

Deep brain stimulation helps sisters with dystonia return to activities they love

VIDEO	AUDIO
Emma Fink Chatfield, Minnesota	We were at gym class, and we were playing sand volleyball. And I went to hit the ball, and when I bumped the ball, my shoulder blade just, like, popped out.
Emma	It was really painful.
Angie Fink Emma's Mother	Her arm was kind of stuck like this, and you could visibly see the tip of her shoulder blade from here.
Emma	When I was in the ER and when they said it wasn't dislocated, I was like, "It has to be. Like it's up by my ear."
Andy Fink Emma's Father	It's excruciating. I mean, to see your child in pain and you can't do anything about it.
Emma	It's pretty scary because I was just like, "Is this ever gonna go away? Like, are they ever gonna find out what's wrong?"
Angie	The physical medicine rehab physician really started to look at it as ... this isn't a normal pattern of injury, there's something else going on.
Keith A. Coffman, M.D. Pediatric Neurology Mayo Clinic	Dystonia can occur in any voluntary muscle within the human body.
Dr. Coffman	A dramatic presentation symptom onset for dystonia, like Emma had, where her entire right upper extremity was stuck and locked in place for months, is very uncommon.
Emma	It was very frustrating, and I was just like, "Why can't I be normal?"
Angie	It seemed like she tried medication after medication. We really started to feel hopeless. Like, is she ever going to be able to use her arm again?

Angie	That hope started to kind of really be restored when Dr. Coffman kind of ultimately recommended deep brain stimulation.
Dr. Coffman	What DBS hopes to do is suppress the abnormal electrical firing that is generating dystonia.
Dr. Miller	You have circuits inside the brain, so you have cells that send signals to one another.
Kai Miller, M.D., Ph.D. Neurosurgery Mayo Clinic	In the case of dystonia, what we can do is we can put wires into those circuits and basically just interrupt the abnormal feedback that happens between areas.
Dr. Coffman	The hardworking part of the device is in the chest. It is a small computer with an electrical pulse generator, and it is programmable by a tablet computer.
Emma	I just wanted to be better, like anything to make me better.
Angie	Meeting with Dr. Miller and understanding what the surgery would be like, what the potential outcome would be like, what his experience has been, and that really helped us make the decision to move forward.
Dr. Miller	Oftentimes, the optimal therapy is months down the line, but for some patients, they get it very quickly. And Emma responded very well.
Emma	When I was in the office getting it turned on, it was, like, immediate. I was like, "My God, I can move again." I was, like, shocked.
Angie	Immediately, it was ... you could just see her upper body relax. You know, she had a very stark reaction to feeling relief, and then her shoulder blade started to slide back.
Emma	How is this even possible?
Angie	I almost felt like this can't be real. This didn't just happen. Like, you can't just turn something on, and it's better.

Dr. Coffman	We all cried.
Angie	It was around the time that Emma was having surgery.
Angie	What we noticed that was really obvious about Lauren is she started to having abnormal blinkings and kind of abnormal head and neck movements.
Lauren	I didn't really know what was happening.
Lauren Fink Emma's Sister	My legs would start to hurt, and then, it was always when I would be active, and then it just got so bad to the point where, like, I couldn't sleep.
Angie	And I had talked to Dr. Coffman when we were in a visit with Emma, and he said, "Just bring her in. I'll see her." I think he already knew that she probably had dystonia. Within a half an hour of him seeing her, he had done an exam and said she has dystonia too.
Angie	So she went through that process of trying the medications, and she was kind of able to say when she was ready to take the next step.
Lauren	Like my legs would hurt really bad, and like it just kept getting worse really quick, so then I just felt like it was time.
Angie	We decided to meet with Dr. Miller, and then she went forward with DBS.
Angie	When the DBS was turned on and we were walking out of Dr. Coffman's office, she's like, "Oh, my legs are so much easier to walk with."
Angie	That's a pretty stark difference to watch her come home from school, be in pain, want to lay down and really do nothing — to go to school, go to softball practice.
Dr. Coffman	There's no better feeling that exists. To be able to just sit there and watch and see it all melt away within seconds of turning it on.
Dr. Miller	The fact that Emma and Lauren are both athletes, and they're both similar ages to my children, I think

	made a special connection, and I'm really happy that they've done so well. Very proud of that too.
Andy	I felt like we were in good hands, right? Like, if there's any place in the world I would want this done, it would be right here.