

Angels Among Us



~ Remembering Our Loved Ones 2024 ~

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Paul Adams (MPS II) >

11/17/1985–10/13/2009

Submitted by his family, Karin, Stuart, and Kathryn Adams

Paul—we remember so many happy moments, your laughter, and your unending excitement for all that was new to you. Quite often you would say, “no, I did that before.” It truly was to be respected! Love you always, Mom, Dad, and Kate

Eli Alonzo (MPS IIIB) >

2/23/2013–7/29/2023

Submitted by his parents and brother, Elvin, Monica, and Elias

Eli, we dearly miss you. We always think of you. Our hearts are not fully filled because you are not with us. You are running and laughing over us. We love you.

Andre Andrews (ML II) >

1/23/1994–5/5/2020

Submitted by his mother, Jane Andrews

Each year brings back the memories of a life well lived and individual well loved. Andre’s agenda was to do all he could despite the odds, and for the most part, he succeeded. He learned to be his own advocate and to try to be as independent as possible. Even though not an easy task, he made it happen, and for 26 years, he was a trooper. He fought the good fight and now has his wings and can fly like an eagle...until we meet again.

Conner Anhalt (MPS II)

1/8/1988–12/1/2013

Submitted by his grandparents, Millie and Mel Anhalt



Kristofer Arnold (MPS VI) ▶

12/6/1981–7/19/2009

Submitted by his mother and bonus dad, Sherrie and Tony Roman

Not a day goes by that we don't think of you and miss you. Your smile and personality always lit up our lives, and you were the greatest joy to our family. You taught us to live every day and to make every day count. Thank you for being you. We know we will see you again one day. We love you always, our dear Kristofer.

Loralei Lee Bell (MPS IIIA) ▶

9/28/2015–11/25/2023

Submitted by her mother, Brandi Amburgey

Loralei was my world. She was such a fighter and truly done all she could to keep going no matter the pain. She had the most beautiful smile. So innocent. She was so loved by her dad Cody and her siblings. For 8 years she taught me so many things that I thank God for. She was truly an angel on earth to me and now she is free from Sanfilippo in heaven.

Faydelisya Bella (ML II)

5/29/2019–5/11/2023

Submitted by her mother, Catherine Raihana



Grace Bellontine (MPS IIIB) >

11/27/2000–8/13/2014

Submitted by her mother, Joan Bucchino

This August will be 10 years since we lost our beloved Grace. Grace was a very smiley girl who truly lit up every room. She opened the hearts of all people she came in contact with. Grace lived every single moment in the present and was a very happy person as a result. Her learning needs inspired an elementary school classroom kit/game that motivates kids to achieve positive, healthy, personal goals for 6 weeks at home, in school, and in their communities. “Graceplay” classroom kits are available for free for siblings of MPS-affected kids (because of a special grant), and the kit also helps to raise awareness toward a cure for MPS. Grace will always shine in our hearts and in the healing actions of all students who play her special game. Learn more and request a grant at smartgame.net.



Colin Berning (MPS IIIA) >

11/22/2007–2/12/2020

Submitted by his parents, Ross and Hilary Berning

Colin is missed every moment of every day by those who loved him. He fought hard for a cure and participated in two natural history studies. Though a cure would not be found for him, we continue to believe and fight for one to be found.



Riain Daniel Bloomfield (MPS I) >

4/13/2021–11/9/2023

Submitted by his father, Edward Bloomfield

Remembering our beautiful son, Riain. We miss you so much, we know you're watching over us. You're forever with us. Mummy and Daddy's love for you never stops.



Trinady Jade Bowen (MPS IIIA) ▶

1/10/2011–12/13/2023

Submitted by her mother, Leigh Ann Wallace

Trinady was an amazing warrior. She is forever free from Sanfillipo. Leaving behind her two brothers and two half sisters, as well as dad, grandparents, and cousins. Not a day goes by that is not talked about. She was a big part in a lot of lives. Everyone fell in love with her. Trinady showed me the real meaning of love, and I will forever be grateful for that. Even though she is missed dearly. She is free watching down on us always.



Blakely Mae Brown (ML II) ▶

5/5/2020–10/25/2022

Submitted by her mother and father, Lauryn and Matt Brown

Our sweet miracle was born at 26 weeks in 2020. Two weeks later she was given the diagnosis of ML II. We were told she would never come home. She loved proving doctors wrong, and after 107 days in the NICU we got to enjoy two years at home with her. She's our beautiful butterfly who spread her wings far too soon. She enjoyed snuggles and playing with her monk monk. We miss and love you, Blakely Mae.



Edie Burke (MPS I) ▶

7/27/1998–5/2/2008

Submitted by her mother, Laura McKeithen

Edie, your legacy of love continues in all who knew you and in the lives you inspire. Give your sister hugs for me until we all are reunited.



Jacob Hunter Burt (MPS II) >

11/11/2000–11/24/2020

Submitted by his mother, Jennifer Wolf

You know that place between sleep and awake, that place where you still remember dreaming? That's where I'll always love you. That's where I'll be waiting.



Joshua Kenneth Burt (MPS II) >

11/26/1998–9/26/2010

Submitted by his mother, Jennifer Wolf

Today, if a smile comes to you, a happy smile that perhaps you can't explain, it's because in that moment I am thinking of you and smiling, too.



Rhett Butler (ML II) >

10/17/2017–6/10/2023

Submitted by his mother, Christina Butler

Rhett Butler. If you think that name set him apart from everyone in the room, you would be absolutely correct. Rhett had a way of making his presence known. Whether it was batting his beautiful blue eyes or giving you the million-dollar grin, Rhett earned the attention of every person around him. He had dance moves that melted your heart and a hug that could fix any bad day. He was the Sunshine to our days, and his life remains bright in our hearts.



Autumn Cooper (MPS I) >

2/5/2006–2/6/2014

Serrina Cooper (MPS I) >

5/25/2000–2/25/2014

Submitted by their mother, Catherine Cooper

To my beautiful daughters Serrina and Autumn...My mind still cannot comprehend how it has been 10 years since you both left this world. You both will continue to be the first thing I think of when I wake and the last thing I think of before I sleep. Never forgotten...
love, mom

Camden Crockett (MPS II) >

10/30/2005–10/30/2005

Submitted by his parents, Billi and Jeremy Crockett

Beautiful Angel, you and your brother play and have fun in heaven. We cannot wait until we are reunited with our beautiful boys. Love you more than life itself always, Mommy and Daddy

Matthew Crockett (MPS II) >

9/18/2003–3/10/2007

Submitted by his parents, Billi and Jeremy Crockett

Our Hero, not a moment goes by without your beautiful face smiling upon us. We love you more than life itself always, Mommy and Daddy



Kelley Crompton (ML III) >

7/4/1963–3/17/2009

Submitted by her mother, Denise Crompton

The morning after our daughter Kelley died 15 years ago, one of the doctors she saw regularly called to say that he was sorry to learn of her passing. He further said that he would miss her because she always brightened his day. That pretty much explained why everyone who knew her thought she was special, not because of her rare disease, but because of her attitude toward life.

Despite the many problems Kelley endured during her life, she never lost her acceptance. There were many things that she never understood, but she did accept the fact that she had a rare debilitating disease.

In her quiet way, Kelley touched many lives, teaching all of us about acceptance, patience, and fortitude. She showed us that one can be pleasant even when in pain, or gasping for breath, believing that it makes no sense to feel sorry for yourself or complain about your situation.

I know our lives would have been different if Kelley had not been sent to us. I think we have all become stronger because of it. We were truly blessed! We do not grieve her passing. We celebrate the life she lived!

They say that God doesn't give you more than you can handle. It makes sense to me because you can ask God for help with anything you have to handle. He can handle anything and everything!

My book, *DIAGNOSIS: RARE DISEASE*, includes Kelley's story along with the stories of another dozen rare disease families.



Ross Davis (MPS IIIA) >

2/7/2008–10/27/2019

Submitted by his mother, Jessica Davis

“For all the things my hands held, the best by far is you.”



Joshua James Downing (MPS IIIC) >

3/22/1979–5/16/2012

Submitted by his mother, Susan Downing

Joshua was a true blessing to all that knew him. He showed us how to be strong and grateful for the little things in life.



Benjamin Durcholz (MPS IIIB) >

1/31/2002–3/15/2016

Submitted by his parents, Chris and Annette Durcholz

We love and miss you, Benny!



Zachary Durcholz (MPS IIIB) >

1/16/1987–5/21/1998

Submitted by his parents, Chris and Annette Durcholz

We love and miss you, Zachie!



Lindsey Whiteleigh Efird (MPS IIIA) ▶

5/17/1998–6/01/2019

Submitted by her mother, Karen (Efird) Russell

This year marks your 5th Heavenly Anniversary. Although it seems much longer because you are missed so deeply. So much has changed here at home, yet I know you are with us and happy for the wonderful changes Hannah and I have experienced. You are in a better place now, but we sure did enjoy your brief healthy years together and treasure the years we got to keep you in spite of MPS. Please know you will always be thought of and loved in our hearts and life. — Karen and Hannah



Maci Grace Eickman (MPS I) ▶

10/1/2015–4/29/2018

Submitted by her parents and brother, Josh, Elizabeth, and Jack Eickman

Maci Grace was only here on this Earth for 2.5 years, but her memory lives on in our hearts. Her contagious laugh, love for Ernie from Sesame Street, and her sweet compassionate nature will never be forgotten. We cannot believe it has been six years...we miss and love you so much.



Russell Forkas (MPS II) ▶

12/27/1961–5/10/1974

Submitted by his sister, Kim Whitecotton

Gone but never forgotten. Take care of Scottyman.



Katherine (Katie) Foshay (MPS I) ▶

6/13/1976–6/29/1984

Submitted by her parents, Maria and Steve Foshay

You're always in our hearts.



Jack Teagan Fowler (MPS II) ▶

9/7/2007–3/28/2022

Submitted by his mother, Jamie Fowler

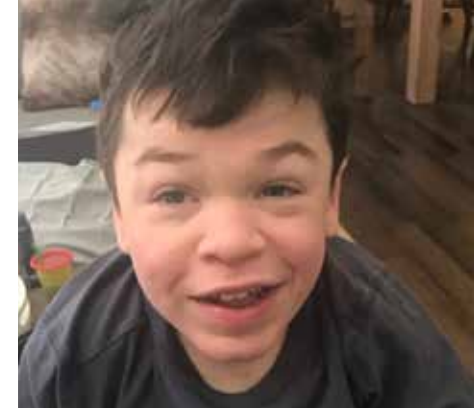
And then 2 years happens.

Some people have told me that the second year was actually more of a challenge. Perhaps because of expectation—expecting to feel better and then feeling even more disappointed and sad when they didn't. Or maybe it's because the more time passes, the longer we've had to live without that person. The longer it's been since we've seen them or heard their voice.

Physically, I am exhausted. More headaches. And sleep sometimes is hard to occur. But time keeps moving on. And I can live bitter or I can live better. I live from a deeper place than I ever thought. Your gifts given.

I am falling down again and again. And getting back up. Again. And again. I will never finish healing until we meet again.

When I lost you, I lost myself. Ever since that moment, I have had to rebuild my life, not by choice, but against my will. You were taken away. And I had to relearn how to be myself. I am rediscovering who I am. A new shell forced around me. Finding the new me based on the boy I loved and lived.



Kimberly Lynne Fowler (MPS IIIA)

12/30/1987–8/17/2014

Submitted by her mother, Betsy Fowler, and her uncle and aunt, Jeff and Barb Harrell

Dear Kimberly is missed every day. Her sweet smile and demeanor will always be remembered. Her name is carried on as the middle name of her new little niece Grace. Memories of Kimberly are precious and everlasting. She truly was an angel who taught us real love and compassion. God gave us a real gift with this amazing girl.

Violet Fox (ML II) ▶

8/21/2015–12/25/2019

Submitted by her parents and sister, Daniel, Bree, and Scarlet Fox

Violet, we think of you every day. You are loved and missed beyond words.

Jeremy Fronczyk (MPS IIIB)

2/20/1974–3/13/2013

Submitted by his parents, Roy and Carrie Fronczyk

Joanna Fronczyk (MPS IIIB)

12/23/1969–11/13/2014

Submitted by her parents, Roy and Carrie Fronczyk

Nick Fronczyk (MPS IIIB)

7/7/1972–1/6/2013

Submitted by his parents, Roy and Carrie Fronczyk



Clara Marie Gibson (MPS IIIA) >

8/27/2001–9/20/2020

Submitted by her mom, brother, mama and papa, Jenifer, Ethan, Patty, and Darrell Saylor

Clara Marie

Our Little Angel,

You are missed each and every day. Often we are reminded of the days we had together and love to tell your story. Thankfully we are blessed with many memories that we cherish every day. We love you so much, sis.



Jackson Gibson (MPS IIIA) >

12/31/2011–2/9/2023

Submitted by his mother, Hannah Clark

You were such a bright light of warmth, and you are so very missed. If love could have saved you, you would have lived forever. Forever 11, sweet baby boy.



Brett Golsteyn (MPS II)

3/28/1997–1/14/2007

Submitted by his grandparents, Mark and Darlene Hesprich

Karina Guajardo (MPS IIIA) ▶

1/28/1992–6/4/2021

Submitted by her parents and sister, Angela, Luis, and Anyssa Guajardo

Kind soul who enlightened our world

Always showing us your courage and strength

Rare and precious, a gift beyond measure

Infinite love constantly filling our hearts

Never forgotten, your life inspires us

Angels surround you, providing us with Hope.

Destiny Dyan Hall (MPS I) ▶

5/24/2000–7/3/2009

Submitted by her mother, Ashley Bell



Joseph S. Hall Jr. (MPS IIIC) ▶

8/23/1979–4/30/2020

Submitted by his mother, Twila Bridges

“In My Heart”

I thought of you today.
But that is nothing new.
I thought about you yesterday.
And days before that too.
I think of you in silence.
I often speak your name.
Now all I have are memories.
And your picture in a frame.
Your memory is my keepsake.
With which I'll never part.
God has you in his keeping.
I have you in my heart.

Adam Tyler Hardy (MPS I)

3/19/1988–3/30/2003

Submitted by his parents, Rodney and Donna Hardy



Devin Heise (MPS I) ▶

4/7/1988–3/21/2021

Submitted by his parents, Tammy and Glenn Heise

If you were lucky enough to meet and know Devin, then you were lucky enough. Devin was pure light and love. Caring, funny, devoted MN sports fan, and a friend to all. We are grateful we were chosen to be his parents. Devin you are so loved and missed.



Rachel Irene Hess (MPS I) ▶

3/23/1991–6/24/2023

Submitted by her parents and sister (also with MPS I), Robert, Michelle, and Jessica Hess

Our dear Rachel, those precious hands of yours, we long to touch them again and hear the beautiful music they played for us every day. You were so much more than what your world viewed you as, and we were so honored to be your parents and sister. You were loved with no bounds, we fought to the end of the earth for you and your quality of life, and we persevered with courage, grace, and dignity...but now you have decided (and deserve) to be in an even more loving place, free from your earthly limitations. You can now see the beauty of colors again, you can run without interruption, speak your wise words all the time, laugh to your heart's content, and be with our beloved relatives. You will be forever loved, and boy are we such a better earth for having you present all those 32 years. We love you big... Dad, Mom, and Jess (and Gigi, too).



Paige Elise Hill (MPS IIIA) ▶

9/27/2001–2/13/2022

Submitted by her mother, Michelle Hill

Sweet Paige fought a long and brave battle with the Sanfilippo monster. She was able to accomplish so much in her life that others only dream of doing. With the help of her three big brothers (Brandon, Alex, and Chris), she played a variety of sports, showed livestock in 4-H at the fair, played in the WPHS band, was a member of Student Council Leadership, loved to travel (especially to MPS conferences), and had many friends. Our family was truly blessed to have had her in our lives, and she is forever in our hearts.



Frederic (Ricky) Hodgkins (MPS IIIA) ▶

2/13/1979–7/10/2020

Submitted by his mother, Anita Hodgkins

Dear Ricky, It's been almost 4 years since you left us. You are missed every day, but we know you are in a better place. Though we still want your hugs and kisses, we hope you are running free with all your MPS brothers and sisters. Ours was not an easy journey, but we are better for it. You taught us so much—many lessons of patience, acceptance, and unconditional love. You will always be in our hearts, our beloved Energizer Bunny. Rest In Peace, my love. Always, Mom, Dad, and Robyn



Maddie Holland (MPS I) >

6/26/1991–1/2/2024

Submitted by her parents and sister, Steve, Amy, and Laynie Holland

Madison was diagnosed with MPS I at the age of three. Within a few weeks, her older brother Spencer, age 4, and her younger sister Laynie, age 1, were also diagnosed with the same disease. From a very early age, Madison developed a skill set that would help her cope with her life with chronic illness. She was incredibly brave, faultlessly kind, and fastidiously selfless, and lived a joyful life, despite having many challenges.

Maddie's biggest joy in life was her family. She lived with her family all of her days and loved every minute she spent with them. Maddie also loved her extended family and friends and often told them how much she loved them. She loved creating art, singing songs, reading books, traveling, and watching family shows on TLC, especially those with multiple children or little people. She also enjoyed attending the circus with her father every year and all things Disney.

Madison, along with her family, has always been very involved with the National MPS Society. She had many friends with MPS all over the United States and traveled to MPS Conferences every year. Maddie also participated in clinical trials that resulted in a new FDA-approved treatment for MPS that improved her health and future generations of children with MPS.

Though she operated at a somewhat younger age much of the time, when necessary, she would woman up and deal with things as an adult. For example, when it became clear that her journey on this earth was coming to an end, instead of being scared for what lay ahead of her, she turned her attention to us, her family. She worried if we would be okay without her here to comfort and love us. Is that not the most mature thought and concern ever? We didn't intend to mislead her when we said we would be okay. I mean, that is what she needed to hear, and we have done this before, so we knew what to expect. The truth is that you never know what to expect. But we are obligated to live up to our assurances to her—so, we WILL be okay.



Spencer Holland (MPS I) >

12/19/1989–1/26/2008

Submitted by his parents and sister, Steve, Amy, and Laynie Holland

WHEN

When we see a son embrace his father,
when we hear a song about bravery,
when we see a bottle of French's mustard,
when we burp extra-long and extra-loud,
when we see an old blue Honda Accord,
when we see a boy with a dog,
when we need a bear hug,
when we are asked at a restaurant, "How many in your party?"
when we sing your favorite songs,
when we dream of Heaven,
when we tell our stories of you,
when we are awake,
when we are asleep,
when we dream,
and when we breathe,
we miss you, sweet boy!

Kevin Johnson (MPS II) >

10/12/2001–8/4/2021

Submitted by his mother, Marqueta Johnson



Liam Ross Johnson (MPS I) >

11/4/2019–7/22/2021

Submitted by his parents, Amanda and Michael Johnson

Our sweet Liam—there is not a day that goes by that we don't think about you. We miss you terribly! I wish I could hold you and give you tons of kisses. You brought us so much joy in your short time with us!! We love you so very much!!!



Andrew Taylor Jump (MPS IIIB) >

10/9/1997–5/19/2009

Submitted by his parents and sibling, Colin, Paulina, and Alex Jump

We love and miss you, Superman!!



Kraig A. Klenke (MPS II) >

12/3/1991–10/26/2010

Submitted by his parents, sibling, and brother-in-law, Brian, Kris, Chelsey, and Matt

If there ever comes a day when we can't be together, keep me in your heart, I'll stay there forever. – Winnie The Pooh

Kraiggy, You brought so much joy, laughter, and love to our lives. We miss your infectious smile, amazing red hair and cute little freckle face. You remain in our hearts forever. Until we see you again!



Nicholas T. Lee (MPS IVA) ▶

11/28/2003–5/25/2022

Submitted by his mother, Mary Jane Lee

Nicholas passed away unexpectedly on May 25th, 2022, just three days after graduating from high school. His big heart was pure, generous, and kind. With his classic wave hello, he brought a smile to every passing face. Godzilla aficionado, Pokémon and dinosaur expert, proud Cat Dad to Sal, stop motion video YouTuber Godzillaguy54, Sonic super fan, and avid collector of Transformers. Nicholas' deep knowledge of his favorite interests made him a human Google.

We are beyond grateful to the National MPS Society. Because we were able to attend the MPS Family Conference Orlando in December 2019, Nicholas' dream came true as he experienced the best time of his life on our visits to Universal Studios. Transformers the Ride, Kong, and Jurassic Park are so Nicholas.

Dear sweet Nicholas, in the two years since we suddenly lost you from this earth, the tears of heartbreak have never lessened. You're always in Mommy's heart, and I think of you every second of every day. Your Aunts Sue, Shortie, and Cherry, Uncle Shawn, and Mommy are so proud of you. We love and miss you forever and ever

JC Lopez (MPS IVA) ▶

11/19/1993–2/2/2021

Submitted by his sister, Jessika Mejia

JC was incredible. He unknowingly changed the lives so significantly of all of us who loved him so much. He lives on through each of us each day as we do our best to mimic his strong, brave, feisty spirit. We love you always, papas; it was an honor to be your sister.



Craig Lupardo (MPS II)

9/19/1987–9/11/2000

Submitted by his parents, Jim and Doris Lupardo

Kyle Joe Manning (MPS I)

7/7/1985–6/19/1997

Submitted by his parents, Don and Carol Manning

Francesca Antoinette Martin (MPS I) ▶

7/24/2022–5/3/2024

Submitted by her parents, Bella and Talor Martin

Francesca (affectionately called Frankie) was a very precious girl, full of life and joy despite facing continuous challenges related to MPS I Hurler Syndrome and MCAD deficiency. Both are rare genetic disorders that made her 1 in 1.5 billion. Born the ultimate teacher, Frankie taught all who crossed paths with her the importance of gratitude, resilience, and patience. She was a happy and loving child who adored her Mama and Dada, her Gigi and PopPop, Mormor and Grandpa, and her doggie, Cow. She loved to ride on her daddy's shoulders and snuggle with her mommy to watch Miss Rachel or Elmo videos. She spent a considerable amount of time doing puzzles, reading books, and practicing animal sounds with her Little People figurines. She never met a stuffed bunny that she did not like.

Her struggle and treatment path will someday help other families facing these devastating diagnoses due to her involvement in several clinical trials and studies, most notably the OTL-203 HURCULES phase 3 trial.

Francesca passed away at 7:40 pm on May 3, 2024, at M Health Fairview Masonic Children's Hospital in Minneapolis, Minnesota, from post-bone marrow transplant complications.

Although she is no longer with us, Frankie's Fight has just begun.



Dylan Michael McClurg (MPS I)

6/16/1995–2/21/1998

Submitted by his grandparents, Stephen and Marie McClurg

Meggie Dawn McCorkle (MPS IIIB) ▶

4/13/1979–8/19/2001

Submitted by her mother, Judi Hauck

Meggie will always be remembered for the difference she made while with us. Because of Meggie, a non-profit organization called the Lighthouse Voc-Ed Center provides programming for individuals with special needs. It started in 1992 with Meggie being their first student and is thriving today to support more than 200 students. A scholarship in Meggie's name is given to a graduating high school senior who is pursuing a career that supports individuals with special needs. She left this world a much better place. She is missed and loved but not forgotten due to the warmth and love she showed to everyone left behind.



Carter Hancock McGraw (MPS I) ▶

3/29/2021–10/26/2022

Submitted by his family, mommy, daddy, Amelia, Campbell, Iris

Loving, missing, and thinking about you always, our sweet Carter Bear.



Penelope Ann Judithlynn Meixel (ML II/III) >

11/19/2023–4/7/2024

Submitted by her parents, Erin and Scott Meixel

Penelope was such a beautiful little girl who changed the world in a short amount of time. You are dearly loved and missed by many. Thank you for being mine and choosing us as your family.



Leila Merrill (MPS IIIA) >

11/29/2012–11/27/2022

Submitted by her parents and brother, Elizabeth, Terrence, and Jack Merrill

Leila–We miss you and love you so much more than words can describe. You will always be our angel.



Lucas Montgomery (MPS IIIB) >

7/31/1997–7/22/2018

Submitted by his parents, Stacey and Lew Montgomery

Our hero! We miss you!!!



Miriam Katherine Nay (MPS IIIB) ▶

9/14/2010–6/4/2023

Submitted by her parents, Josh and Kathy Nay

Miriam was loved by all who knew her, and in her way, she showed you that she loved you back. Her hugs were legendary. She was the best cuddler. Laps were among her favorite seats. Her laugh was infectious. She smiled with her whole face. And she loved laughing with others, up close, face to face, or right in her ear, which only made her laugh harder.

While she is no longer with us physically, Miri's spirit and the lessons she taught us will live with us forever—to smile through tough times, to not be afraid of what others think, to be patient, to love unconditionally.



Ryan O'Steen (MPS IIIA) ▶

12/25/1983–1/5/2001

Submitted by his parents, Eileen and Lawrence O'Steen



Reiley Osterhoudt (MPS II)

8/4/2008–5/16/2020

Submitted by his grandmother, Mrs. Sharon Gillham

Jordan Ostwalt (MPS IIIA) >

4/21/2006–6/14/2021

Submitted by his sibling, Taylor Ostwalt

This is my brother Jordan. He was 15 years old when he passed away. He had such a big attitude and sure was not afraid to show it!! Miss you forever, bub!



Whitney Ostwalt (MPS IIIA) >

6/13/2004–12/26/2017

Submitted by her sibling, Taylor Ostwalt

This was my sister Whitney. She was 13 when she passed away. She was definitely our little sassy girl of the house. She had her dad wrapped around her finger. Miss you forever, sis!



Mia Pruettt (MPS IIIC) >

5/21/1993–3/24/2013

Submitted by her mother, Dr. Kimberly Pruettt

It was Mia's world, and we just lived in it. I'm so glad we were her parents. She left us on her own terms, and I expected nothing less.



Evan Reed (MPS II)

12/24/1994–1/15/2006

Submitted by his parents, Randall and Jean Ann Reed

Beau Thomas Reyes-Pickett (MPS I) >

2/19/2021–8/25/2022

Submitted by his parents, Tarin and Steven Reyes-Pickett

Beau was the most amazing and strong person everybody knew. He made everybody smile until his last day. He is still loved and beyond missed.



Cooper John Rieg (MPS IIIA) >

7/26/2003–4/15/2024

Submitted by his parents, Pete Rieg and Shannon O'Hara

Cooper Rieg passed away peacefully at home surrounded by his parents, Pete Rieg and Shannon O'Hara, and his two older brothers, Connor and Cayden Rieg. Cooper battled Sanfilippo Syndrome for 20 years and is now free. The family is eternally grateful for the gift of Cooper in their lives and the impact he made on them, his caregivers, and anyone who had the chance to know him.



Jordane Robjohns (MPS IIIA) >

3/10/1996–10/2/2021

Submitted by her mother, Paula Robjohns

Your wings were ready, my heart was not. I miss you more than life, darling pie.



Lily Rogers (MPS IIIA) >

3/9/2010–3/12/2024

Submitted by her mother, Michelle Rogers

Lily was a light in our lives, and we are all forever changed because of her. She is greatly missed by her two brothers, one sister, and her parents.



Christopher Rousseau (ML II) >

9/11/1991–3/18/2001

Submitted by his mother, Maggie Rousseau

Dearest Christopher, you live! In the work I do, in the fun we have, in the love we share. Thank you, sweet boy!



Brandon Cesar Salazar (ML II/III) >

9/24/2017–10/8/2017

Submitted by his mother, Kimberly Villarreal

My little Benjamin Button, he was so tiny and our time together was so short, but he made the biggest impact on my life. Always thinking of you, kid. I love youuu, I ain't eva gonna stop lovinn you.



Daymein Sanders (MPS I) >

8/27/2006–12/1/2023

Submitted by his mother, Helen Moss

My sweet boy was the light of my life and was always happy and smiling.



Esme Schlipp (MPS IIIA) >

6/30/2016–4/22/2023

Submitted by her parents and brother, Josh, Maelynn, and Samuel Schlipp

To our sweet girl baby who we miss more than words can say. We love you. You are the strongest, bravest, and most beautiful girl we will ever know. I wish everyone in this world could Love Like Esme.



Nathan Scotting (MPS IIIA)

11/20/1988–5/30/2003

Submitted by his parents, David and Diane Scotting

Nicholas Segura (MPS II) ▶

6/11/2011–3/28/2024

Submitted by his mother, Amanda Haro

My son Nicholas was born on June 11, 2011. At the age of 3 and a half he was diagnosed with severe autism. We noticed changes to his body that were not of normal development. The doctors would just send us to therapies and specialists to try to fix the problem. Nothing really helped. In 2020 we felt hopeless. I couldn't do anything to help my son, and I could see that these changes to his body was causing him pain. I begged the pediatrician to help in some way. She referred us to a genetic doctor and shortly after he was diagnosed with MPS II. He was eight years old at this time. He started with infusions within two months. The diagnosis of MPS II was really difficult to receive because it felt like a death sentence for him. In 2024 he was admitted to the hospital due to a decline he was having from a choking accident during one of his infusions. He refused to eat and therefore was placed a feeding tube. On March 28th he passed from complications from the feeding tube in the hospital. Nick was a precious baby boy and we wish we could have had more years with him. He left three brothers which one has MPS II as well. Because of Nick, we are able to help his brother much sooner. Thank you God for letting me be Nick's mom. He was surrounded by love, and we will always treasure his memories.



Garrett Wayne Shelton (MPS II)

12/29/1989–7/24/2011

Submitted by his parents, Wayne and Glenda Shelton

Michael J. Sochacki Jr. (MPS II)

7/5/1969–4/27/1986

Submitted by his parents, Michael J. Sochacki, Sr. and Angela M. Sochacki



Timothy (Timmy) Stringer (MPS I) >

7/15/2002–11/12/2020

Submitted by his family, Natasha, Terry, and Casey Stringer

Beloved and inspiring forever.



Mitchell Stump (MPS IIIB) >

8/6/1989–10/19/2003

Submitted by his mother, Donna Stump Simon

My Darling Angel—We miss you so much every day. I love you! Mommy



Clinton Jared Szemanski (MPS IIIA) >

1/18/1985–3/3/1989

Submitted by his mother, Tracy Szemanski

While your time here was so short, your impact has been long lasting. Not a day goes by without a thought of my firstborn son.



Zachary Harris Szemanski (MPS IIIA) >

11/26/1987–9/9/2004

Submitted by his mother, Tracy Szemanski

Zachary Harris was born November 26, 1987, Thanksgiving Day. So thankful to have spent the good times with him and that I was able to support him in the bad times. He is a part of me and thought of daily. He is missed.

Giovanni Wayne Thompson (MPS IVA) ▶

1/13/2018–3/18/2023

Submitted by his great grandmother, Darlene LeClair

He was loved. He loved people and was so caring and sweet.



Gavin Townsend (MPS II) ▶

10/25/2011–4/20/2024

Submitted by his parents, Thomas Townsend and Amanda and Chris Langhamer



Alyson Von Handorf (MPS IIIA) ▶

6/13/1989–2/12/2022

Submitted by her parents, Mary Beiting and Jeff Von Handorf

Aly was a real “trooper” just like many MPS kids, overcoming numerous obstacles throughout her lifetime. Many people who knew her have commented that her example changed their lives and made them better people. We miss you, little girl.



Scotty Whitecotton (MPS II) ▶

9/29/1997–5/3/2024

Submitted by his parents, Tom and Kim Whitecotton

Scottyman, your mommy and daddy’s hearts are completely broken. It’s been one month today since we kissed your beautiful face and held your hands for the very last time. We are forever grateful for the gift of being your parents for 26 incredible years, and we will always treasure the memories we made together. You will always be our #1 Superhero!!! We love you to the moon and back.



Kevin Michael Witt (MPS II)

8/23/1985–11/8/2006

Submitted by his mother, Lynn Ann Sembach

Forever in my heart.

Kyle John Witt (MPS II)

1/15/1991–11/3/2012

Submitted by his mother, Lynn Ann Sembach

Loving you forever.

Christian Yard (MPS II) >

9/7/2007–4/26/2024

Submitted by his parents and sister, Jim, Amy, and Ella Yard

We miss you terribly “our little man.” Your big heart and pure love blessed our family each and every day. We learned more from you than you will ever know and live with those values as we endure the suffering of living without you. You had a super power to battle your diagnosis with a smile on your face and a positive attitude that made all the treatments, trials, and procedures easy on your parents. We miss your voice and seeing you swimming, splashing, smiling, and clinking your Legos. Knowing you are now in a better place and free of MPS is our only solace. We will love you always.

