

The Journey Matters

pikespeakhospice.org



PIKES PEAK
HOSPICE & PALLIATIVE CARE

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"Our little nugget is such a fighter," wrote Teagan's parents, Kelsey and Shaun Romano.

HOPE AND HELP FOR A 'TENACIOUS' 4-YEAR-OLD AND HER INSPIRING TEAM

To her parents, she is "our cuddle bug" or "sweet Teagan Ann." But to the hundreds of people who are following her young life's journey on Facebook, 4-year-old Teagan Romano is known as "Tenacious Teagan."

"Our little nugget is such a fighter," wrote Teagan's parents, Kelsey and Shaun Romano, in a recent post.

Teagan has been facing serious illness most of her life. When she was nearly two years old she developed a light tremor. The first pediatrician her parents consulted in the summer of 2018 believed she would grow out of it. Unfortunately, that would not be the case. After further examination, including an MRI, she was diagnosed with metachromatic leukodystrophy (MLD), a degenerative and terminal genetic condition affecting the brain and nervous system.

It was a devastating diagnosis. MLD would eventually rob Teagan of her ability to walk, speak, eat and move

on her own. It would leave her with a compromised immune system and require many trips to the emergency room at Children's Hospital Colorado Springs from their home in Elbert, Colorado. Against many odds over the past few years, Teagan continues to brighten each day. And her parents, despite the immense heartache from a terminal diagnosis for their child, are choosing to make the most of every day they can have with Teagan.

"The grief is constant. Grief for the past, grief for the present, grief for the future," Kelsey said. But with the help of palliative and hospice care, the family manages Teagan's symptoms so they can be present in each moment with her.

"We loved the idea of the extra layer of support and medication management," Kelsey said about first learning of palliative care on one of their trips to the ER. That's where they



Teagan is supported by hospice in her home in Elbert.



met Dr. Brooke Geyer who leads the Pediatric Pathways Program at Pikes Peak Hospice & Palliative Care (PPHPC). As Teagan's illness progressed, the visits to the ER continued. Just before her third birthday, Kelsey and Shaun had to decide if Teagan would undergo surgery to remove her gallbladder. Dr. Geyer was there with the family as they grappled with the challenges that could arise from the procedure because of her weakened condition.

"Do we do a DNR [do-not-resuscitate order]? Do we not? Those talks that no parent wants to have, we had to," said Kelsey. That's when Dr. Geyer gently brought up hospice.

Kelsey said they were hesitant at first. They worried that "hospice" meant giving up. But Dr. Geyer helped them understand it differently. The increased level of care that comes with hospice would mean extra support for Kelsey and Shaun. It would also mean fewer ER visits for Teagan, and that has become particularly important during this pandemic to protect Teagan from exposure to COVID-19.

"We've been able to treat aspiration pneumonia from home because of Pikes Peak Hospice," Kelsey said.

Teagan has been receiving at-home hospice care from PPHPC since her third birthday. Her care team consists of Dr. Geyer, registered nurse Joan Goodfellow, and social worker Becky Gardner, along with physical, massage and music therapists who make regular trips to the Romano's home.

"It is such a tough decision for families to choose hospice support," Becky said. "Even talking about terminal illness is very difficult. Families always want their kids to be okay and hospice can help make sure they are as comfortable as possible."

Kelsey is Teagan's primary caregiver day-to-day — and even went back to school in 2019 to become a certified nursing assistant (CNA) to better care for Teagan. Kelsey said her education program made her realize most training for caretaking is oriented toward geriatric patients. She is grateful to have so many pediatric experts on Teagan's hospice team.

Teagan's dad, Shaun, said it means a lot to him to see how much the PPHPC team cares about his daughter.

"Our hospice team, it's like an extended family," Shaun said.

There are many hard days for Teagan and her family. But they also have high hopes for many great days and joyful experiences ahead. After enough people have been vaccinated against COVID-19, Kelsey and Shaun are excited to take Teagan to visit other friends, family and the Grand Canyon. The Romanos are currently converting an old school bus into "Teagan's Trolley," a house on wheels specially equipped to take Teagan on these trips.

"I want to see her light up when she sees these places," Shaun said.

For now, Teagan and Kelsey remain quarantined in their home in Elbert, while Shaun goes to work as a contractor. They listen to music, finger paint and cuddle beneath a wall of stuffed animal friends. Though she is now non-verbal, Teagan still finds other ways to communicate with her parents.



"She just adapts, and she's so patient," Shaun said about his little girl.

"Her life still matters," Kelsey added.

The Romano family is also hopeful for a better future for others diagnosed with MLD. Through sharing Teagan's story on social media, they are raising awareness about the critical need for early detection. MLD is most often diagnosed in late infancy, though juveniles and adults can develop the illness. Often by the time symptoms show, treatment to slow the progression is ineffective. The Romanos are now advocating for MLD to be included in newborn blood screening.

"We won't ever stop spreading awareness and being our child's voice. And helping be voices for others like her too," wrote Kelsey in a post on the "Tenacious Teagan" Facebook page.

"I love you so so much Teagan Ann. I will be your voice until my very last breath."

HELPING OTHERS GRIEVE: HOW A PATIENT'S WIFE SHARES HER KNOWLEDGE AND EXPERIENCE

Jami Leahy lost her husband, Scott, long before she could have ever expected. Their three boys were still young. There was so much more they hoped to share. And Scott wasn't the kind of guy who would give up easily.

"He would always bounce back, and he was always fighting his disease up to the very end," said Jami.

Throughout Scott's battle against a rare type of neuroendocrine cancer, he refused to let the disease hold him back. He continued coaching his sons' baseball and soccer teams and remained active as a Scouts leader. Meanwhile, he sought out clinical trials and traveled to try out various treatments. When those treatments were not successful, the Leahy family began to think about their other options for care.

Choosing Inpatient Hospice Care

Most people receive hospice care at home, because that is where they feel most comfortable. Home is where Jami's mother received hospice care before she passed away in 2007. But as Scott neared the end of his life, he made the decision that he did not want to pass away in his family home because of concern about the memories that would leave for Jami and their children. In May of 2017, when Scott opted for care with Pikes Peak Hospice & Palliative Care (PPHPC), he and his family spent the last five days of his life at our inpatient unit at Penrose Hospital.

PPHPC was able to provide the family a large room with a beautiful view of majestic Pikes Peak and Garden of the Gods. Jami says it was a comfortable space where she and the boys — ages 6, 10, and 13 at the time — basically "camped out" and shared precious memories.

Among those memories is the way the staff at PPHPC took the time to teach the boys how to help care for their dad. Jami says they adopted a "pitch in and help" attitude, and it helped the whole family be able to work together to make Scott comfortable until the very end. She says the boys gained an increased level of empathy because of this experience, and in fact, her oldest son is now interested in attending medical school because of his experience helping care for his dad.

Finding the Right Grief Support

After Scott passed away on May 16, 2017, Jami sought out grief support services to help her navigate this difficult time. She began by attending groups at PPHPC but was usually the youngest in the group, and she desired to connect with others who were experiencing grief at a similar stage in life. She found a group for young widows at the Heartlight Center in Denver, but found it difficult to travel from Colorado Springs to

Denver on a regular basis. In the same spirit of her late husband, Jami didn't give up easily. She found a solution by creating one — and helping others in the process.

Instead of frequent long trips to Denver, Jami started her own support group for younger widows in Colorado Springs. The group started at the YMCA three years ago and now regularly meets on Zoom with sessions of four to nine people.

People often choose to handle their grief quietly and discreetly, but Jami has learned that more transparency and openness can help us process our grief.

"I believe coping with grief is something that should be talked about openly, and I have tried to normalize grief to help others through the process," she said. "I have learned a lot, and if I can share with someone to help them, I want to help."

Jami now shares the knowledge and wisdom attained through her own experience with grief to help others on their path through a similar difficult experience.



UPDATE: SUPPORT GROUPS ARE NOW MEETING IN PERSON.

For more information on available groups, please visit <https://pikespeakhospice.org/our-services/grief-support/>

Foundation News



SAFELY HONORING OUR LOVED ONES DURING THIS CHALLENGING TIME

Pikes Peak Hospice Foundation Tribute Receptions are held throughout the year allowing family and friends the opportunity to honor their loved ones. During this challenging time, virtual tribute receptions have allowed us to safely commemorate loved ones. The Tribute Program honors and recognizes loved ones when donations received in their name total \$1,000 or more as a one-time gift, or given cumulatively over a period of time. Those who have made a memorial contribution, as well as family and friends of each individual being memorialized are invited to attend a brief, but meaningful reception. Each family is encouraged to submit a story about their loved one along with a photograph to be displayed during the reception, and afterward on our virtual Tribute Wall.

Guests who attended the most recent virtual tribute reception were welcomed by Pikes Peak Hospice & Palliative Care President Dawn Darvalics. Names of all those being memorialized are read aloud in remembrance by one of our chaplains. Music performed by local musician Phil Volan creates a special environment for

reflection. Each family also receives a family keepsake to commemorate their loved one.

Following the reception, the names of those being memorialized are added to our virtual Tribute Wall along with their story and photograph. We are pleased to offer this benefit in addition to the option to participate in the reception virtually. Families are invited to view the virtual reception as often as they like at <https://pikespeakhospice.org/pikes-peak-hospice-foundation/virtual-memorials-2/>

If you are interested in honoring someone special in your life or have any questions about our Tribute Receptions, please call Pikes Peak Hospice Foundation at 719.457.8105 or reach out to Lindsey Cherry, Development Manager at lcherry@pikespeakhospice.org.



"Thank you so much for the touching and honoring tribute to my wife, Angela and the others.

It warmed my heart.

Thank you especially for pronouncing Angela's name correctly."

- Tom

"I'm remiss in writing to say how much the Tribute Reception meant to us. I was taken aback by how touching it was to hear the tribute about my mother as it was being said by someone else, it felt like I was hearing it for the first time.

Your efforts in putting that ceremony together were "first-class" and very emotional yet healing.

Thank you so much for giving me a second opportunity to pay tribute to my mother and the gold leaf remembrance.

Thanks again for all your help."

- Richard

Foundation News



TREES OF LIFE TO HONOR LOVED ONES IN A UNIQUE WAY

Every year we gather to honor our loved ones at our Trees of Life ceremony. While we were unable to gather in person in 2020, we still collected names of loved ones to honor. Below are names that were inadvertently left off our first list. We cherish our time together and honoring loved ones and look forward to an in person Trees of Life ceremony on November 13, 2021.

Kenneth Amerine
 Winona Amerine
 Randy Amerine
 Oscar Anders
 Charles A. Anderson
 LeeRoy F. Aragon
 Al & June Aune
 Terri Babauta
 Cleo Bagley
 Norma Bailey
 John T. Baker
 Phyllis E. Baker
 Kent D. Baker
 Carolyn R. Barber
 Joseph B. Barron
 Dolores Barrowman
 Sam Beach
 Marjorie Boese
 Frances Bowers
 Adelaide Bowers
 Rick Braudis
 John Briggs
 Pearlle Briggs
 Donald Callihan
 Gerda Callihan
 Marianne Caminiti
 Richard Campbell
 Marion Cervantes
 Mickey Cervantes
 Helen Chlupek
 Howard "Hal" Church
 Earnest & Jean Clemons
 Charles A. Closson
 Sybil Coblentz
 Donald Coblentz
 Ilse Corey
 James F. Cox
 Georgie Crosson
 Tony Da Silva
 Charlotte DeLange
 James J. Dorobiala
 Melvyn W. Doubleday
 Sally Drabing
 Sherry Ekerholm
 Yvonne Elliott
 Marie Field
 Dr. Calvin & Pat Fisher
 Michael Flora
 Ethel Flora
 Harold Flora
 Kari L. Fogle

Stephen Fullerton
 Richard Ganstine
 Georgia M. Gardner
 Charles Gilland
 Janice Gilland
 David Gilson
 Ella L. Grueter
 Pam Hafemann
 Bill Hanchey
 Mineko Hara
 Margaret Hedemark
 Richard Heikes
 Raymond P. Herrera
 Loraine Herring
 Emilie G. Hesse
 Margaret Hines
 Charlene Ikeya
 John Irwin
 Leona Jones
 Barbara Kafka
 Ingeborg Kawamoto
 Darlene Keller
 Alice M. Kennedy
 Richard P. Kennedy
 Ila A. Kitamura
 Frederick O. Kuehl
 Fred H. Kuehl
 Grace P. Kuehl
 Dennis Lang
 John W. Link
 Joanne Lykens
 Alexey Malyshev
 Bob & Evelyn Marsh
 Arthur Martini
 Mikie McDonald
 Mary Jane McHenry
 Warren Glenn Miller
 Armando "Mando" Montano
 Ben & Georgina Moon
 Fred Muchmore
 Edith Mundell
 Phyllis Narvaez
 Nicholas W. Natelli
 Kevin Scott Natelli
 Esther Newingham
 D.W. Niswonger
 Dora Norris
 Lawrence Norris
 Lucretia Novack
 Stephen O'Neill
 Jeff Paffendorf

Leonie Panton
 Gene Parsley
 Pearl Parsley
 Fr. James J. Pillar, O.M.I.
 Helene Poyzer
 Eileen Quaney
 Frieda Raabe
 Betty Raabe
 Grant Ralston
 Sharon Reese
 Jim & Mary Rhyne
 Anna Ringler
 Judy Rockwell
 Annie & Sophie Rovella
 John Salimeno Jr.
 V. Chris Schaefer
 Chad Schlenger
 Herbert Schloendorf
 SgtM. Paul E. Schossau
 Anna Schossau
 Joyce Schuck
 Mecky Schuler
 Richard N. Schultz
 David P. Schuster
 Ronald James Sebben
 Evelyn Sees
 Debbie Sloup
 Elton Smith
 Larry Sonner
 Larry & Kelly Strauch
 Robert Stubenvoll
 Kristian L. Swint
 Bernard Szczytkowski
 Adeline Tasher
 Robert W. Terry
 Jeanne L. Terry
 William E. Thompson
 Lilly Twiddy
 Dr. Richard A. Uhrman
 James A. Vertes
 Joanne Wall
 Alvin Paul Wegeman
 Gordon West
 Clyde Wilkinson
 Yates S. Williams, Jr.
 Claudia Wilson
 Fred Wolf
 John Max Wolf
 Frank Kunio Yashiro

Foundation News

COLORADO LAWMAKERS CONSIDER NEW LICENSE PLATE TO HONOR HOSPICE AND PALLIATIVE CARE

Denver, Colo. — Colorado drivers may soon have another license plate option. A bill before state legislators creates a new hospice and palliative care license plate that would raise awareness of this important health care for people facing serious illness.

[House Bill 21-1128](#), sponsored by Representative Dafna Michaelson Jenet, D-Commerce City, and Senator Chris Hansen, D-Denver, will allow Colorado drivers to choose the new plate if they qualify for it. To qualify, Coloradans will need to make an annual donation to a designated non-profit organization promoting hospice and palliative care in the state.

“Hospice and palliative care workers are heroes, bringing comfort, support and presence to individuals and families facing an often difficult journey,” said Care Synergy President and CEO Tim Bowen.

Bowen testified in support of the bill at its first hearing in the House Transportation and Local Government Committee on March 24.

“There are too many Coloradans who get hospice care much too late,” said Bowen. “The purpose of this opportunity is to help fund education and awareness throughout the state to provide better access and more timely access to care.”

The proceeds from the special license plates will fund awareness and education initiatives including professional development for health care workers who support hospice and palliative care patients, as well as public campaigns aimed at connecting more families and their loved ones with end-of-life care.

After passing the House Transportation and Local Government Committee, the bill moves on to the Appropriations Committee. If passed into law, the new license plates could be available to the public next year. Care Synergy is thankful to the bill's sponsors for their efforts to help more Coloradans receive expert, compassionate care during a life-limiting illness. We encourage our fellow Coloradans to support the effort and to [contact their elected representatives](#) to urge passage of the bill.



Help the
PPHPC
community
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1 Get Online.

Visit www.kroger.com/communityrewards/ and create an account or log in.

2 Choose

Choose Pikes Peak Hospice Foundation. Under Community Rewards, enter our Non-Profit Organization number: **EN851**

3 Shop

Shop at King Soopers or City Market and use your King Soopers Plus Card at checkout.

Thanks to you, Pikes Peak Hospice & Palliative Care will receive King Soopers/ City Market donations to help keep giving back to our community!



Providing a special kind of care,
a different kind of hope.

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2550 Tenderfoot Hill Street
Colorado Springs, CO 80906
719.633.3400 Fax 719.633.3800
PikesPeakHospice.org

Pikes Peak Hospice & Palliative Care, Inc. is a community-based nonprofit serving the Pikes Peak region since 1980.

Our Mission

- Provide compassionate & expert end-of-life care to patients & their families.
- Partner with those who share our vision.
- Lead change in the community to ensure comfort for all who face serious illness.

Our Core Principles

- Hospice care is about living.
- End-of-life events are universal.
- Comfort & dignity should be accessible to all.
- Every life experience is exceptional.
- To listen is to understand.
- Hospice & palliative care is ever-changing.
- Optimism is powerful & contagious.

Honored to walk this journey with you.