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## Jack Zemsch: A Little Person with a Big Voice

By Sophie Braccini



Jack Zemsch knows resilience. He's needed a lot of it just to grow up, and he's only 11 years old. The Moraga resident has been supported by his community since the days when his family was fighting to get coverage for a procedure that was critical to his survival. Zemsch was diagnosed in early infancy with an extremely rare condition called metatropic dysplasia. This form of dwarfism is characterized by severe spinal deformity. By age 6, his spine was bent beyond 90 degrees, which compromised his lungs and heart. After he met with pediatric surgeon William MacKenzie in Delaware, he underwent spinal ligament surgery in 2009, followed by nine weeks in halo traction. "It's been miraculous; the surgery changed his life," says his mother, Kim Zemsch. "He was losing his lung and heart function. After the surgery he came back standing straight, he was part of the upright world and he could breathe." Zemsch continues to get treatment, including expandable rods inserted in his back that allow his lungs' growth and normal breathing. They need to be adjusted every six months. Now his energy and smarts have made him a national spokesperson, going to Washington, D.C. to advoca

continues to do research. Because of budget cuts, every association risks losing funding," says Zemsch. Everyone from Delaware pledged support; the vote will come soon and the family hopes that the NIH will at least continue to receive its current level of funding.

Zemsch believes that cutting resources to fundamental science is dangerous. "If they stop research they will kill a lot of people and the economy at the same time," he says. His mother understands that fundamental research is very expensive and has very little direct return on investment, but it is also the building block on which new cures and medications are found, and is what makes this country a leader in the medical field.

Zemsch is also a powerful voice at the local level. When the Moraga School District was working on its strategic plan, it interviewed Zemsch.

"I said that it would be nice to have more hands-on science in class," he says. "When we reach the end of a science chapter, the experiments are scheduled as the last part, and we rarely have the time to do it." He was also asked what his favorite class was. "I answered 'music,'" he says, "because it is the only class where I feel comfortable, even with my disability."

Moraga mobilized for Zemsch. The 'Team Jack Fund' was started by Karin Hein and Leanne Parsons. Today

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"When we've met with politicians to talk about funding for research, they'd listen to figures and facts, but the person in the room who had the most impact was Jack," says his mother.

"If research had not been done by the time I was 7, I might be in the grave, or at least not living a very healthy life," Zemsch says.

"He is a great spokesperson because he is passionate, he has a story to tell, and he is a great example," adds his mother.

The Camino Pablo Elementary fifth grader now lives a normal life. He is in Boys Scouts, swims competitively, and was elected to the student council last year. "My goal in life is to become a leader and a spokesperson," Zemsch says. When his family went to Washington, D.C. to meet with the Delaware Senator Tom Carper and Senator Chris Coons, since his surgery was done in that state, he was one of the first to speak.

"I talked about keeping the NIH (National Institutes of Health) funded, so every association, such as the AAOS,

the fund helps send a family with a rare spinal condition to meet with MacKenzie. "They can meet with him at his hospital or at the yearly Little People of America (LPA) convention," says Zembsch's mom. LPA had its genesis with the filming of the Wizard of Oz; it was the first time that little people from all over United States got together and exchanged perspectives. They decided to continue to meet and created the LPA. Every year, patients and doctors meet there, interact and debate for two days, and patients can get a free doctor appointment.

Zembsch is waiting for the results of the budgetary vote. On the line is cutting-edge research on the gene that causes his condition. "If they find a cure for my disease," says Zembsch, "they can find a cure for other diseases related to that same problem."

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