



# HopeNotes

## Building a Supportive Community One Family at a Time

**“It shook my whole world for a full nine months. Nothing about me could accept it and get over it. Somehow, I didn’t ever know that children had cancer. I didn’t feel like my son would survive this.”**

Melissa Gess admits her tears flow freely today as she recalls the devastation of her son’s cancer diagnosis. Charlie was one year old when they heard “neuroblastoma”—a cancer that forms in certain types of nerve tissue. Melissa remembers, “The only person I wanted to talk to was a cousin who had a little girl with spina bifida. It just eased my heart to talk to someone who could totally get having their child’s life on the line.”

Melissa describes how helpless she felt as the treatment took a toll on Charlie’s body. He was skinny and sickly. She wrestled with the uncertainty that, “Day-to-day, we don’t know what’s going to happen.”

It’s been over 11 years since Charlie was diagnosed. Today Melissa dwells in a place of gratitude much more than fear. But she has deep compassion for others who are fearful; she recognizes it almost instinctively. At a chance—or perhaps providential—

encounter, she saw much of herself in the eyes of another mom.

Mark and Jenny Nickell were excited about the HopeKids party and bowling event. Since their son Drew was diagnosed with neuroblastoma this past June, they hadn’t been out much, and bowling happened to be a favorite activity. Mark describes how a casual conversation with Josh Taylor, HopeKids president, led to meeting the Gess family. “I must have shaken Brandon’s hand 15 times,” Mark said. Brandon is Charlie’s dad.

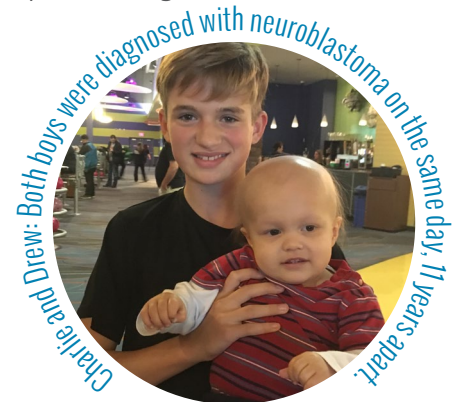
“I looked at Charlie’s parents and siblings, and I could tell that they had been through something,” Mark says. “And when we talked to the family—just the look on Melissa’s face, she could tell that [we] were in pain. But in her face we also saw hope, and sincerity, and [a belief] that we can [get through Drew’s cancer].”

Both Melissa and Jenny used the same word about their meeting: “Chills”. Jenny describes the tremendous hope of hearing how well Charlie has managed since his treatment. The story got more chilling when they discovered that Charlie and Drew were both just barely a year old when they shared the

same diagnosis date of June 2nd, 11 years apart. And then the moment came when someone suggested Charlie hold Drew for a photo. Jenny and Mark tried to warn everyone that it probably wouldn’t go well. Being poked and prodded through treatment has made Drew much more anxious. To Mark’s astonishment, “For some reason Drew liked being held by Charlie. It was so amazing.”

**“Just to know that they’re there, and to know that we got connected through HopeKids is just really special,” Jenny says. “I hope that someday we are someone else’s inspiration.”**

Mark adds, “I think that if this sort of thing can happen for one or two families, everything that [HopeKids] is doing—it’s worth it.



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# ARIZONA HOPE DAY PROGRAM



HopeKid Tanner, age 8, builds a Hope Chest; HopeKid Lily and sister Zoey, age 2, enjoy dropping the puck at the ASU hockey game; HopeKid Jovani, age 5, and sister Jariana meet Santa on The Polar Express; HopeKid Lily, age 5, receives her medal at the HopeWalk; HopeKid Ruby, age 5, enjoys Sky Zone; HopeKid Isaac and mom enjoy a flight at Pegasus Airpark.



## WHAT IS YOUR CHRISTMAS WISH?

"My Christmas wish is for treatment options for Mito depletion."

"For my child to have a pain-free day."

"For Tanner to not be confined to a wheelchair his entire life. Praying he continues to get stronger and can walk on his own: run, jump and play!!"

"To watch my son grow up."

"For a cure for porphyria so my son can feel the sun and lights without excruciating pain."

"For 22q11.2 micro deletion syndrome to not define my child."

"My wish is that my daughter gets to spend every Christmas with us until I'm no longer on this earth. I want to see her grow into a young woman, mother and wife!"

"For doctors and scientists to somehow find a way to regenerate and repair damaged nerves so that my Jazmyne can walk on her own."

"For one day doctors to be able cure genetic diseases before they affect the child."

"For people to be more accepting of others with disabilities."

"To see my son, McKenzie, enjoy life pain-free; for him to enjoy his first meal; to watch him take his first step; to hear his first words; but those are only wishes. I want my son to enjoy and explore his senses. To feel, hear, see, touch and began to taste. I wish for my Auggie to enjoy his childhood. As an older brother to a medically-fragile child, his life has been hurry up and go, as well. My wish is for all the sick kids to enjoy just one day pain-free and illness-free!"

"For Matthew and all the kids to be pain- and disease-free. No children should be fighting or living like our babies do."

"For a smooth, non-eventful, successful surgery as my husband donates a kidney to our son in a couple months. For quick and complete healing and for technology to advance to where my son will never need another transplant because this one will last him a lifetime."

"For my pixie to stop throwing up EVERY day."

"For Robin to no longer have daily fevers, a new immune system and our kids to be completely healed."

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# COLORADO HOPE DAY PROGRAM

Cameron, age 5, poses with his mom at family portrait day; Kolton, age 6, enjoys the circus; Zipporah, age 8, packs meals for Feed My Starving Children; Carter, age 7, cheers on the Colorado Avalanche with his family; Gavin, age 13, and his family dress the part for the *Trolls* movie screening; HopeKids families at the Monster Trucks Winter Nationals VIP experience.



## WHAT IS YOUR CHRISTMAS WISH?

“My Christmas miracle wish is for a cure for childhood cancer that doesn’t require years of chemo, radiation, surgeries, and for the child to lose out on being a child. I wish kids didn’t have to fight this disease, and that they didn’t have to deal with the long term effects of the treatments.”

“A cure for cancer!!”

“My Christmas miracle was that my 13-year-old son was told he was in complete remission on November 3, 2015. He was diagnosed with grade III anaplastic astrocytoma brain tumors and went through 34 radiation treatments and 15 months of several different chemo infusions and his chances of survival were very minimal at best. I wish that miracle for every parent of a child that is dealing with cancer. I am one of the lucky parents that will get more time with their child. Chances of the tumor coming back into my son are higher than normal, but at least we have him this Christmas, cancer-free.”

“My Christmas Miracle Wish is for no child to suffer.”

“My greatest Christmas Miracle Wish is that all families can seek comfort in finding hope, and knowing you are never alone through some of the most darkest of times that you may be facing. To have remembrance of faith in all things possible, and to cherish and create memories with all the time we may have together. To soak in all the joy of the journey, and to turn your pain into great purpose.”

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# MINNESOTA HOPE DAY PROGRAM

HopeKids Jaydan, age 6, and Jacob, age 4, with their mom and brother at Cookies with Santa at the Sky Deck at Mall of America; HopeKid Maddie and her mom enjoy The Belong Tour from the HopeSuite at the Xcel Energy Center; HopeKids families explore Sever's Corn Maze; HopeKids sibling, Will, at the fall festival presented by Pediatric Home Service; HopeKid Nathan, age 8, cheers on the Minnesota Wild with his family in the HopeSuite; HopeKids Moms Night Out HopeCommunity program at Paint & Pallet in Ramsey.



## WHAT IS YOUR CHRISTMAS WISH?

"My wish is to be able to provide the best quality of life for my daughter with a rare genetic disorder."

"I pray for understanding and acceptance of our children who are fighting medical and psychological disorders."

"My daughter's wish is for all the kids who have cancer or illness that they can be home with their families for the holidays."

"Continued cancer-free diagnosis for my son."

"I wish for all people with differences, facial or otherwise, to be treated with kindness."

"I wish for a cure for Sanfilippo syndrome, in time to save my son's life."

"Peace for all of the HopeKids kids and families this holiday season to feel the presence of God as we walk through hard times and some days celebrate joyous news too."

"I want no more children to die as children."

"My wish is for Natalie to have beaten cancer for a 2nd time and that it never comes back ever."

"Cure for all diseases."

"I wish for all of our children to feel peace and comfort and joy in the form of sustained health, ample space, and lots of love. For parents and siblings I wish for sustained peace free of worry and stress."

"No kiddos going through the trials our kids face."

"My wish is to find a better quality of life for my daughter. Find out answers to all of her pain/discomfort/anxiety/incontinence, the rare disorders, etc. We are tired and burned out from all the ER visits, hospital stays and doc appts that result in very little answers. My wish is for inner happiness, peacefulness, unconditional love and financial stability for everyone."

"My wish would be for our children to spend a day feeling the love, joy, and hope that is Christmas - free from the burdens of their diseases."

"I wish for all us medical parents to have one night a week for a year of uninterrupted, peaceful sleep!"

"My wish...an end to judgment. No judgment from others on how we parent our children, on the care we receive, the choices we make, on how disabled my child "looks", on behaviors, on financial conditions, on how tired we are, on why we need to cancel plans, on our lives."

"For kids to be kids!"

"For my daughter to have and understand true friendship. For me to understand this pace we are at is unique and should not be compared to other races. To dream. To hold hope like a blanket. To love all her parts even the ones I hate because they are a part of her and I love every hair of her."

# NORTH TEXAS HOPE DAY PROGRAM

“Chefs for the Day” Connor, Austin, and Harmony prepare food at Taste Buds Kitchen for the *Roaring Twenties* gala: Super heroes, princesses, mascots, and the Dallas Cowboys Rhythm and Blues Dancers pose at the HopeWalk: HopeKid Blaise trick or treats with Tiffany Chisnall, COO of Texans Credit Union: HopeKid Wesley meets that cast at *Elf Jr.* at Artisan Center Theater: Board Member and volunteer Steve explores the NASCAR event with the Smith family: HopeKid Jelani at “Helping on Horseback.”



## WHAT IS YOUR CHRISTMAS WISH?

“We would love a cure for NF!”

“Our greatest wish is that Jonathan and his siblings have happiness and opportunities to know love and joy and ease his suffering (if even temporarily).”

“My greatest Christmas wish is that there are no more specialists, chemo meds, medical fears or anxiety. It seems like even too much to wish for.”

“To not have the overwhelming anxiety of something happening or popping up symptom wise.”

“A cure for my guys’ (cystic fibrosis) of course!!”

“A handicap van so that loading/unloading Ruben would be safer and easier.”

“I pray for no more heart defect issues for Erin.”

“To stay out of the hospital for the holidays, a week without any doctors appointments, health issues to stabilize, and that we would get much needed answers from the NIH”

“Our Christmas miracle would be a cure for the diseases that plague our family - CVID, Lupus, and cancer.”

“A cure.”

“There would be a cure for mitochondrial disease and affordable medical equipment.”

“For Wiley to get a kidney transplant this year.”

“My wish would be for the advancement of prosthetic kidneys to decrease the need for antirejection meds.”

“No hospitalizations for Erikah in 2017!”

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