ALS
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#whatwouldyougive

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WHEN A SEVEN-YEAR-OLD IS YOUR GREATEST REASON TO EMBRACE ANOTHER DAY

Mother in desperate fight to defy ALS odds and continue her life’s work: being a parent

JULY 2017 | SAN FRANCISCO, CA - Sarah Coglianese is 38. She lives in San Francisco with Rob, her husband and Scarlett, their feisty seven-year-old daughter. They live with a crazy dog called Otto. Their contemporary Monterey Heights space overlooks the wild Pacific. They love music. Art is important. Books are everything. And everywhere.

Sarah writes when she can (Speed4Sarah.com, *The New York Times*, CNN.com, *Redbook Magazine*). Rob rides his bike long distances. Scarlett is in her Harry Potter phase and is “active” on Twitter.

Sarah uses a wheelchair to move around. She cannot move her arms or her legs. She needs help brushing her teeth. Scarlett helps with her hair. She cannot dress herself. She is fed her meals and she drinks wine through a straw. Her arms ache. Breathing is a chore. Getting through the day is like pushing your hardest through mile 21 of the hardest marathon. And then you get up the next day and do it all over again.

Sarah used to run marathons.

It was during a run back in 2012 when she felt an unusual weakness in her legs. That was her earliest symptom of what turned out to be ALS (Amyotrophic Lateral Sclerosis or Lou Gehrig’s Disease), a fatal disease of the nerve cells in the brain and spinal cord. In people with ALS, motor neurons deteriorate leading to muscle weakness and paralysis. With no known treatment or cure and a prognosis of 2 to 5 years to live, ALS is a devastating diagnosis to receive.

Regardless of the disease and the new future it unveiled, Sarah's priority never wavered; Scarlett is the reason she wants her weakened body lifted out of bed and into her wheelchair each morning. And the reason she will keep doing it for as long as she is able.

The two are connected. Yes, it's a mother-daughter connection, but something that is much more complicated. They are connected by their quick wit. Their love of reading. Their words and where and when they fit. Their penchant for a solid story. Their hair. Their painted nails. Their dark and beautiful eyes that succeed at holding you accountable. Their natural inclination to challenge, to compete, to intimidate. To create, to entertain, to win. Their authenticity. Their lust for life. Together.

These two need each other.

So, in an effort to keep meeting this mutual need for as long as possible, Sarah launched the #whatwouldyougive campaign in 2015 to build awareness of ALS and raise funds for research taking place at the ALS Therapy Development Institute (ALS TDI), a non-profit biotech focused 100% on discovering treatments and cures for ALS. ALS TDI is currently working on advancing AT-1501 and other promising treatments toward clinical trial. Sarah is counting on ALS TDI to help her continue to be a mom. So she is doing all that she can to raise dollars to fund a treatment. And fast.

Since #whatwouldyougive was launched in 2015, almost 1,600 individuals have raised $400k to help bring Sarah and those living with the disease closer to a treatment and cure. This year, the goal is an ambitious $250K.

Sarah describes the campaign as an "exercise in empathy," in that it challenges participants to give up a physical ability (e.g. voices, arms, hands, legs) for a self-chosen certain amount of time, to develop even a small understanding of what life with ALS is like. Participants are encouraged to document their experiences on social networks, to help build awareness of this devastating disease. "I wanted to create a fundraiser that helped people understand just a bit of what it feels like to be stripped of these basic abilities," said Coglianese. "The things that most of us take for granted. The things that I absolutely took for granted until I received an ALS diagnosis when I was 33 years old. I'm 38 now, and even after all I've given up, I'm not giving up."

This summer, participants will spend time on fundraising and awareness-building efforts. Between **August 1st and 8th**, the campaign will culminate in a week of coordinated participation. This “National #WWYG Week” will see a nationwide series of challenges, celebrity involvement, social media take-overs and sweeping publicity.

For more information or to take the challenge, visit als.net/whatwouldyougive or email wwyg@als.net. You can also follow @whatwouldyougive4als on Instagram and the #whatwouldyougive and #wwyg hashtags across all social channels.

About the ALS Therapy Development Institute

The ALS Therapy Development Institute (ALS TDI) and its scientists actively discover and develop treatments for ALS. It is the world’s first and largest nonprofit biotech focused 100 percent on ALS research. Led by people with ALS and drug development experts, ALS TDI understands the urgent need to slow and stop this disease.

Based in Cambridge, MA, ALS TDI has over 30 full-time, industry trained, drug development experts on staff. ALS TDI is internationally recognized as a leader in optimizing preclinical models of neurodegeneration for clinical translation, and partners with pharmaceutical companies and biotechs around the world. Rated a CharityNavigator.com four-star charity, ALS TDI spends 87% of each dollar raised on research to find an effective treatment and cure. Visit www.als.net.

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