



January 8, 2020

Skyline Kiwanis is excited to announce our First "Topgolf" Golf Tournament to support the **The Skyline Kiwanis Foundation and the Isaac Crane Family**. This fundraiser will be at Topgolf's new facility in Thornton on **Sunday, February 23rd from 2:00 to 5:00 (registration beginning at 1:00)**. Topgolf is located at: **16011 Grant Street, Thornton, CO 80023**. Kiwanis is a global organization of volunteers dedicated to changing the world, one child and one community at a time.

Primary Beneficiary of proceeds from this event will benefit the Isaac Crane Family from Mead CO (See last page for details). As with our other fundraising events 80% of Proceeds will go to the Primary Beneficiary and the remainder to the Skyline Kiwanis Foundation supporting other local causes.

I am writing to ask for your support of this year's event. This event is one of many initiatives Skyline Kiwanis supports throughout the year in the Longmont area. In all cases, we rely 100% on community support to meet our goals. Please consider supporting this event in the following ways:

- Golf Tournament Participation
- Auction Item Donation
- Sponsorships (Title, Food, Bay)

Thank you in advance for your commitment to support this wonderful event, and please feel free to call me with any questions or for more information. Or you can visit our website at www.skylinekiwanis.org.

Best wishes,

Dick

Dick Larsen
Member, Skyline Kiwanis
Email: rl1508@aol.com
Phone: 970 219-5856

Skyline Kiwanis
www.skylinekiwanis.org
PO Box 565
Longmont, Colorado 80502



Golf Tournament Participation Form

Skyline Kiwanis “Topgolf Event”

Sunday, February 23, 2020

Golf Tournament Details:

- \$75 per player
- Cost includes 3 hrs of “Top Golf” with snacks
- Specific rules detailed at registration
- Registration begins at 1:00 pm
- Golf begins at 2:00 and goes until 5:00
- Heavy appetizers served during the event
- Drawings for prizes right after completion

Tournament Team Name: _____

NAME: _____	PH: _____	e-mail _____
NAME: _____	PH: _____	e-mail _____
NAME: _____	PH: _____	e-mail _____
NAME: _____	PH: _____	e-mail _____
NAME: _____	PH: _____	e-mail _____
NAME: _____	PH: _____	e-mail _____

TOTAL: _____ golfers @ \$75/each = \$ _____

Team Name: _____

Skyline Kiwanis Contact: _____

Please make checks payable to Skyline Kiwanis

_____ payment enclosed

All inquiries can be directed to Skyline Kiwanis Club Member Dick Larsen at either rl508@aol.com or 970 219-5856. Or you can visit our website at www.skylinekiwanis.org.

Help a great cause – please reserve your team today!

Skyline Kiwanis
www.skylinekiwanis.org
PO Box 565
Longmont, Colorado 80502



Golf Tournament Donation & Sponsorship Form

Skyline Kiwanis "Topgolf"

Sunday, February 23, 2020

Donor Information

Name of Company and/or Donor: *(as listed on all promotional collateral)* _____

Contact Name: _____ Phone: _____

Skyline Kiwanis Contact: _____

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Tournament Sponsorship Options

Auction Item Donation: Donor and item recognition will be listed in Tournament Program

Item Description: _____

Item Value: _____

_____ item to be delivered

_____ item to be picked up

Sponsorship Options: Tournament sponsor recognition via Tournament Program and sign and/or banner, please see following form for sponsor details.

Sponsorship Options	# Available	Price	Total Price
Title Sponsor	1	\$3,500	
Food Sponsor	1	\$1,500	
Bay Sponsor	27	\$675	
TOTAL			

Please make checks payable to Skyline Kiwanis

_____ payment enclosed

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Sponsorship Opportunities Detail List

TITLE SPONSOR

\$3,500.00

- Twelve complimentary golf tickets (two bays)
- Banner with company logo posted at check-in
- Recognition during Tournament Awards Ceremony and Auction
- Full-page ad in Tournament Program
- Assigned two bay sponsorship, with (2) signs including logos

FOOD SPONSOR

\$1,500.00

- Six complimentary golf tickets (one bay)
- Banner with company logo posted at check in
- Half-page ad in Tournament Program

BAY SPONSOR

\$675.00

- Six complimentary golf tickets (one bay)
- Sign with logo at assigned bay
- Recognition in Tournament Program

Primary Beneficiary of Skyline Kiwanis “Topgolf” Golf Tournament: Isaac Crane & His Family in Mead

Isaac Crane was born in February 2014. At the age of four months, he was diagnosed with Spinal Muscular Atrophy (SMA), Type 1, a severe condition that is the leading genetic cause of death in children. His medical team did not expect him to live to see his first birthday. His parents, Jeremiah and Jenna, both left their jobs to spend as much time as possible with him. Defying all odds, Isaac lived to see his first birthday, then his second birthday. Just before he turned three Children’s Hospital began treating Isaac with a new drug called Spinraza, and Isaac has slowly but steadily gotten stronger. Now he is about to celebrate his sixth birthday, attends



kindergarten, drives a power chair, loves sharks and dinosaurs and playing with his sister Natalie and friends. He is truly a fighter and a miracle. His mother has returned to work as a speech language pathologist, and his father works full-time as Isaac's caregiver. Since his diagnosis, the Cranes have been grateful for the blessings they have received and they look forward to seeing Isaac continue to grow and learn. However, Isaac's physical and medical needs have outgrown their 118-year-old home. Isaac requires 24-hour care and a room full of medical equipment and supplies. In order to make their home handicap accessible, it needed to be remodeled from the foundation up. The necessary changes include a staircase and wheelchair lift, wider doorways, an accessible bathroom, and structure to support a ceiling lift, as well as Isaac's own bedroom. Last July, the Cranes moved into a 500 sq. ft. rental house while they remodel their own home. Jeremiah has been overseeing the project and has been working on the house nearly every day for the last seven months. The project is far from complete, but the money that the Cranes saved for the project is depleted. The family has four months remaining on their lease. They need financial help to complete this project so that Isaac and his family can move home.

Recently Skyline Kiwanis chose to designate Isaac Crane and his family as primary beneficiary of the “Topgolf” Golf Tournament, 16011 Grant Street, Thornton, CO, Feb. 23, 2-5 pm, registration at 1 pm.

Skyline Kiwanis started an active fundraiser for “The Crane Family Project” in Nov. 2019, <https://www.skylinekiwanis.org/2019/11/15/crane-family-project/>

To view & download a picture story about Isaac’s life, visit http://www.skylinekiwanis.org/wp-content/uploads/2019/12/JoyOfContributingToCraneFamilyProject_Final.pdf

Isaac’s medical heroes at Children’s Hospital Colorado, <https://www.childrenscolorado.org/doctors-and-departments/departments/neuroscience-institute/programs/neuromuscular-clinic/spinraza-nusinersen-treatment/>

A newspaper story about Isaac Crane and his family — “Mead Family Building New Home for Son Fighting Genetic Disease” — appeared in the Longmont Times-Call on Sunday, Jan. 5, 2020 and in the Boulder Daily Camera on Jan. 6, 1B, 2B (printed on reverse side).

<https://www.timescall.com/2020/01/05/mead-family-building-new-home-for-son-fighting-genetic-disease/>

Read the story of how the Cranes won a difficult two-year battle against Medicaid to get approval and payment for a “medically necessary” power chair, <http://www.ccdonline.org/2019/06/26/issacs-new-chair-by-jenna-crane/>

To get updates about Isaac’s courageous battle against spinal muscle atrophy, follow posts on his Aunt Amy’s GoFundMe account started 5 years ago and averaging \$20,000 per year, <https://www.gofundme.com/agbytg>

Mead

Building for his battle

Family renovating house to make it accessible for son with genetic disease

By John Marinelli
Staff Writer

When a nearly 4-month-old Isaac Crane was diagnosed with Type 1 spinal muscular atrophy, the most serious form of a rare genetic disease, his family dropped everything.

Doctors gave him five months to live, predicting

that his muscles would weaken to the point where he wouldn't be able to eat or breathe. After hearing the news, father Jeremiah and mother Jenny Crane left their jobs.

"Jenna quit her job. I quit my job, so we could spend the last five months of his life with him and just do

everything — go to the zoo, go to the aquarium — do everything that a little boy should be doing," said Jeremiah Crane.

But as time passed, Isaac began to defy his doctors' predictions. Under the watchful eye of his father, who revived Isaac more than 10 times in the first couple

years of his life, he managed to survive until he could receive a breakthrough form of gene therapy.

"Later on Spinraza came along and he started to get just a little bit stronger and a little bit stronger, and all the doctors and everybody were amazed at how he was

See HOME, 2B



Cliff Grassmick / Staff Photographer

Natalie Crane, 7, hugs her brother Isaac in their Berthoud home. Their parents, Jenna and Jeremiah, also are in the photo. Isaac, a young boy with Type 1 spinal muscular atrophy, and his family, will be getting a remodeled home in Mead that is handicap accessible.

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doing," said Jeremiah Crane.

Isaac now uses a motorized wheelchair, which he got over the summer after a long battle with Medicaid, along with an "eye-gaze" device that uses his eye movements to help him communicate.

And as Isaac comes up on his sixth birthday, he's attending kindergarten, and his father is overjoyed to see him learning along with his peers. Life is beginning to look a lot more normal for the Crane family, with Jeremiah Crane working full-

time as Isaac's nurse and Jenna Crane back working as a speech pathologist.

So the family decided to build, quite literally, for the future. In June, they moved out of their 118-year-old home in Mead and began work to make it handicap-accessible.

'A privilege and a blessing'

David Emerson, the executive director of Habitat for Humanity of the St. Vrain Valley and treasurer for the Skyline Kiwanis Club of Longmont, was approached

by a family friend of the Cranes, Marilyn Blackmon. She told him about the project the family was undertaking. Emerson, in turn, decided to spark up a fundraiser.

Arranged through the Skyline Kiwanis Club of Longmont, the goal is to raise \$20,000 to add to the more than \$105,000 raised by a GoFundMe page set up by Isaac's aunt, Amy Martin, that has been active since Isaac's diagnosis in 2014. Both Blackmon and Skyline Kiwanis seeded the new fundraising effort, dubbed the "Crane Family Project," with \$500 each, and it's gathered thousands so far.

Emerson said Skyline Kiwanis offered the opportunity to have donations be tax deductible, adding that the club is planning on conducting a Feb. 23 fundraising event at Topgolf in Thornton for the Cranes.

"It's been a privilege and a blessing to get to know Jeremiah and Jenna and their story," said Emerson. "I think it's inspiring, the devotion they've (shown to) Isaac, who really had such a bleak prognosis and through some medical miracles is doing much, much better. And, hopefully, as we go here, he can do even better than he's doing now."

The family's renovations are now seeing them finish the internal framing of the house and install a staircase, according to Jeremiah Crane, and while they're going on, all four Cranes, Isaac, his mother, father, sister and their pets are squeezing into a 500-square-foot house in Berthoud.

A cause for celebration

The way the house was built before was entirely inaccessible for Isaac, due to his requiring a large motorized chair to get around, Jeremiah Crane said. And since the house is so old, they had to start from "literally the



Cliff Grassmick / Staff Photographer

Isaac Crane, a young boy with Type 1 spinal muscular atrophy, and his family, will be moving to a remodeled handicap-accessible home in Mead. This will be their new residence.

foundation up." Only the front section of the house will be kept, he said.

"I used to be in construction and when Jen and I bought this house, I loved it, because of the old, early-1900s woodwork and stuff in there," said Jeremiah Crane. "Obviously, that was before Isaac was born, so we had no idea what we were up against."

Currently the house still is without such amenities as plumbing, air-conditioning and electricity, and recent heavy snowfall has caused some problems.

"We got a lot of water damage," said Jeremiah Crane. "So that old part of the house, the lath and plaster ceilings started to fall in, and there was damage to the walls, lath and plaster."

Despite the setbacks, Blackmon, who works at the Institute of Cognitive Science at the University of Colorado Boulder and followed Isaac's story for a long time through a blog authored by the family, wants to see the family move back into their

home quite soon.

"It would be cause for celebration if the family is able to move from their tiny rental back into their home in time to celebrate Isaac's sixth birthday February 11, 2020," Blackmon wrote in a message to the Longmont Times-Call.

Though it may be a large step, the home that Jenna and Jeremiah Crane are building for their son represents only the latest in a series of challenges they've faced for their son.

Dr. Julie Parsons, a pediatric neurologist and Isaac's doctor at the Children's Hospital Colorado, said that the two have been "amazing champions for" Isaac.

"They've been here, they've been compliant with everything we've ever suggested," she said. "They are thrilled with every new skill that he develops."

"They've provided amazing care for him and have been joyful at every stage of his life, having celebrations and birthday parties and everything else."

Parsons added that both have been open to helping the medical community learn more about Isaac's disorder, something critically important to helping doctors treat children like him.

Progress is being made, too, with spinal muscular atrophy recently being added to Colorado's newborn screening panel, meaning that every baby in the state will be tested after birth for the disease.

"With newborn screening, we can identify kids before they even have symptoms and be able to give them an opportunity for treatment," said Parsons.

Aside from modern medicine, though, Jeremiah Crane said that his relatives, friends, neighbors and those at Guardian Angels Catholic Church are what got his family through such a difficult time.

"If it wasn't for the support that we have from our community, our family, our church, we wouldn't have even made it this far," he said.



Story published in Boulder Daily Camera, Jan. 6, 2020, Local 1B,2B