

Montana Hope Project



Sponsored by the Association of Montana Highway Patrolmen

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HIGHWAY OF HOPE

2 girls the recipients of dream playhouses



JAMES WOODCOCK/*Billings Gazette Staff*
Rylie Kaiser, 4, above, was diagnosed with leukemia last year. She recently received a playhouse through the Montana Hope Project.

By **BECKY SHAY**
Of The Billings Gazette Staff

Two little girls are getting some space of their own from the Montana Hope Project.

Both girls — Rylie Kaiser, 4, and Brittany Riley, 3 — were diagnosed with leukemia last year and both are recipients of their dream playhouses. The

wish-granting Montana Hope Project is a non-profit organization created and administered by Montana Highway Patrol officers and other volunteers. The luxury playhouses come complete with scalloped trim, bay window and specialty touches like a slide and a sand box.

“It’s all about just giving them some joy and giving them something to smile about,” said Jill Riley, Brittany’s mother. “It’s a space of their own, to sit and be and think. Everything in their world is out of their control, everything is done to them. This is their space and they can play and be kids. They have to grow up fast. This is a chance just to be a little girl and have that time.”

Rylie’s reaction

Rylie’s playhouse was delivered Feb. 10 and the same model was recently delivered to Brittany.

Rylie grinned and giggled as the playhouse was pushed off a flatbed trailer to be placed in her backyard.

“I wanna see it!” she said and wiggled in her mother’s arms to get closer.

Rylie has decorating plans for the playhouse. There are two rooms upstairs — one will be pink for her and the other green for her 6-year-old brother, Tyler. The rest of the color scheme includes “fabulous grape with rose trim,” in Rylie’s words, and a yellow kitchen and a blue dining room. Brittany will share her playhouse with brother Alex, 5, and sisters Emily,

7, and Taryn, 17 months.

The two-story playhouses are 8 feet by 15-1/2 feet and 11-1/2 feet tall. The playhouses are custom built at Wood Manor in Corinne, Utah. Business owner Colby Earl personally delivered Rylie’s playhouse on a flatbed trailer he pulled behind his big red pickup, arriving with the entire outfit and playhouse covered with snow and slush from the trip. The houses cost about \$3,900. Earl said Rylie’s was the first house the company has built for Montana Hope Project and they have been asked to build Brittany’s, too. The Kaisers, the Rileys and Earl are together in their admiration for Montana Hope Project. Jill Riley said for her and for Brittany’s father, Kyle, Montana Hope Project is an extension of the community support they have received since Brittany’s diagnosis. “They are all about taking care of people who are in-state,” she said. “They are just wonderful.” Jill Riley credits Kim Kaiser with helping to connect her family with the Montana Hope Project. The parents filled out applications and Montana Hope Project volunteers went to work fulfilling their children’s wishes.

Bringing joy to kids

Steve McDonald, the Billings area coordinator for Montana Hope Project, said the quick response shows the organization’s commitment to bring joy and hope to critically ill Montana children. The project, which is not affiliated with any national wish program, has

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From the President's desk.....



LEANNE SMITH/Editor

Cyle Geiser and Montana Hope Project President Kelly Mantooth at the 2002 Montana Hope Project Reunion in Essex.

WOW! Nineteen wishes granted in 2002!! The average cost per wish is \$5,688, which translates to over \$107,000 spent on wishes for Montana kids last year alone. These wishes are granted only because of the generosity of our donors – whether through outright donations, or support of our fundraisers. Unlike other wish-granting organizations, The Montana Hope Project strives to include the entire immediate family in the wish. A couple of years ago, we sent a family of 10 to DisneyWorld!

The cost of wishes has increased – like everything else in this world! With the unstable economy and world unrest, donations to the Montana Hope Project are down. We would appreciate your continued support of the Hope Project as we continue our quest to help dreams come true for Montana children facing life-threatening illnesses.

I would like to compliment our volunteer staff. This volunteer staff consists of 12 people, including myself.

Our volunteers are wonderful and accomplish phenomenal things for the Montana Hope Project.

Just a quick reminder, the Montana Hope Project is not affiliated with any other wish-granting organization, whether in Montana or nationwide. We have received some calls about an organization called “Child’s Wish Foundation.” We really know nothing about this organization and want to make sure people understand we are not associated with them. If you are anyone you know ever have any questions, please feel free to contact any Hope Project coordinator. The Montana Hope Project does **NOT** use telephone solicitors to raise funds. We do **NOT** solicit funds through direct or mass mailing.

We hope to see you at a Montana Hope Project fundraiser this summer. These fundraisers are our main source of income.

I’d like to take this opportunity to recognize the contribution of the Kurt Berliner Foundation. The foundation has

donated \$6,000 to cover the expenses associated with the Annual Hope Project Reunion. We are very pleased to have them on board and grateful for their recognition of the importance of the work we are doing in Montana. The annual reunion is an important added benefit to the recipients and their families and we are dedicated to ensuring we continue to come together the first weekend in June to renew old friendships, forge new ones and share the joys of being part of the Montana Hope Project family.

Remember the Montana Hope Project motto, “*May their prayers be their hope, and their hope become reality.*”



MONTANA HOPE PROJECT

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The **Albertsons Community Partners Program** continues to raise funds for the Montana Hope Project. Last year the program generated \$X<XXX for the Hope Project.

Albertsons donates three percent of each cardholder's sales to the project when shoppers present their card at the checkout register.



Call Perry Brown at (406) 227-9287 or e-mail him at mtride@centric.net to request your free card today.

Kleen King kindness

Each fall Kleen King donates a portion of their duct cleaning sales to the Montana Hope Project. Kleen King donated \$2,775 from duct cleaning services performed in Helena, Bozeman and Great Falls.

A big thanks to Kleen King for their continued support through donations, television, radio and print ads.

Birthday boy Disney World bound

By PAULA CLAWSON
Of The Livingston Enterprise

Cameron Butler of Clyde Park celebrated his third birthday in Florida with Mickey Mouse.

The April 17 birthday boy had a lot more fun this year than he did on his second birthday, when he was far too sick battling cancer to enjoy a trip to Disney World.

Cameron, The son of Jeannie and Kevin Butler of Clyde Park, has been in remission for six months.

Recently the Butlers applied the Montana Hope Project, a non-profit organization supported by the Montana Association of Highway Patrolmen that grants wishes to Montana's critically and chronically ill children.

Their family was awarded an all-expense paid trip to Disney World. Cameron is taking his entire family - mom, dad, as well as brothers Brandon, 18 and Aaron, 16.

Montana Highway Patrol Sgt. Jeff



Courtesy photo

??????????, center from the Corporate office of Town Pump presents Butte Area Coordinator Alice O'Donnell, left and Captain Janet Baker, right with a check. The money was raised at their annual golf tournament. The Montana Hope Project thanks Town Pump for it's continued support of Montana's critically and chronically ill children.

Mount gave Jeanie Butler a check for \$1,300 to cover expenses such as souvenirs and ice cream cones to cool down in the Florida heat.

The Montana Hope Project covers all costs, including airfare, a rental van, hotel rooms, meals and passes to Disney World, Sea World and Universal Studios.

"Cameron's really excited about 'Mickey's Play House Live' at Universal studios. He knows all the characters," Jeanie Butler said.

See Birthday ... page 4



Paula Clawson/Livingston Enterprise

Three-year-old Cameron Butler and his mother, Jeanie Butler of Clyde Park, accept a check from Montana Highway Patrol Sgt. Jeff Mount. The \$1,300 check helps families with expenses such as souvenirs and cool treats in the hot Florida summer sun .

Thank you for making Arika's dream come true

Nov. 2002

We wanted to take the opportunity to send you a note attempting to express our heartfelt thanks and gratitude for your organization's existence, its mission and all its volunteers.

Our youngest daughter, Arika, was granted a wish to go and see Mickey Mouse at Disney World in Florida through your organization on November 7, 2002. Words cannot even express the tiniest measure of our gratitude and thanks for you. Our family could not have ever gone on such a trip without your assistance. The entire trip from start to finish was perfect. We really do mean perfect. Not one thing was wrong. In fact, everything so far surpassed all our hopes and expectations, that we spend the first couple of days wandering around in a stunned fog of amazement.

All of our kids were pampered, spoiled and treated like royalty while in Florida. Every detail was taken care of and went off without a hitch. We cannot begin to tell you how magical, wonderful and overwhelming the whole wish trip was.

We sincerely wished while there, that everyone who helped make Arika's wish come true could have come with us to experience this once in a lifetime thrill.

Arika and her siblings had a wonderful time and came home exhausted but oh so happy. The extra spending money that your organization provided enabled us to bring home souvenirs and to spoil the



Courtesy Photo
Lee and Kristen Johnson and Caitlin, Lindsay, Felicia, Blake and Arika.

children while there even more.

Thank you seems so small and trivial in comparison, but it is all we have to offer. We send you our heartfelt thanks, gratitude and love. We are forever indebted to you and your organization and all its volunteers.

With love and appreciation,
Johnson Family, Bozeman, MT

Birthday...from page 3

Cameron was born with a chromosomal defect called Blooms Syndrome. The syndrome leaves patients very susceptible to cancer.

Cameron has already battled Wilms tumors in his kidneys; one of the most common cancers associated with Bloom's Syndrome.

He still has to see a cancer doctor in Salt Lake City every three months and will have to be carefully monitored throughout his life for cancer.

"They can cure cancers but they cannot cure Bloom's Syndrome," Jeanie Butler said.

Sutey/Oil Thriftway boasts record logo sales for 2002



Sutey Oil/Thriftway Corporation, headquartered in Butte, posted record April and November 2002 logo sales of \$6,800. Thriftway grocery stores and Sutey Oil gas stations sold the logos for \$1 each at their locations throughout Montana.

The stores have just completed the April logo sales and will again be selling logos in November. Next time you stop into your local Sutey Oil/Thriftway store, please take the time to tell them how much we appreciate their continued support.

Three-and-a-half year old takes trip of a lifetime

Mickey Mouse and Peter Pan top his must see list

By BUCK TRAXLER
Of The Conrad Independent Observer
and LEANNE SMITH, Editor

The Montana Hope Project is sending him and his grandmother, Rhonda Fenner to Disney World in Orlando, Fla.

The Hope Project helps children with life-threatening diseases or problems fulfill a wish they might not otherwise have the opportunity to.

"I'm going to see Mickey and Peter Pan," said Chase as Montana Highway Patrolman Walter Berry, stationed out of Cut Bank, presented him and his grandmother with a \$1,000 expense check.

"All their other trip expenses have already been taken care of. This is for money to spend in Orlando." Berry said.

Young Fenner's heart has three chambers instead of four. He has

endured four surgeries. "His doesn't get enough oxygen," his grandmother explained. "The best way to explain (his last surgery) is that it (was) like rerouting rerouting plumbing in a

house. This operation will reroute oxygen."

The surgeries postpone the inevitable and Chase will require a heart transplant before he reaches his 30th birthday.

Dear Montana Hope,

Reviewing this year, apart from Lorretta finishing her 2 months of treatment for Leukemia December 2, 2002 (our Christmas gift and hope), the high point was, without a doubt, our trip to Disney World in Florida.

I was skeptical that it would really be the fun experience it turned out to be, but it was great!

It really brightened things up for us and provided a lasting and memorable opportunity for joy and enchantment.

We are so grateful for the work you do to enable many children and their families to have quality time together spent in a way that is meaningful and special.

Blessings to you all,

*Ronald, Teina and Lorretta Lichtwardt
Gardiner*

Give the gift of HOPE

Help make a wish come true for a critically ill Montana child. Make a donation to the Montana Hope Project in the name of a family member, friend or recipient. A donation to the Montana Hope Project directly benefits Montana children.

HOPE - always the perfect gift

This gift is made in: honor of _____
memory

It is being given by: _____
Your Name

Send confirmation card to: _____
Name

Address _____ City _____ State _____ Zip _____

Complete and send to: The Montana Hope Project, P.O. Box 5927, Helena, MT 59604

Dear Montana Hope Project...

Brock Stoddard provided this detailed accounting of his trip to Florida where the candy, ice cream and fun flowed freely.

My name is Brock Stoddard. My family and I just recently returned from a trip to Disney World in Orlando, Florida. This was a wish granted by the Montana Hope Project. This wish was approved in May of 2001 but our family couldn't go until March 2002. So there was plenty of time for me to get excited. I am grateful to those who made this possible and want to share some of my favorite memories of this trip.

We flew out of Bozeman early in the morning and landed in Orlando around 4 pm. It was warm and green. We were met by a nice man who took us to our vehicle and told us how to get to Give Kids The World. The guy checked us into our villa, gave me a stuffed Mickey Mouse and gave me and my brother and two sisters all a t-shirt that had a big parrot on it called "Panama Jack". We stayed in the apartment until 1:30 and when we walked in, there was candy all over the table. We went to The Ginger Bread House to eat that night and we met Mayor Clayton. He gave me a hug. He is very soft. Before we went back to our apartment, we found a talking garbage can that looks like an elephant.

I laughed when it said, "Feed me paper. I like paper."

I played games that night in the train station.

The next morning after breakfast, we found the Castle of Miracles. I laughed hysterically at the magical cupboards that made funny noises when I opened them. I saw some small lizards running around on the ground and my big brother tried to

Words cannot express the gratitude in my heart. I am so thankful for the wonderful opportunity we had to go to DisneyWorld as a family because of your love and generosity. It was truly a dream come true for all of us.

Everyone was so kind and helpful. They made sure Brock and his family were taken care of and having a good time. It was such a happy place. The memories we have will always be treasured. We hope you like the picture. It was taken at The Gingerbread House.

Thank you from the bottom of my heart,

Pam, Seth, Whitney, Shaundra, Colt and Brock Stoddard

catch one. They were very fast. We went to The Magic Kingdom that first day. My first ride was driving my own race car. I went on my first roller coaster ride at Space Mountain and I rode it twice. I shot aliens with Buzz Lightyear. I got wet on Splash Mountain. It was so fun. I bought an autograph book to get signatures from the Disney characters. By the end of the week, I had over 30 signatures. Some of the characters I met at Magic Kingdom were Chip and Dale, Mickey and Minnie Mouse, Pooh and Tiger, Cinderella and Pluto. We watched an electrical parade and fire works that night.

The second day Mickey and Minnie Mouse came to Give Kids The World. My family got our picture taken with them. Then we went to Sea World and watched some trick water skiers. We watched the whale show. The trainers rode the whales around the pool and under water. The whales got some of the crowd wet and others got soaked. I got to see dolphins, penguins, a polar bear and got to touch sting rays. I got to ride "Journey to Atlantis" and we got wet. We didn't get to see sharks because it was closed.

The third day we headed to Animal Kingdom. The first thing we did was go on a safari ride through Africa. We saw elephants, giraffes, alligators, hippos, lions, monkeys and rhinos. We went to see "Bug's Life" in the "Tree Of Life"

which was a 3-D show. We got sprayed by a huge stink big. I met Pocahontis and she gave me a kiss. I saw a talking garbage can that moved around. I asked him if he wanted to race and he did. I won. I got my picture taken with him and he told me to say, "cheeseburger," when we smiled. I got to pet animals at a petting zoo. I watched a fun parade where all the characters were dressed in safari clothes. We went to the "Lion King Show". One of the people in the show came to the audience and picked me to shake a shaker. He wheeled me around while everybody danced. We went to Dino Land and I won a stuffed dinosaur. I was so proud. When Animal Kingdom closed, we went to Epcott and watched the

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Courtesy Photo
Pam, Seth, Whitney, Shaundra, Colt and Brock Stoddard at the Gingerbread House.

Playhousesfrom page 1

granted about 197 wishes since it was established in 1984. There were 19 last year. Only Montana children are eligible to receive Montana Hope Project wishes. Because Montana Hope Project is a volunteer, non-profit organization, about 90 cents of every dollar donated goes directly to wishes, which on average cost more than \$5,000 each.

For more information about the Montana Hope Project, or to make a donation or refer a child, contact Officer Steve McDonald at the Montana Highway Patrol office in Billings, 245-6193; or sign onto the organization's Web site at www.montanahope.org.



JAMES WOODCOCK
Gazette Staff
Brittany Riley, 3, left, was also diagnosed with leukemia last year. She too received a dream playhouse through the Montana Hope Project.

The two-story playhouses are 8 feet by 15-1/2 feet and 11-1/2 feet tall. The playhouses are custom built at Wood Manor in Corinne, Utah. Business owner Colby Earl personally delivered Rylie's playhouse.

Dear Mt Hope...from page 6

Tapestry of Dreams parade and more fireworks. We walked around the big lake at Epcott.

The next morning we slept in a little. Whitney and I went swimming at the Give Kids The World pool. We stopped at the Ice Cream Palace several times while we were there for free shakes. One time Whitney had a banana split for breakfast.

We saw little lizards every day. We always watched for them after breakfast. One day my dad and I saw a turtle sitting in the sun on a rock by the lake next to where we stayed. Late that morning we went to Universal Studios. I met Shrek and Sponge Bob. I chased a pigeon around while I was in my wheelchair. He never did fly. He just ran ahead of me.

We went on the King Kong ride. I didn't like that big black dude. My favorite show was Animal Planet. Different animals did all kinds of tricks. We saw a monkey and an orangutan, a huge yellow snake and we met Lassie. We went on the Back To The Future ride. It was wild. We went to the Wild, Wild, West show. They had a gunfight. We went to Jaws. A big shark tried to eat our boat. We went to the Mardi Gras parade. The people in the

parade threw colorful bead necklaces for us to wear. We went to the new part of Universal (Studios) called Adventure Islands. It had huge roller coasters and lots of rides for big people. I did go on a unicorn roller coaster ride. It was fun. That night, we ate at the Hard Rock Café. They had good ice cream. They were good to us. They gave us our meal free of charge and gave me a Hard Rock Café t-shirt.

"I am thankful to those who made it possible."

**Brock Stoddard, Bozeman
2002 Recipient**

Our last day to play in Orlando, we went to MGM Studios. We went to Indiana Jones Stunt Spectacular. We rode on the "Great Movie Ride". We went to Playhouse Disney-Live On Stage. Bubbles came down from the ceiling and my favorite part was when Zowie roared. We watched the Disney Stars and Motor Cars Parade. Our last ride was The Tower Of Terror. It was a motel elevator ride where we were taken to the top and dropped. I wanted to go again but mom

said, "no".

We went to Epcot one last time and so we could go to "Honey, I Shrunk The Audience". I got to be a helper. The workers dressed me up like a professor and let me hand out 3-D glasses. A huge dog sneezed on me. We watched some neat water fountains and went to the Test Track where we got to see how cars and trucks are tested. We rode in a yellow car; then we headed to Downtown Disney. We shopped a little for souvenirs and ate a Fulton's Crab House.

The morning we had to leave we were all sad it was over. But we had had a wonderful time with memories that will last a lifetime. Barney and Baby Bob were at Castle of Miracles and we got to find the star with my name on it. We were on the plane by early afternoon. We flew to Dallas/Fort Worth, Texas and then to Salt Lake City, Utah; from there we went to Bozeman. We were all tired. Saturday we watched the home movies mom had taken. She filmed 2 1/2 hours of our trip and we took lots of pictures.

I am grateful my family and I were able to go on such a fun trip. I am thankful to those who made it possible.

Join us this summer at the following events



LEANNE SMITH/Editor

Last year's Ride For Hope 500 raised more than \$52,000. This year's event will converge upon Red Lodge, Mont. The ride marks it's 14th anniversary this year and remains the Hope Project's largest fund-raising event.

June 6,7,8

Annual Hope Project Reunion Essex, MT

Each year the Montana Hope Project gathers its recipient children and their families together at the Izaak Walton Inn, near the South edge of Glacier Park. The annual event is provided to the children and their families at no cost. For more information on this event, contact Project President Kelly Mantooth at (406) 538-4673 or mthope@lewistown.net

June 28, 2002

Helena Millennium Car Show Helena, MT

The Helena area car clubs will be holding their third annual car show with proceeds to benefit the Montana Hope Project. The event will be held in historic downtown Helena during the Mount Helena Music Festival. Participants are encouraged to collect pledges for the Montana Hope Project. The registration fee is a \$10 donation to the Montana Hope Project. Each participant who collects over \$50 in pledges will receive two free admission buttons to the festival, courtesy of the Mount Helena Music Festival, and we will waive the \$10 registration fee. For

those participants who do not collect \$50 in pledges, the Mount Helena Music festival is offering admission buttons for \$8; a savings of \$2 off of the regular price of admission. Incentive prizes will be available based on the pledges collected and are listed on the back of the pledge form. Registration and pledge forms can also be found by visiting www.montanahope.org. Choose "events" from the home page. Contact Duane Preshinger at (406) 443-7069 or preshingerfam@msn.com for more information, to volunteer or to donate prizes.

July 26

Ride for Hope 500 ending in Red Lodge, MT

The 14th annual Ride For Hope 500 will be held July 26. This year's route takes us to Red Lodge. Ride routes have been set. Registration and pledge forms as well as ride routes can be found on our website at www.montanahope.org. choose "events" from the home page. They are also located in the brochure which is available at local motorcycle shops.

Check-in is from 5 - 7 a.m. the day of the event. Riders will begin their ride from check-in points in Missoula, Great Falls,

Three Forks, Billings, Kalispell or Havre.

Pre-register by July 1 and become eligible to win a get-a-way for two, compliments of Main Connection Services of Choteau. Incentive prize criteria are listed in the brochure. Each \$100 in pledges earns 1 point. Apply those points to prizes and choose from a wide variety of cloth and leather items.

Each \$100 in pledges also earns a ticket that will be entered into the grand prize, a cruise for two, including airfare to be drawn at the End of Tour event 2003. You must be present to win.

For more information, to volunteer or to donate prizes call Cal Janes at (406) 266-3330 or bacon244@hotmail.com.

August 23

Fun Run

Washoe Park, Anaconda, MT

Participants can choose to walk or run in a 2 or 4K race.

For more information contact Alice O'Donnell at (406) 563-5504 or e-mail her at xraygrl@imine.net.

September 6

Kalispell Charity Golf Scramble Buffalo Hills Golf Course

Kalispell, MT

Brochures and entry forms are being printed up. The first 15 teams to register by the end of July will be entered into a special drawing. The field is limited to 25 teams. Lunch will be provided. Local recipients will be on hand to award prizes and trophies. For more information or to obtain a registration form contact: Blaise Wingert at (406)755-0884 or sundogz@centurytel.net

See Upcoming Events..... page 11

For more info...

For more information on any upcoming event, please visit our website at:

www.montanahope.org

Thank you for caring! Volunteer retires

Montana Hope Project President Kelly Mantooth announced the retirement of volunteer Larry F. Wolford, 62, of Polson. Mr. Wolford had been a volunteer with the Montana Hope Project for 10 years. A luncheon was recently held in his honor in Helena where he was presented with a plaque thanking him for his years of service.

Mr. Wolford was well-known in the Polson area for his fund-raising efforts. He raised more than \$10,000 as a volunteer through major events such as The Ride For Hope 500 annual motorcycle ride and many smaller local events.

The Montana Hope Project is an all-volunteer organization under the umbrella of the Association of Montana Highway Patrolmen. The Hope Project grants wishes to critically and chronically children in Montana. It is **NOT** associated with any national wish-granting organizations and relies solely on fund-raising volunteers and donations from local businesses, organizations



Courtesy Photo

Montana Hope Project President Kelly Mantooth, left, and Hope Project Vice-President Perry Brown, right, presented Kalispell area volunteer Larry Wolford, center with a plaque of appreciation for his years of dedicated service.

and individuals. The Hope Project granted 19 wishes in 2002 at an average cost of \$5,500.

Since the Montana Hope Project began in 1984, it has granted more than 190 wishes to Montana's chronically and critically ill children.

The Montana Hope Project wishes to thank Mr. Wolford as well as the Polson area businesses and residents

who have donated to The Montana Hope Project.

All future inquiries may be directed to Kalispell Area Coordinator Blaise Wingert at P.O. Box 2144; Kalispell MT 59901, phone 406-755-0884, e-mail sundogz@centurytel.net or directly to the Montana Hope Project at P.O. Box 5927, Helena, MT 59604. For more information please visit the Montana Hope Project web site at www.montanahope.org.

How can you help?

The Montana Hope Project can use donations of:

Auction Items

- art work
- merchandise
- vacation packages
- event tickets
- golf course passes
- t-shirts, hats, travel mugs
- guided fishing and hunting trips



To donate contact:
Perry Brown (406) 227-9287
Kelly Mantooth (406) 538-4673

The Montana Hope Project is a non-profit organization registered with the Secretary of State. It is a 501(C)(3) organization and follows all Federal guidelines to maintain its status.

Wondering what to do with your old license plates?

Turn them into your County Treasurer's office when you pick up your new plates or take all those old plates gathering dust in your garage to your local Montana Highway Patrol Office.

The license plates are recycled and the Montana Hope Project receives a monetary donation.

Jesse's world:

For the parent of a child with rare disorder, the days are filled with challenges



JAMES WOODCOCK/Billings Gazette Staff

Jesse Justice and his mother Mellissa Taylor of Miles City.

By DAN CARTER
Of The Billings Gazette Staff

It's day 906 in young Jesse Justice's life and his mom wonders how events will unfold. Will Jesse forcibly whack his head again?

Will he crawl more today or just rock back and forth?

How long can they make it at Wal-Mart before a well-meaning smile from a neighbor or a glance from the greeter sends Jesse into a tirade?

cate medical procedures all day long. What would be emotionally and physically draining to most parents is now a way of life, an existence filled with unforeseeable reactions around every corner and an uncertain future.

A rare disorder

Joubert syndrome is a rare genetic disorder that primarily affects the cerebellum, which controls balance, muscle tone and fine motor skills. The most common

W i l l things ever seem "normal?"

Such is life for Melissa Taylor, a soft-spoken woman dealing with hard realities of raising a son with Joubert syndrome.

"It's been p r e t t y rough," Taylor says.

Later, she admits, "it's frustrating."

She says these things in the kind of matter-of-fact tone one would get from talking with a doctor about what it's like dealing with deli-

features of the disease, according to the National Institute of Neurological Disorders, include lack of muscle control, abnormal breathing patterns, sleep apnea, abnormal eye and tongue movements. Some Joubert patients also have extra fingers and toes (Jesse has six on each foot and hand), seizures and moderate retardation.

The syndrome, first diagnosed in 1969, is caused by an auto recessive gene shared by both parents who then pass it on to a child. There have been roughly 200 documented cases of Joubert syndrome in the past three decades, Taylor says, and about 100 of them are still living.

Taylor and her husband, Bryan Justice, have two other children, Michael and Autumn, who are not affected by the syndrome. Jesse, however, has had a big effect on the entire family.

A lifetime of doctors

Born in Kentucky on Jan. 31, 2000, Jesse has been seen by numerous doctors and specialists.

After experiencing some trauma at birth, Taylor says, and has had diagnoses ranging anywhere from normal behavioral issues to being developmentally delayed to cerebral palsy.

"The cerebral palsy diagnosis was the closest thing that fit," Taylor says.

About 18 months ago, the family moved west to find drier air (Jesse is particularly susceptible to upper respiratory infections and pneumonia). After a stay in North Dakota, they landed in Miles City, where Justice works for Badlands Taxi during the day and Taylor works at the local Wal-Mart at night.

Dr. Annette Grefe, of Yellowstone Pediatric Neurology in Billings, diagnosed Jesse with Joubert syndrome in May.

Grefe says she noticed some abnormalities in MRI film that matched details

she had recently read about the syndrome.

"The MRI was originally read as normal (by doctors elsewhere) but because it has subtle signs, it is hard to see," Grefe said in a recent phone interview.

Basically, Grefe said, the syndrome did not allow Jesse's brain to formally develop. And like a computer network with a faulty server, the signals that travel from Jesse's brain to his work stations (arms, legs, sense of balance) don't make the right connections.

Panic and shyness

As a result, Jesse can't stand, even with help, without feeling dizzy and going into a panic attack. He only recently learned to crawl. His only words are "momma" and "dadda." He doesn't sleep right.

"It's terrible to have to go through all this," Taylor says. "He's stopped breathing so many times (at night) that I've lost count."

Because Sudden Infant Death Syndrome is common among Joubert syndrome children, Taylor and her husband catch themselves getting up at night at the smallest sound.

And the autism that accompanies Jesse's condition makes him sensitive to sights and sounds around him, Taylor says. He screams when he is in an unfamiliar place, and it's not the typical temper tantrum of a 2-year-old.

"It's a self-stimulating thing," Taylor says. "It could be the bright lights at the store, I don't know. But it doesn't just make him mad, it terrifies him."

Jesse doesn't like to be looked at, either, and constantly puts his think folded arms in front of his face.

"He's really shy and doesn't want people to see him," Taylor says. "He just thinks that if he does that people can't see him. If anybody looks at him or says 'hi' it just sets him off."

Grefe said now that a solid diagnosis has been made, the symptoms can be treated.

"I think the mom is both relieved and

frightened," Grefe says. "She was relieved because there is a name, but she is frightened because most children who have this die."

Grefe pointed out, however, that Joubert's is not always a death sentence and Jesse's condition won't likely get worse. With speech and occupational therapy, Jesse could develop motor and speech skills he needs.

Taylor says Mike Kounhov with Physical Therapy in Motion of Billings comes to Miles City twice a month to help with some physical therapy. And early intervention services in Miles City and Medicaid have helped make medical ends meet.

What's next?

What Taylor says she really wants is a sense of normalcy.

By outward appearances, Jesse seems to be a normal toddler, eager to explore the world around him. He's got hair the color of a sun-bathed Eastern Montana wheat field and an infectious smile (when he's not hiding it). But while mothers of other newly minted toddlers are usually thinking about preschool, Taylor's daily thoughts are elsewhere.

"The only thing on my mind right now how to make things simpler," she says.

Because Jesse can't always control his arms and legs, carrying his 26 pounds is challenging, Taylor says, and getting him from his kiddie cart to the car and out again after a quick outing can be exhausting. She is hoping the family can eventually afford a van with wheelchair access to make transportation a bit easier.

"It would help us be a family again," she says.

A Miles City auto dealership has agreed to help with some of the cost, but the rest is up to the family. And Stockman's Bank has set up an account for those who want to help with donations.

Jesse's parents plan to continue with the therapy. They also hope to eventually travel to Columbia, Mo., to meet with Dr. Bernard L. Maria, the nation's foremost expert in Joubert's syndrome.

In the meantime, Taylor continues her vigilance.

"When he has his good days, things are good," she says. "But when there are bad times, they are really, really bad."

And tomorrow is day 907.

2003 Upcoming Events...from page 8

September 13

Billings Dinner Fundraiser

The Perfect Place, Billings, MT

The Montana Hope Project will hold a dinner and silent auction at the Perfect Place, in Billings.

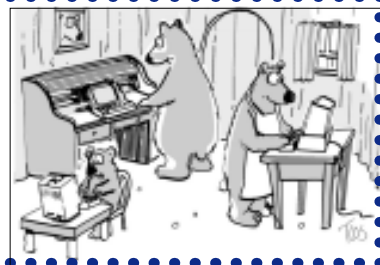
The event will feature a fabulous dinner, entertainment and a wide variety of items up for auction. Some of the items

include art work from well-known Montana artists, gift certificates for valuable merchandise and several entertainment and travel packages.

Contact Steve McDonald at (406) 655-4332 or jksmac322@attbi.com for ticket information or to donate auction items.

**Check out our
website at:**

www.montanahope.org



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Jacob Landis is a 10
year old boy from
Columbia Falls, MT.
Jacob is dealing with
neurofibromatosis
and astrocytoma.
Jacob has had sur-
gery for his brain tu-
mor, and they are
currently on a "wait
and see" basis.
Jacob's wish was to
go to Disney World.
Pictured are Jason,
Mom-Jeannie, Dad-
Jason, and Cousin
Jerry. Presenting the
certificate and check
are Officer Roy

Christensen, MHP 272, and Hope Project Coordinator Blaise Wingert. Jacob prom-
ises to provide pictures upon his return to share the joy and fun that he and his
family had. Jacob and his family also are excited to attend the Reunion in Essex.

Hope Project Facts

90 cents of every dollar raised directly benefits Montana children.

The Montana Hope Project is NOT affiliated with any national organization.

The Montana Hope Project granted 19 wishes in 2002 at an average cost of a
\$5,688 per wish.

The Montana Hope Project is funded entirely by your donations and local
fund raising events. We do not share our mailing lists. We do not utilize direct
mail or telephone solicitation in our fund-raising efforts.

The Montana Hope Project invites each recipient and their immediate family to
an annual reunion held in Essex, on the edge of Glacier Park.

The Montana Hope Project has granted more than 197 wishes since 1984.

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