THE Morgan Adams FOUNDATION

NEWS

AN UPDATE ABOUT THE IMAPACT OF YOUR GIVING

FALL 2019

FUNDING RESEARCH:
Learn how your support is enabling great strides in kids' cancer treatment.

AMBASSADORS:
Read about Ambassadors whose lives are changing because of your support.

ADVOCACY:
Learn more about two Ambassadors' efforts to raise awareness and money for kids with cancer.

You made it possible for researchers to find "miracle" drug to treat tumor with unique genetic mutation.

Thanks to your support, a little boy named Eli is getting back to a more normal life as a four-year-old.

It was late March of 2017 when Eli's parents noticed he was having problems with his left arm. Eli, just about two-years-old at the time, was a lively and active boy, always playing with his siblings, so his parents assumed he had a minor injury from everyday play. They followed up with a routine doctor's checkup for good measure and Eli's pediatrician thought the same thing. The family went on with day to day life until just a couple of weeks later when it appeared Eli was having trouble turning his neck from left to right. Eli's parents, Dave and Heather, took him to Children's Hospital Colorado where a CT scan revealed a mass that spanned from Eli's brainstem down to his spine.

A few weeks before his birthday, Eli underwent an extremely complex 11-hour surgery where doctors removed all they could of the tumor. Following surgery, Eli couldn't lift his head or move the left side of his body and it was almost a week before he was able to walk again. Pathology reports indicated the tumor was a juvenile pilocytic astrocytoma (JPA). Eli's parents were relieved to hear from doctors that Eli's outlook was positive: he had a "good" type of brain cancer and there was a 90% chance the tumor would not come back.

Six weeks later, their relief turned to anxiety when a follow-up scan showed the tumor had grown by 50 percent forcing Eli's team to figure out a new roadmap for his treatment. Eli began radiation the next week, enduring 20 treatments over six weeks that required sedation each time. The radiation treatment led to hydrocephalus, the buildup of excess cerebrospinal fluid in the brain, which necessitated an additional surgery to relieve pressure and provide a path for fluid to drain away from Eli's brain by drilling a small hole in the right side of his skull.

Meanwhile, Eli's neuro-oncologist, Dr. Nick Foreman, was not satisfied with radiation as the only treatment option, so researchers in the Morgan Adams Foundation Pediatric Brain Tumor Research Program analyzed Eli's tumor and found that it harbored a rare genetic fusion called FGFR1-

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Thanks to your support of kids' cancer research, Eli went from an 11-hour brain surgery in 2017 to learning how to ski last winter and attending his first day of preschool this August!

continued from page 1

TACC1. With that knowledge, researchers then screened Eli's cells against more than 100 different FDA-approved drugs to determine those that were effective in killing the cancer cells. In the end, trametinib, a MEK-inhibitor typically used for metastatic melanoma in adults, showed the best potential and was selected for Eli's treatment. Heather calls it a "miracle" drug – because it worked for Eli even though it hadn't really ever been used in kids before.

Eli's parents say he's the toughest kid they know. Even after enduring difficult procedures, Eli was happy and unfazed by the tremendous obstacles presented to him. He is going to preschool regularly, plays soccer, and even learned how to downhill ski last year. On the outside, Eli looks like a normal kid, but his family knows the reality of the deep impact of this disease and how much it affects each of them on a daily basis.

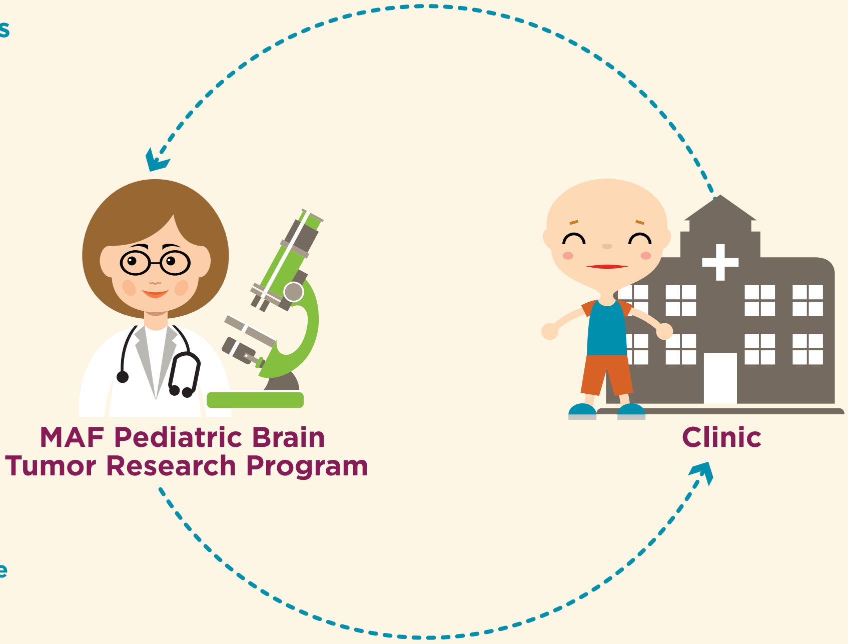
For now, Eli is doing really well. He had good scans in September that showed no change in his brain and spine, so he will be taking a break from the once-a-day trametinib pills and enjoying life as a four-and-a-half-year-old preschooler. Heather and Dave will try to put aside the anxiety in anticipation of his next scan in December. They are incredibly grateful to you for supporting the research that is improving outcomes for kids like Eli and families like theirs who are on this cancer journey.

Your support and the close relationship between the Lab and the Clinic are helping doctors find more effective treatments for kids with cancer!

Real-time drug screening for cancer patients

- Tumor samples are collected from patients undergoing surgery at Children's Hospital Colorado and added to the tumor bank in the Morgan Adams Foundation Pediatric Brain Tumor Research Program laboratory.
- The genetic material from the sample is sequenced and analyzed for evidence of genetic mutations or fusions common in pediatric cancers.
- Then, researchers test various FDA–approved drugs and share the results with the patient's treatment team.

Testing the patient's tumor cells' sensitivity to drugs in the lab may prevent kids from going through a treatment only to find out that their tumor cells are not sensitive to that drug. Alternatively, if a drug is effective at killing their tumor cells in the lab, this knowledge could change the patient's treatment plan and improve their overall prognosis.



Your support is helping speed up the search for genetic causes of pediatric brain cancer

Your support enables doctors and researchers in the Morgan Adams Foundation Pediatric Brain Tumor Research Program to connect the dots between causes of pediatric cancer.

There are three traditional treatments for cancer: Surgery, chemotherapy, and radiation. But now a golden age of cancer research driven in part by new technologies and seed grant funding made possible through your support is not only adding new cancer treatments, but entirely new classes of cancer treatments.

One of these new classes is targeted therapies – basically, carefully engineered drugs switch off the faulty genes that cause cancer. Take chronic myeloid leukemia (CML). In 1959, researchers in Philadelphia found that when a bit of chromosome 9 was mashed together with a bit of chromosome 22, the resulting "fusion" gene caused CML (they called this gene, creatively, the "Philadelphia" chromosome). In 2001, the FDA approved the drug Gleevec to turn off the Philadelphia chromosome, effectively curing CML.

Doctors and researchers spent the 2000s searching for similar genetic needles in the haystack of the cancer genome. However, it turns out that instead of one genetic "needle" creating cancer, more often, there are hundreds of genetic variants in any single cancer. The problem was not necessarily finding a needle in the haystack, it was that the haystack is riddled with needles.

Which of these thousands of genetic changes are essential to a cancer? Which of these genetic changes, when muted, would kill cancer? From a single tumor, you could never know: any change could be chance. That's why the researchers you support decided to compare haystacks, gathering genetic data from the cancers of all the patients they treat for pediatric brain tumors. They do it with a tool called RNAseq – basically, researchers use very nifty technology to identify all the genes that the cancer is actively manufacturing.

"Conceptually, the whole idea of RNAseq is to try to understand quite literally which genes are on or off at any given time in a tumor, allowing us to see what is the processing machinery within a cancer cell," says Rajeev Vibhakar, MD, PhD, professor of pediatrics at the CU School of Medicine, pediatric brain tumor specialist at Children's Hospital Colorado, and head of the Morgan Adams Foundation Pediatric Brain Tumor Research Program. In fact, not only does your support allow CHCO to offer RNAseq to every young brain cancer patient who walks in the door, but the hospital also offers the service to patients at other centers in the region.

The first benefit may be to the patient: If a doctor finds a known cancer-causing change in a patient's brain tumor, the doctor may be able to match that patient with a targeted treatment to mute that cancer-causing gene. For example, if a patient's tumor shows changes in the genes mTOR, BRAF, IDH1, or MGMT, there are available FDA-approved drugs that may slow or even reverse tumor growth.

"Our work has even found new genetic targets, for example fusions in genes like ALK and NTRK that are known causes of adult lung cancer, but have been cropping up more in our work with pediatric brain cancer. Those patients can be pulled out and put on what are called basket trials – if you have the genetic alteration, you can go on a trial of a therapy targeting that alteration," says Andrew Donson, BSc, senior research associate in the MAF Pediatric Brain Tumor Research Program.

These trials have helped save lives. "We have examples of kids who have come in and gotten RNAseq that showed a type of tumor that responds to a particular type of therapy. It's allowed us to give them effective treatment," Donson says.

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continued from page 3

The second benefit of being able to sequence pediatric brain cancers is to future patients. Think about it this way: Say a single tumor has an odd change in the gene ABCDE. That might not mean much. But if 30 percent of 300 pediatric brain tumors have mutated ABCDE (and additional research shows a suspicious function for that gene), then all of a sudden you have a likely target and a therapeutic potential.

> "We're learning the biology, understanding so much more than we ever did, and knowledge is going to get us the power to make those treatment breakthroughs," Donson says.

Thanks to previous funding support you've enabled, the research group at Children's Colorado now has the largest collection of pediatric brain tumors in the United States. And early MAF funding has allowed the program to attract additional support, along with top talent.

"The size of our research program is a direct result of the money Morgan Adams put into it," Donson says. "We started with three researchers and now it's three dozen, including six principal investigators whose work has been able to attract funding from the NIH, NCI and Department of Defense. Our work has made us an internationally recognized center for the study and treatment of pediatric brain tumors."

In the future, the group hopes to add new technologies beyond RNAseq that will allow them to look at their bio-bank of tumor samples in new ways. For example, rather than mixing up a cell's DNA sequence through mutation or fusion, some cancers adjust the way DNA is folded. If a gene is hidden inside a fold, it may not be expressed; if a gene is exposed, it may be over-expressed.

"It's a really special project, unifying the clinical side, surgery, patient care, and research in a nice way," Vibhakar says. "And fundamentally, the project wouldn't exist without Morgan Adams funding."

"I tell people to live big when it comes to your kids."

At four months old, Charli's mom Jamie noticed her baby girl was very fussy. One day while changing her diaper, she noticed that Charli was smiling but her eyes were darting down like she wasn't looking at her mom. Jamie struggled to find the words to describe what she was seeing to her husband who was then on military deployment. After some nudging from friends, she called the doctor's nurse line to describe what she'd been seeing. Something Jamie shared in that call promoted the nurse to have her bring Charli into the ER, where she was told Charli had hydrocephalus. This finding led to scans, which ultimately revealed the reason Charli seemed "off."

Charli was diagnosed with a medulloblastoma brain tumor at just five months old. Jamie and her family were living on a military base in Georgia but needed to travel to a hospital in Florida for Charli's treatment. With heavy hearts, Charli's parents arranged for their two older kids to live with friends and family at home in Georgia while they found temporary housing in Florida for the next six and a half months during Charli's aggressive treatment. Too young to receive radiation, Charli endured three rounds of standard chemotherapy followed by three rounds of high-dose chemo and three stem cell transplants. Jamie describes the treatment as grueling, but after it was all said and done, Charli was cancer-free.

"It's been a decade, but those memories are all so vivid," says Jamie, "and now we're left to deal with the impact of treatment." Those impacts include a recent finding of a benign softball-sized tumor in Charli's liver that required surgery, hearing loss, cognitive decline, and slow growth. Jamie also acknowledges the effect this experience has had on Charli's older brothers, who are now teenagers and remember vividly being away from their parents and sister for more than six months.

"No kid should have to deal with all of these things at such a young age. Despite all these challenges, we're doing our best to take it one day at a time. As a cancer parent you never get over the fact that this cancer might come back, so now we celebrate birthdays in a big way. I tell people to live big when it comes to your kids."

Thanks to your support of pediatric cancer research, kids like Charli have a better chance at beating their cancer!

Teenage cancer survivors advocate for childhood cancer awareness at state and national level

Hannah and Gabe are teenage survivors of medulloblastoma, a type of brain cancer that is found primarily in kids. Medulloblastoma is the most common malignant brain tumor found in children, accounting for about 20% of all pediatric brain cancers.

Prior to being diagnosed with cancer at age 12, Hannah was a huge athlete, competing in swimming, track, basketball, and volleyball. But frequent unexplained headaches over the course of several months finally lead to a diagnosis of a 6cm (tennis ball-sized) brain tumor in her cerebellum. Surgery, 31 radiation treatments, and 6 months of chemotherapy followed over the next 10 months as Hannah took on the toughest opponent of her life. She endured countless procedures, needle pokes, and hospital stays and came out the other side of cancer-free, but not unscathed.

Gabriel was a normal, healthy, and active boy who was 9 years old and had just started 4th grade in the fall of 2013 when he was diagnosed with Stage IV medulloblastoma that had already spread to his spine. Gabe had emergency surgery to relieve the pressure in his brain and remove a portion of the tumor for biopsy. He spent a month in the hospital recovering, then endured radiation every day for 6 weeks, as well as 6 months of high dose chemotherapy and supplemental surgeries. Gabe missed an entire year of school because of treatment, often feeling lonely and isolated from his friends, but he hasn't ever given up despite all of the challenges he continues to face.

Hannah and Gabe are teenage survivors of medulloblastoma. They're cancer-free and out of treatment, but they still deal with medulloblastoma every day.

> 1 in 4 kids who survive cancer will have severe or life-threatening side effects from their treatment.

Hannah and Gabe are two such kids.

Hannah was nearly blind in the days following the surgery to remove her tumor. Her vision has improved in the years since, but she is visually impaired and legally blind in one eye. Gone are the days of volleyball and basketball. The adult doses of radiation mean that Hannah can never bear her own children, something she was told at the age of 12. The chemotherapy drug used resulted in neuropathy in her hands, fingers, feet, and toes, which causes tingling, burning, numbness, and sensitivity. Hannah lost her long blonde hair and it will never grow back the same again. The list of treatment late effects goes on and on.

Hannah at an Air Force Academy football game before cancer entered her world (above). Hannah and Ned at the United States Capitol this Fall.

Gabe, now almost 16, takes nearly a dozen medications each day and has to give himself injections every evening in an attempt to manage the pain, dizziness, and lethargy. Not being able to keep up with his old friends is incredibly difficult for Gabe, and has resulted in a growing distance between them.

Turning personal experience into advocacy

After all they've been through and all they continue to face, Hannah and Gabe aren't letting cancer get the best of them. Instead, they're speaking up and doing – all in support of other kids like them with cancer.

This past September, Hannah and her parents traveled to Washington, D.C. to participate in the 10th Annual Childhood Cancer Summit at the United States Capitol. Hannah spoke to the audience about her experience with cancer with her trusty sidekick and mobility dog, Ned, by her side. Hannah explained that Ned's name is a reference to the medical acronym short for "no evidence of disease," the term patients and their parents long to hear from their oncologist. While introducing Representative Michael McCaul, founder and co-chair of the Congressional Childhood Cancer Caucus, Hannah made the audience laugh, cry, and provided them with an idea of the extent of the effect

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continued from page 5

medulloblastoma has had on her life. "I've had to find new activities, like tandem bike riding and a sport for the blind called goalball. I've had to find new ways to do old activities, like skiing and running. Now I use a guide. My life is different, but I didn't let cancer win."

During his treatment, Gabe asked his mother, "Why don't kids have special plates with the gold ribbon so people know about us? Can we make license plates for all the kids who have cancer?" Of course, his mother promised him she would do everything she could to create a license plate to promote childhood cancer awareness.

Gabe completed his treatment in 2014 and together they embarked on the journey to make the Colorado Childhood Cancer Awareness license plate a reality, and they have done just that! After more than a year of gathering petition signatures, attending and testifying at legislative hearings and and votes in the Colorado Senate and House of Representatives, "Gabe's Plate" was signed into law by Governor John Hickenlooper on May 22, 2018!

Thanks to your support, Hannah and Gabe know they are not alone in the effort to raise awareness of childhood cancer. You help bolster their resolve and commitment by listening and sharing their stories. Your donations and support of pediatric cancer research that improves and saves lives proves that they can be a voice and make a difference in the world. Hannah and Gabe are making a difference and so are you.

Gabe was a healthy and happy little boy before being diagnosed with cancer in 2013 (above). In 2018, then-Colorado Governor John Hickenlooper congratulates Gabe for his efforts creating the Childhood Cancer Awareness license plate.

The Race Against Kids' Cancer Hits the Road!

The last few years have seen remarkable things happen for raising awareness and money to defeat pediatric cancer within the vintage motorsport community! The amazing growth of the RMVR Race Against Kids' Cancer weekend has brought folks from around the vintage motorsport world to Colorado to race with RMVR, and through that fellowship, we have been introduced to a few other clubs and are creating a fantastic MAF Racing / motorsport group all of whom are "going flat-out" for kids with cancer!

Sportscar Vintage Racing Association's (SVRA) Brickyard Invitational Charity ProAm

August 1-4, Indianapolis Motor Speedway

Again this year, The Morgan Adams Foundation was selected as one of the charity partners for SVRA's Vintage Race of Champions (VROC) Charity ProAm series. SVRA's CEO, Tony Parella, and the whole team has been incredibly supportive of efforts on behalf of kids with cancer and this marks the second event for which MAF has been a beneficiary at the Brickyard Invitational.

To add a powerful element to the weekend, 10 kids from The Pediatric Cancer & Blood Diseases Department at Riley Children's Hospital were able to come out to the track! They really were the stars of the weekend and were able to be on stage with Tony as he addressed the drivers at the Friday night dinner. MAF Ambassador AJ was our willing representative of the group, talking to the dinner attendees about what his journey through leukemia was like.

The kids also attended the Saturday ProAm Driver's meeting AND were a huge part of the Saturday race festivities! They were in the green room just before the fan walk, and got to get autographs of some fabulous Legends of Motorsports, including Johnny Rutherford, Bobby Labonte, Geoff Brabham, Davy Jones, Roberto Guerrero, Johnny Benson Mark Dinsmore, Lyn St. James, Wally Dallenbach, Jr., Willy T Ribbs, and Boris Said before they were escorted by the ProAm team partners out to pit lane where they were given CHAMPION medals and joined the annual photo shoot "on the bricks" and the fan walk that preceded the Charity Race.

And, important to note – Willy T Ribbs and Boris Said came away as the winners of the VROC Race at IMS! Read more about the SVRA Vintage Race of Champions online at **www.svra.com/news/svra-announces-vintage-race-of-champions-vroc-for-2019/**

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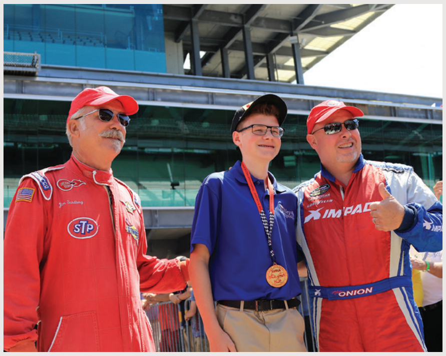

MAF Ambassadors from Riley Children's Hospital (Indianapolis, IN) were the stars of the 2019 Brickyard Invitational weekend! At dinner on Friday night, MAF Ambassador AJ explained what it's like to go through chemotherapy as a kid. Later, SVRA CEO Tony Parella presented the kids and MAF Executive Director Joan Slaughter with a $10,000 check from the VROC Charity ProAm race. On Saturday, all of the kids were escorted to the bricks and fan track walk by their VROC Charity ProAm partners, where they were awarded winners medals to honor their immense courage in the face of cancer.

THE KIDS WERE ECSTATIC AND LOVED GETTING TO BE OUT "ON THE BRICKS"!

Corinthian Vintage Auto Racing's (CVAR) 3rd Annual Race Against Kids' Cancer

September 20-22, Texas Motor Speedway

Three years ago, our partnership with RMVR took a turn toward Texas and it has been a heck of a road trip! Larry Reyburn, CVAR member and Race Chair for the 2016 CVAR Race at Cresson Motorsports Park, met and chatted with a few members of RMVR, learned about the Race Against Kids' Cancer, and decided that CVAR's Board and members should consider also undertaking a charity race. Through his work and efforts on our behalf, CVAR adopted The Morgan Adams Foundation and the CVAR Race Against Kids' Cancer got fully underway!

This year, the event was held for the second time at Texas Motor Speedway, where the club ran along the "ROVAL" – a combination of part of the NASCAR oval and an infield course. For motorsports fans, running along that 24-degree banked curve on the back of the track was an amazing – and FAST – experience!

With the help of the team at Children's Health in Dallas, we were able to bring some kids out to the track and have a little fun at the races, including some track rides in Corvettes and a GIANT Chevy truck!

The weekend featured a car show along the infield on Saturday, an amazing lunch BBQ, and a truly fantastic Saturday night dinner and auction where club members battled it out for a hotly-contested helmet signed by as many of the CVAR drivers as we could find!

We had amazing support from our corporate partners, including Charles Schwab and Pacheco Koch who supported through event sponsorship and their very generous volunteers, as well as IceCOLD Technology, Garrett Heilbrun Technology Partners, LLC, and Gateway Classic Cars.

HUGE thanks to the tireless work of the CVAR Race Against Kids' Cancer Steering Committee: Elliott Barron, Brandall Binion, Jack Marr, Tom O'Grady, Herb Hilton, Bill Wolff, Steve Seitz, Greg Matlack, Larry Reyburn, Danny Piott, John Strand, Clyde Stutzman, and Bobby Whitehead. Our appreciation to the ever growing, tireless, and amazing MAF Dallas Volunteer team: Rick Plonka, Kelly Williams, Heather Jefferson, Christy Nestroyl, and Meghan Bargas.


Mac and Bill Wolff with Bobby Whitehead (center), happy winners of his live auction donation, "The Stars of CVAR" helmet.


MAF Ambassador Eric rides shotgun with Tom Atlas in the C7 Stingray Pace Car on Saturday.


Eric sits in Mac Wolff's Formula Vee surrounded by his family.


MAF Ambassador Grayson gets ready to go out on track with TMS Manager, Brian Brookhouse.


Gary & Tracy Allen and the team from "Smoke on the Water" BBQ chef'ed up a fantastic lunch on Saturday.

Race Against Kids' Cancer
CVAR
To Benefit The Morgan Adams Foundationn

The proceeds from the CVAR Race Against Kids' Cancer and the SVRA Brickyard Invitational Charity ProAm remain directed to pediatric cancer research and building collaborative work between leading research institutions across our region and the United States.

UPCOMING EVENTS:

Holiday Sweet William Market

December 7-8 | 10am-4pm
The Cube - Stapleton MCA
Denver, CO

Buffalo Wild Wings Restaurant Night

December 9 | 11am-11:30pm
415 S Wadsworth Blvd
Lakewood, CO

Colorado Gives Day

December 10 | All Day
www.coloradogives.org/morganadamsfoundation

artma 2020

February 8 | 6-10pm
Denver Design Center
Denver, CO

FOLLOW US!

We share news and updates about our research, Ambassadors, and events on social media daily!

@MorganAdamsFdn

ABOUT THE MORGAN ADAMS FOUNDATION

The Morgan Adams Foundation is an organization dedicated to improving the quality of life and survival rates of children diagnosed with pediatric cancer. Officially established as a 501(c)(3) in October of 2003, the organization is inspired by the memory of Morgan, whose life was taken in 1998 by a brain tumor when she was 6 years old, and all the children and young adults we have come to know who are bravely battling this disease.

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THE
Morgan
Adams
FOUNDATION
Funding Kids' Cancer Research

SHOW YOUR SUPPORT

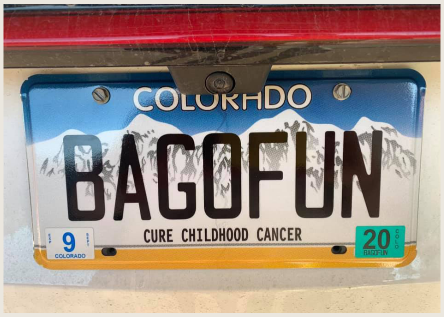
The Childhood Cancer Awareness special license plate is here!

A new license plate in honor of kids with cancer is now available to Colorado motorists! Created by MAF Ambassador Gabe, nearly 450 people are proudly displaying the Childhood Cancer Awareness special license plate on their vehicle. Keep an eye out – if you haven't seen one of these license plates on the road yet, you will soon.

Individuals or businesses who want a Childhood Cancer Awareness plate need only donate a minimum of $43 to be eligible to order the plate. Why 43? That's because every day, 43 children are diagnosed with cancer in the United States.

Proceeds from these qualifying donations are used to enable life-saving pediatric cancer research through The Morgan Adams Foundation and financial support for families through Cops Fighting Cancer.

The license plate features a gold ribbon and stripe along the bottom to signify childhood cancer awareness, as well as a thin stripe in gray representing brain tumors in recognition of Gabe's journey with Stage IV medulloblastoma in his brain and spine. Finally, the plate features a blue sky in honor of our beautiful state and symbolizes the strength and trust we put in the doctors and researchers who work every day to give hope to kids and families dealing with cancer.



More information at www.gabesplate.com