



The Power of Positivity: How Did One Teenager Handle Having Multiple Concussions?

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AN INTERVIEW WITH KOBY BERNSTEIN

We are pleased to introduce Koby Bernstein, a 17-year old student at the Dalton School in New York City. Koby is this year's youth honoree of the Brain Injury Association of New York and his team is raising funds for *The March On-Long Island 5K* (<https://marchon.bianys.org/longisland/Team/View/79117/Simply-Concussions>). Koby takes us through his experiences with a traumatic brain injury, how he stayed positive and is an amazing example of how one person can change the world!

Q – Can you tell us about your brain injury and how it happened?

A – My first concussion happened in the middle of 9th grade. I was playing high school basketball. I was driving the ball and collided with an opposing player. I thought I was fine but during my last class I had a headache, was nauseous, felt dizzy and most of all I just did not feel “right.” Some of my symptoms lasted for over 3 weeks. I was fully back at school and sports after about 4 weeks. My second concussion happened in 10th grade. I was trying out for the varsity basketball team and was at a practice in the gym. The back of my head collided with a taller player’s chin. I don’t think it was a harder jolt than my first concussion, but this time my symptoms were much worse and I was out for the entire basketball season. It took me 3 months to fully return to school and sports. I have had a few other bumps since then, like the time a friend threw a football in the park to the back of my head, that would ordinarily not be anything to think too much about, but when these bumps have happened to me following my other concussions, I am much more sensitive and I experience concussion symptoms that someone else would not have.

Q – Can you describe to us how you are doing now? Have you fully recovered from your injuries?

A – Even though I have recovered, I am not the same as before. I have chronic pressure in my sinuses and head. After trying different medications, having a cat scan and nasal endoscopy, the doctors cannot relieve the pressure. I now see a chiropractor regularly and also started acupuncture treatments.

Q – What was it like to be sidelined from school and sports for extended periods of time?

A— It was honestly very isolating and depressing. My whole identity has been wrapped up in my athletic persona and team sports, so not being able to play was very challenging. Not only because I enjoy playing and am so passionate about it, but also not getting to do what I love was hard, yet it was much more than that – I missed seeing my friends and teammates everyday. I also experienced a withdrawal of endorphins. I went from several hours of exercise per day to nothing. On top of all of that, there was very little I could do at home. I could not watch television or play on my phone- I was staying away from all digital screens because my eyes were sensitive to light and loud sounds bothered me too. I had to get up from chairs or beds slowly so I didn't get dizzy. My whole system was completely off. Missing school may sound great to someone who is healthy, but it was really tough. I hated getting more and more behind every day. I slowly got back to school. Some days I could go for one class or two. It took a long time before I could handle an entire day, keep up with homework, and be fully functional. I also have to point out that when you have a health issue that people cannot see, it makes it that much harder for people to understand your issue and accept it. When you see someone with a physical disability, you recognize that they may need accommodations. It was very different with traumatic brain injury as there was no outward signs like a cast or crutches. In my experience, some teachers were more understanding than others.

Q – Why did you create Simply Concussions (<http://www.simplyconcussions.com>)?

A— I had found that some things helped me like a particular ice pack that wrapped around my head, blue light blocking glasses, and some supplements that I was taking. These were not necessarily things that are on a typical treatment plan and they are not things that your neurologist or pediatrician tell you about. I wanted to share with others what helped me. I also needed to connect with others to see if I could find anything else that might help me. Without regular contact with my friends and teammates, I needed a community to connect with that understood what I was going through. Concussions are all unique, but people who have experienced them were much more understanding than others.

VIDEO: Simply Concussions (<https://youtu.be/fn0xT1orjy4>) with Koby Bernstein



Q – What inspired you to work with the Brain Injury Association?

A— I wanted to find a way to raise concussion awareness and I discovered that the Brain Injury Association (<https://marchon.bianys.org/longisland/Team/View/79117/Simply-Concussions>) had a chapter in New York, which is a non-profit entity that advocates on behalf of individuals with brain injuries and their families. I started out volunteering at their Long Island Walk. From there, I got more involved. It helped me turn around my negative feelings. By doing something good, I started to feel more hopeful and positive.

I also wanted to raise concussion awareness in my community and raise funds for the Brain Injury Association. During March, which is March Madness for basketball fans and also Brain Injury Awareness Month – I created and organized a fundraiser, "Basketball for a Cause (<http://www.simplyconcussions.com/march-4.html>)." I was fortunate to have a lot of help from friends at the New York City High School Leadership Academy (<http://www.highschoolleadershipacademy.com/>), a non-profit leadership development program where I am the president. Together we invited kids of all ages to shoot hoops, compete in contests, learn about concussions. I partnered with Dr. Elizabeth Barchi (<https://nyulangone.org/doctors/1588084347/elizabeth-barchi>) and the NYU Concussion Center (<https://nyulangone.org/locations/concussion-center>); Dr. Barchi helped take some of the confusion out of concussions. I also connected through instagram with an organization called Protect Your Skull (<http://www.protectyourskull.com/>); two former football players created a lifestyle clothing brand all around concussion awareness, and they generously donated clothing to help our fundraising efforts. I learned a lot about organizing an event, building a community wide effort, and more importantly, how to turn my individual nightmare from playing basketball into something positive for the greater good.



Koby Bernstein with Dr. Elizabeth Barchi, NYC Concussion Center, March 4, 2018

Q – What has been the best part of your experience?

A— I had a great opportunity this past Spring to participate in a Concussion Roundtable at Mount Sinai (<https://twitter.com/SinaiTBI/status/984521330577100801>). That was an incredible experience. I was the only student in a room filled with doctors, nurses, clinicians, athletic trainers and more. The Roundtable was focused on discussing best practices for concussion treatment. We collaborated on protocols that work and don't work. I was able to provide the student perspective and share the challenges that I faced in returning to school and sports. There is so much emphasis in schools on the protocols to return to play, but very little procedures exist on best practices and support to return to school. There needs to be more focus on returning to life too. Being able to advocate for changes in the system was empowering. I found that I have a voice and, even as a teenager, I can help effect real change and do something meaningful through advocacy. I got so much out of my time participating in the roundtable.



Koby Bernstein speaking at the Concussion Roundtable at Mount Sinai Hospital, April 12, 2018

**"I found that I have a voice
and can help effect change."
- Koby Bernstein**

Q – What is your message to others with traumatic brain injuries?

A— I had to stop thinking about all of the things I could not do and was missing out on. I realized I had no alternative but figure out how to move forward. I learned to appreciate Nelson Mandel's message that "the greatest glory in living lies not in never falling, but in rising every time we fall." My greatest discovery was learning to be positive and resilient in the face of setbacks. My message to others with traumatic brain injuries is to not give up; whatever you can do on a given day is just enough for that day. You are stronger than you think and happiness is a choice you get to make for yourself. **I call my formula the 4 P's: positivity, persistence, perseverance and perspective.**

Q – Last question – What is next?

A— Right now, I am raising funds for the Brain Injury Association of New York's 5K Walk on Long Island. It takes place on Saturday, September 15th at the New York Institute of Technology in Old Westbury, New York. I am appreciative of being the youth honoree and I am building a team to raise funds. I am grateful that I have recovered from my concussions, but also for how the tough times have shaped me. I am lucky that I can now help others. The money raised will go towards the Brain Injury Association of New York's mission, which includes providing education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families. The Association offers a toll-free family helpline, chapters and support groups throughout the state, prevention programs, and publications library. And, BIANYS plays a central role in the development of public policy on the federal, state and local level.



Koby Bernstein with BIANYS Executive Director, Eileen Reardon, April 12, 2018

Are you ready to join Koby's team?

Click here to get involved! (<https://marchon.bianys.org/longisland/Team/View/79117/Simply-Concussions>)