these stressors, Johnson constantly felt sick and not like her normal, cheery self.

She suffered extreme fatigue, had little to no energy, and felt nauseous or dizzy on a daily basis. No one had any answers as to why she was feeling like this.

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She started out her freshman year on the field hockey team but missed most practices and g because of her worsening symptoms. She also had to stop playing club lacrosse because jus getting through practices was a burden.

Her mother, Kathleen Johnson, knew that something was genuinely wrong and reached out to an endocrinologist in hopes of finding out what was really going on with her daughter.

"The phrase I used to tell my doctor was that I lost my daughter and that I do not have my daughter anymore," Arielle's mother said.

December 2nd, 2015.

The day that everything suddenly changed for Johnson and her family.

It was just another cool, winter day Johnson thought. She was in the car with her mom on the way to her pediatrician's office when everything started to become one big blur.

She suddenly found herself in the back of an ambulance en route to one of the nation's most prestigious hospitals – UMass Memorial Medical Center in Worcester. Doctors swarmed her room – from taking her blood pressure, to conducting blood tests and taking her vitals.

Her blood tests and lab results were rushed, and her doctors finally informed Johnson and her family that she suffers from an extremely rare condition known as **Addison's disease**.

Residents and interns came into her hospital room every twenty minutes writing down notes about her case, since her condition is so uncommon. Johnson was her doctors' second patient ever with this disease and the first ever female.

“It was all like an episode of Grey’s Anatomy,” Johnson said. “Except this time, I was the patient with the extremely rare illness.”

Addison’s disease, a condition in which the adrenal glands do not produce enough cortisol, is extremely rare, as there are less than 200,000 cases yearly in the United States.

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Symptoms are nonspecific, which makes the disease hard to classify and diagnose. In Johns case, it took doctors over six months to pinpoint her symptoms as Addison’s disease.

“It was just so overwhelming, and fast, and a change in my life,” Johnson said. “One day I was normal, and the next day I needed all this treatment, so it was just weird.”

From that day on, Johnson had to make drastic life changes regarding her overall health and body. It took about a year for her doctors to figure out the correct dosage that suited Johnson’s needs.

This period of time was challenging because her symptoms of fatigue, lack of energy, and nausea were still affecting her everyday routine. Lacrosse, however, was the light at the end of a very dark tunnel.

“I think lacrosse helped me to get to school and motivated me to actually attend an entire day of school,” Johnson said. “If I did not have lacrosse, it would have been a lot worse.”

After about a year of testing out different dosages, Johnson and her doctors finally figured out a solution.

Currently, she has to carry extra medication everywhere she goes, as well as wearing a medical ID bracelet 24/7. She also has to carry an injection (similar to an EpiPen) with her at all times, just in case of a medical emergency.

On top of taking her medication four times a day, Johnson must take salt tablets daily, since her body cannot maintain proper salt levels, as well as taking electrolyte packets a few times a week.

“Knowing that she depends on something, like her medication was a big struggle for her,” Arielle’s mother said.

Coping with Addison’s Disease is just as hard mentally as it is physically. Dealing with the fact that she has a chronic disease that currently has no cure was very challenging, especially for a young teenager.

She questioned herself asking, “Why did this have to happen to me?’ and “Did I do anything cause this?” Itching to get off of the sidelines and get back into action on the lacrosse field h Johnson the most.

“Will I ever be the same player again?” she thought. “Will my condition prevent me from being the best player I can be?” These kinds of questions consumed her everyday thoughts for months.

Her mother was noticing how hard this was for her, and she decided to quit her job as a college professor and discontinue her pursuit of a Doctorate Degree so she could be there for her daughter.

She even decided to start coaching the Woodstock Academy lacrosse team. With the continued support of her family and friends, Johnson started to play lacrosse again and thrived. She soon became a dominant, aggressive player on the lacrosse field.

Her position of attacker suits her perfectly: attackmen are the “quarterbacks” of the game, controlling the offense and scoring goals. The position of attacker requires advanced stick skills and explanatory leadership.

“She is just a really hard worker and she is a true attacker, so she sees the field very well and has a very strong lacrosse IQ,” Springfield College Women’s Lacrosse Head Coach Kristin Mullady said. “She is also a creative and dynamic player on the field.”

Entering her freshman year at Springfield, Arielle was the 26th-ranked high school lacrosse player in Connecticut. She continues to thrive on and off the field, and because of her perseverance through the lowest time of her life, Johnson attacks every challenge with a smile, and of course a colorful scrunchie pulling her hair back.

Whether it is on the field, in the classroom, lifting weights at the gym, or just hanging in a social setting, Johnson succeeds in all aspects of life, despite her incurable illness.

“She has definitely shown me that not everyone has it so easy and that there are other people who have to work harder for their health,” roommate Emily Sardo said. “She is one of those peop must make sure that she is doing things that are good for her body.”

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Obstacles, to Arielle, are seen as just another way to improve and grow. No matter what comes her way, she is a true attacker, and can handle any challenge that is thrown at her, just like how she plays on the field.

Photo Courtesy Arielle Johnson