



MOONLIGHTING *Jade Moon*

When Special Needs Kids Turn 18

Trevor Bierwert is a handsome young man with an open, easy smile — and he has epilepsy.

He started having seizures before he was 4 years old, and from age 4 to 6 they got progressively worse and worse.

"He was wearing a helmet because they would knock him to the floor," his mom Sheila says. "He split his chin, he'd hit his head ..."

It was bad. So bad that, when he was 6, they took him to Michigan for surgery, where 75 percent of his right brain was removed. When he came out of it, the left side of his body was paralyzed but he was, blissfully, seizure free. With physical therapy and hard work he regained most of his movement. But when he was 16, the seizures came back. I sat on a park bench with the Bierwerts as they told

their story — mom Sheila, dad Dave, little brother Blakely and Trevor, who is now 23 and still having seizures at least every other day. Trevor is healthy and happy and athletic — he participates in Special Olympics, which, in fact, named the Bierwerts "Ohana of the Year." But the seizures have left him with the academic level of about kindergarten. He'll need services and support all his life. Every parent of a special-needs child knows how challenging it is to procure all the services that child requires. When Trevor was in school, state Department of Education provided him with occupational, physical and speech therapies, as well as an aide.

But what happens when the child grows up and ages out of that support system? The Bierwerts had people they could turn to for advice. One

was the transition coordinator at Kaiser High School, who started talking to them about Trevor's future well before he graduated. The other was Scott Suzuki, a local attorney who specializes in special-needs planning and elder law. He's also president of the national Special Needs Alliance.

Suzuki describes what happens to these kids and their families as "hitting a wall."

"That's often what it feels like," he says. "As they're growing up, they get services from the Department of Education. When they become adults, they have to make all their own decisions."

And that, says Sheila, is a scary proposition. "We didn't know that we'd have to apply for guardianship. There are all these things that you really need to do."

The guardianship was critically

important.

"It's being able to make decisions for somebody who can't," says Dave. "Otherwise you wouldn't have the right to talk to his doctors, technically, or request information or set up appointments. It'd be up to him. We weren't even thinking in those terms. You think, automatically, he's our kid. But when he's 18 he becomes his own person. So if you don't have that guardianship, you lose the legal right to make decisions for him."

And the process to get that guardianship becomes much harder after the child turns 18. Suzuki set up the Bierwerts' guardianship and trust. He drew up the legal documents and set up their court appointments so they could go before a judge to present their case. He was their attorney and their coach.

The family was lucky they had the

funds to hire an attorney. Many don't. Suzuki says people should start looking for help anyway.

"There are low- or no-cost legal services like Legal Aid," Suzuki says, "and some attorneys do pro bono (free) cases or can work out payment plans."

The important thing, say Suzuki and the Bierwerts, is to start looking and asking questions early. You can start by going to the Special Needs Alliance website at specialneedsalliance.org. And don't stop there.

"Start asking the questions as soon as they get to high school," says Sheila. "That's when you need to start because it's going to take a long time. You can't wait until they're 18."

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