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ALS Awareness Month: OIS Students Create "Virtual Walk" for ALS

By Jennifer Sulyman

Playing video games or getting into the regular sort of thirteen year old mischief is not on Alexander Sulyman's or Bryan Capedeville's to do list. These thirteen-year old Orinda Intermediate School students put a lot more on their plate than most kids their age. Currently the two are working on a project that requires true dedication. Alex and Bryan are organizing an Amyotrophic Lateral Sclerosis (ALS) fundraiser called the Lamorinda Virtual Walk for ALS.

ALS, or Lou Gehrig's Disease is a terminal, progressive neurodegenerative disease that according to the ALS Association affects an estimated 30,000 people in the United States with 5,000 new cases each year. It's an orphan disease with no known cure. ALS affects nerve cells in the brain then to the spinal cord and to all muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to the victim's death.

Alexander's father is a victim to the disease and so he wants to raise awareness for how serious it is. "My dad was diagnosed in October [2008] and he already can't even walk and is losing strength in his arms and hands. There is no cure so maybe Bryan and I can help raise money to find it [the cure]."

However, his dad wasn't the only inspiration for the walk. It wasn't a simple project that Alex and Bryan decided to take on out of the blue, "It's really kind of a school project. We had to do a business-planning thing and everyone else was doing lemonade stands and that was too boring for me. I wanted to do something cooler, and Bryan offered to help."

Alex's task of taking on a "cooler" project isn't easy. He and Bryan work on it on their own with a little help from the ALSA. "I talk to Lori Gould of ALSA and she helps me a lot with legal things and publicity stuff too."

The walk is not a physical walk; it's called a virtual walk. Alex explains, "We decided to do a virtual walk because we couldn't find a set location. Then, my dad mentioned May is ALS Awareness month, so we decided to have people register then send in their miles so our sponsors could pay 10 dollars per mile." The KNL Foundation already gave the virtual walk a grant of \$12,500 and the boys' goal is to raise another \$37,500 during May.

Alexander and Bryan are giving hope to the men and women and their families who suffer through this horrendous disease, one mile at a time. Their compassion is inspiring to many. To register or to find more information log on to www.ALS-Walk.org.

Reach the reporter at: info@lamorindaweekly.com

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