

Please Donate to “The Crane Family Project” to Help Pay Remodeling Costs for Making the Crane Home Handicap Accessible for Isaac and Ready to Move Back in by Isaac’s 6th Birthday, 02/11/2020

SUMMARY. Isaac seemed to be a totally normal baby until he was four months old, when his father first saved Isaac from choking to death. Isaac was diagnosed at Children’s Hospital Colorado with the worst variant of Spinal Muscular Atrophy (SMA 1), a rare genetic disorder. SMA then had no treatment, and Isaac was not expected to survive beyond age two. Two years later, however, a breakthrough bio-tech drug called Spinraza was invented, and in 2019 Isaac is expected to live a long life and needs a handicap-accessible home.



Skyline Kiwanis in Longmont is inviting **tax-deductible** donations to “The Crane Family Project” at <https://www.skylinekiwanis.org/2019/11/15/crane-family-project/>

Visit www.gofundme.com/agbytg to learn about Isaac’s courageous battle against SMA 1. Isaac’s aunt set up this GoFundMe website nearly 6 years ago and her recent posts provide updates about the remodeling project. Donations there are **NOT** tax-deductible.

Visit <https://www.roarwithisaac.org> to read 6 years of posts by Isaac’s parents sharing a riveting story of loving their family and saving Isaac.



Posted Jun 19, 2014 1:18am
Eyeing his pacifier, making do with his fingers.



Posted Jun 22, 2014 6:04pm
Smiling at Grandpa!



Posted Aug 30, 2014 11:52pm



Isaac’s first birthday party February 11, 2015. Theme: Roar Like a Lion. Guests were asked to donate to Cure SMA care packages for newly diagnosed patients, <https://www.curesma.org/newly-diagnosed/>



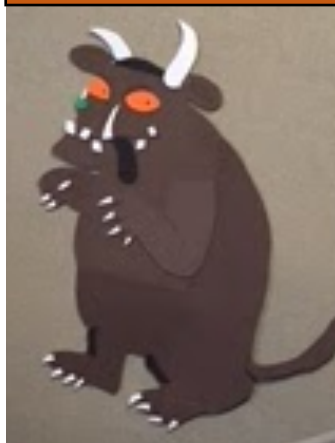


Posted May 11, 2015 12:11am
Mother's Day photo!



Posted Jun 14, 2015 3:51pm
Isaac's first carousel ride!

When Isaac was almost 2 he was crazy about Gruffalo books, so *The Gruffalo* was the party theme for celebrating Isaac's second birthday, Feb. 11, 2016. By then Isaac had outlived the predicted lifespan for SMA 1





August get-together in Estes Park with Isaac's loving, forever steadfast, family — his parents, sister, grandparents, aunts, uncle and cousins.



Isaac's parents were excited to announce that Isaac's team of doctors at Children's Hospital would give Isaac his first three injections of the new bio-tech drug Spinraza (Nusinersen) by Jan. 1, 2017. During the 3 years since then Spinraza has slowly increased muscle strength and slowly reversed damage SMA had caused by 2016. Can Isaac live a long life? Will his SMA damage ever be fully healed? <https://www.childrenscolorado.org/doctors-and-departments/departments/neuroscience-institute/programs/neuromuscular-clinic/spinraza-nusinersen-treatment/>





Isaac started MWF preschool in January 2017, when his big sister was in kindergarten. Isaac was assigned a full-time para-professional to help with accessibility issues, assistive devices for learning, and breathing equipment. Like other children with SMA, he has a normal brain and is expected to learn what all his classmates will learn. There is no glass ceiling on what Isaac can accomplish in life. Treatment with Spinraza makes his muscles grow stronger, and new drugs may be invented to accelerate recovery of strength. SMA is like ALS, the disease brilliant Stephen Hawking had.

When Isaac turned 3 on February 11, 2017, his favorite underwater explorers were "The Octonauts." Every year guests contribute to CureSMA.org in honor of Isaac's birthday.



A tough 18-month battle finally won Medicaid approval for a power chair for Isaac, delivered in June 2019. Isaac loves driving it and drives it very well. An accessible home is crucial for Isaac, but the total costs for Isaac's needs are enormous for a family of ordinary means, even with Medicaid benefits.



Isaac's father had experience in construction, and when Isaac started kindergarten Aug. 2019 his father started remodeling the home to make it handicap accessible for Isaac, who needs a usable bathroom & barrier-free space to move independently in his power chair. Steps done so far: lift the house, dig a hole for a basement, pour a foundation, add a room in back, and lower the home on its foundation. Much more must be done before they earn a certificate of occupancy to move back home from a crowded 575 sq. ft. rental cottage.