

Lily Allison is a 9-year-old girl from Colorado who loves fishing, swimming and biking, spending time with her friends, mom, and dog Amsey, and baby-sitting her neighbor's cats. Lily enjoys crafting and cooking, singing, playing the piano and the ukulele. She is a Special Olympics Athlete, a three time Colorado Miss Amazing Rising Star, and a third year graduate of CO Little Medical School.

After searching for a diagnosis that could explain her more than three dozen health conditions, Lily was finally diagnosed with Ehlers Danlos Syndrome-Hypermobility Type (EDS-HT) shortly after her sixth birthday. She has been recognized by many in the rare disease community as an incredibly positive advocate, receiving honorary Patient Spotlights with organizations such as We Health, Keck Graduate Institute, the Hearing Health Foundation, Global Genes and Horizon Pharma. She has made it a point to share the journey of her own battle with rare disease and an invisible disability to help act as a voice for those who may be unable to do so. Although Lily remains private about certain aspects of her disease, she is confident sharing with others some of its main effects when both filming and speaking to large groups such as the Colorado Congress, as she did at the Colorado State Capitol on Rare Disease Day 2018 to help raise awareness of the complex needs of those living with health conditions as well as to pre-med students at Colorado University. She has spoken at Children's Hospital Colorado, Seattle Children's Research Institute, the University of WY and The Ryan Seacrest Foundation. Lily has been featured on both local and nationwide news media highlighting her advocacy work including Denver 7 Everyday Hero with Ronald McDonald House Charities, Fox 31, The Five, Channel 2 Denver, King 5 Seattle, KX North Dakota News, Fox 31 Denver and more. *Videos links available upon request.*

Prior to COVID-19, Lily's work included traveling the US to further advocate for those with disabilities and share her kindness program at educational institutions of both collegiate and primary/secondary levels through the message in her book BE KIND, Silly which she co-wrote with her mom after working through her own feelings of being bullied by an older girl for her differences. Lily's passion is to inspire others that the power to change the world lives inside each one of us, and that even if you make mistakes, you can always choose kindness the next time. In 2019, she spoke to more than 2500 students across Colorado and North Dakota inspiring kindness, while also advocating for her own rare disease and oftentimes, invisible disability. Lily has been featured for her book in Story Monsters Ink Magazine, Colorado Parent Magazine, and on the front covers of the Loveland Reporter-Herald and Voya Financial's 2020 Calendar.

On April 28th, Lily was scheduled to speak as the featured author at a special event called the Read Aloud Program in Loveland, CO. However, after the Coronavirus Pandemic began, Lily found new virtual ways to reach her audiences since in-person presentations were no longer an option. In early May 2020, Lily presented her first kindness seminar via Zoom to the families of VOYA Financial, nationwide. On June 4th, Lily will kick-off the Summer Reading Program virtually, as their first ever Young Author Ambassador for the Loveland Public Library and the City of Loveland, CO. Lily will guide young readers in her own community to challenge themselves to expand both their reading and humanitarian skills, while exploring new ways to be kind, volunteering in their

neighborhoods, and completing missions to expand their ways of thinking in order to reduce the factors involved with the “summer slide”.

Lily is an active volunteer for BE KIND humans, a service-learning initiative designed to support the BE KIND Project and internally fund the L3C organization her mom founded in early 2017 called Some 1 Like You (S1LY) to connect patients with health conditions. The BE KIND Project works with partner school districts in both Colorado and North Dakota, advocating for kindness and raising their own funds in order to make a kind impact for their communities. Her message is inspiring, and encourages her peers to look within themselves to make a difference.

Lily is an honorary NHL Avalanche Ice Girl/Ice Patrol and continues to use her platform as an Ambassador for Colorado Rare 501c(3) to raise awareness for the 1 in 10 who suffer from a rare disease alongside her by hosting BE KIND CO Avalanche games semi-annually.

Although it can be exhausting and painful for her at times doing up to a half a dozen school assemblies in one day, Lily pushes through her own challenges and does not allow it to be a barrier to her mission. Lily is currently filming her second video for Children’s Hospital Colorado on patient safety. Upcoming projects for Lily also include speaking for the second time at the University of Wyoming and one of its partner Community Colleges, by advocating for those living with disabilities. Lily also has projects planned with Voya Financial to continue to help raise awareness for people with special needs and their caregivers along with her pen-pal, mentor and fellow zebra, Mandy Harvey. Along with Mandy Harvey, Lily and her rope team recently completed a summit of A-Basin Colorado with No Barriers 501c3 co-founder Erik Weißenmayer, the first person who is blind to reach the summit of Mount Everest, and more than 100 individuals with disabilities. The hike to 12,500 feet was an inspiration to many, and empowered people to break through barriers and contribute their best to the world.

Lily recently co-authored a Counselor and Educator Companion for her first book, BE KIND, Silly, allowing teachers and social workers a tool to actively use the story in their school environments and small group counseling sessions. Lily and her mom are currently writing their second book in their Silly Series called BE BRAVE, Silly, with an expected release of 2021.

Lily will be honored at the 2020 Colorado Miss Amazing Event on September 26th, 2020 for her self-advocacy work. Click here to view her video feature: [SHE IS](#)

*Message from her mom, Makayla:*

Lily has positively and innately advocated for herself in regards to her own rare disease and oftentimes invisible disability since she was just a tiny child. This beautiful and independent strength through her own adversity was just a precursor to the ripple effect she has now initiated in our world. By sharing her story and asking others to take time to consider that everyone is going through something, even if you can’t always see it, she has empowered humans near and far to consider how their own actions impact those around them. She inspires both adults and children to be patient with each other, even in times of trial or adversity, and to realize that the power to change our world truly lives

inside each one of us. Lily has encouraged thousands of people including senators, physicians, researchers, professional athletes, patients, teachers, non-profit leaders, students, the leaders of a Forbes 500 company, and her own peers by standing up for what she believes to be true and using her voice without fear. Her empathetic spirit is full of hope and kindness, and her incredibly positive being, despite any pain she may be experiencing, is a warrior force we could all stand to admire. At the tender age of 9, she has already created a spark and left her mark in the lives of all of those she has come in contact with, and that fire doesn't appear to be diminishing anytime soon.

Click here to view a [video](#) about the book, *BE KIND, Silly*. Due to COVID-19, we have temporarily suspended shipping, but it is still available through [Amazon](#)! Additionally, here is a link to the [Counselor Companion](#) for educators and counselors to use as a tool along with the book in their classrooms.