DRAGON MASTER INITIATIVE



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Hello Friends.

I hope this letter finds you safe and healthy. I was recently reminded of a quote from author Elisabeth Elliot. She wrote, "The deepest lessons come out of the deepest waters and the hottest fires." Cancer is like a fire that burns everything it touches and as the saying goes, you must fight fire with fire. For us that means matching that intensity in everything we do.

As Dragon Master Initiative continues working toward our goal of ending the threat childhood cancer poses to our loved ones, we are faced with both the challenges and promises, what I see as fires of the mind and heart.

Through your generous donations, we've helped support the childhood cancer community in a variety of ways. We helped individual families burning through all available resources to cope with a cancer diagnosis. We helped light fires to signal to legislators to fund programs that are changing how childhood cancer research is conducted and shared. Perhaps the most important task is getting researchers to share and use data accessible through Cavatica and CBTN. By funding programs like CAVATICA and the Children's Brain Tumor Network (CBTN), Dragon Master Initiative is changing the way researchers, scientists, and doctors access data previously out of their reach.

Navigating the devastating news of a cancer diagnosis is difficult enough, but the lack of information and guidance during the stressful period after a cancer diagnosis can be a crippling emotional burden. Of course, the burden is also financial and through our support of programs like Noah's G.I.F.T.S., Dragon Master Initiative helped cover a portion of the travel expenses for numerous families who enrolled their children in cancer related medical trials far from home.

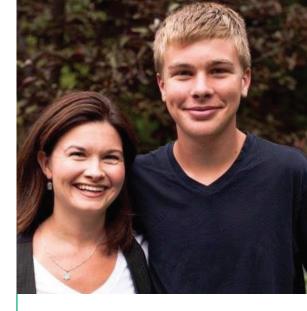
We're making progress, but we're committed to continuously stoking the flames that drive us toward a world in which cancer is no longer taking our loved ones away from us.

Together in Cures,

Amanda Haddock

Amarda

President, Dragon Master Initiative



David Pearson, the inspiration for Dragon Master Initiative, made a commitment to help families thrust into a battle with cancer however he could, whenever he could and that's what drives this organization. While a pediatric cancer diagnosis can have serious financial consequences, David believed in helping people in every way possible. As David once said to a friend, "Be a Giver, not a Getter."











ACTION PLAN

Through programs like CAVATICA, Dragon Master Initiative funds large-scale, cloud-based environments that transcend existing consortia and databases and house linked molecular and clinical data, as well biological samples.

While the initial primary focus was brain tumors, starting with data collection in the pediatric population and then expanding into adults, the infrastructure has grown to include some other types of cancer and birth defect data.

Dragon Master Initiative believes that the key to finding cures and treatments begins by prioritizing rewards for qualified researchers and institutions who share data with the database by giving them free access to the database, leveraging existing grant funding, and creating new grants through fundraising efforts.

Through this process, Dragon Master Initiative invested resources that made the greatest impact over the course of many years, including creating opportunities for researchers to work with each other and with other experts outside of their field of expertise to expand the horizons of research by pushing their experiences outside the box.



INFLUENCE GOVERNMENT

Speaking at scientific events is an essential way to advocate for increased resources for cancer research. Early in 2022, President Biden announced a reignition of the Cancer Moonshot, highlighting new goals: to reduce the cancer death rate by half within 25 years and improve the lives of people with cancer and cancer survivors. That September, Amanda Haddock went to Washington, D.C., to attend the White House Office of Science and Technology Policy's Cancer Moonshot Childhood Cancer Forum. There she spoke on a panel that focused on a variety of topics, including conversations about the Childhood Cancer Data Initiative (CCDI), the Research Acceleration for a Cure and Equity (RACE) Act, and the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act.

SOME RECENT HIGHLIGHTS OF OUR WORK:

- Speaker at the White House Office of Science and Technology Policy's Cancer Moonshot Childhood Cancer Forum.
- Served on the National Cancer Institute's CCDI Cross-Cutting Working Group that is seeking to help make the Childhood Cancer Data Initiative a reality.
- Invited as an advocacy partner at the annual American Association of Cancer Researcher meeting.
- Published two white papers:
 "Towards FAIR Data in
 SAFE Environments" and
 "Challenges and Opportunities
 for the Interoperability of
 Cloud Platforms" for the NIH
 Cloud Platform Interoperability
 Effort (NCPI) Community
 Governance Working Group.
- Provided input to a Clinical Data Interchange Standards Consortium (CDSiC) Focus Group to help them better understand patient perspectives.
- Sponsored the attendance of a young investigator at the international CBTN Conference that highlights the data sharing and research projects happening with the data provided by CBTN.





CULTIVATE PARTNERSHIPS



CBTN

Dragon Master Initiative is a founding member of the **CBTN Executive Council.** Amanda Haddock and the Dragon Master team fearlessly advocate for CBTN's approach to empowering scientific research through data-driven discovery, working to support and advance collaborative research. CBTN started with 4 member institutions participation in contributing data and biospecimens and now includes more than 30, thanks in part to the advocacy and support of Dragon Master. And, Haddock continues to be a key patient-centric advisor for CBTN leadership.



CAVATICA

While advances have been made against cancer in recent years, childhood brain tumors are the leading cause of cancer related death in children. **Dragon Master Initiative** is known as a big data champion. We helped build CAVATICA. This platform provides a sustainable solution for researchers to collaborate, store and analyze genomic tumor information in the hopes of accelerating scientific advances for these devastating childhood diseases.



AWS/AI

Dragon Master Initiative's guiding light is to leverage technology to speed research and development of new cures for rare childhood diseases. With support **Dragon Master Initiative Amazon Web Services** partnered with CBTN to enable researchers and clinicians to share and analyze medical record, imaging, genomic, and other data in near real-time to speed development of new therapies for pediatric brain cancers.



INVEST FOR IMPACT

The past decade of service to the cancer community gave the Dragon Master Initiative a chance to look back at where we have had the most impact, and really focus on those areas for the future.

From the first step of the journey, when a patient is diagnosed, we are there to help guide them to resources that can assist with everything from a second opinion to funding for medical travel to help paying their bills. We fund travel for care at centers of excellence through the Noah's Gifts program and through the DPI/DMG Nurse Navigator program we helped establish in partnership with the ChadTough Foundation. This navigation program greatly expands the number of patients that can be helped by providing free, individualized guidance given by registered nurses with years of oncology experience.

Considering the lack of curative treatments for the majority of brain cancers, we have shifted some of our focus to ensuring patients have access to promising treatment options. We have funded individual clinical trials but refined our emphasis to specialize in treatments with broader potential impact across multiple clinical trials.

In 2022, we helped fund an imaging trial to better see tumors in the human body. MRI scans are very open to interpretation, but PET scans offer far less variability between observers. This project seeks to combine MRI and PET scans for pediatric patients. This is an up-and-coming technology already for adults, but it has been more complicated for children because of the high-volume contrast injection at a very fast rate. It is hard to establish large enough IV lines to accomplish this in children, especially younger children. This project uses fluciclovine EPT to establish tumor recurrence vs. necrosis.

We also funded projects on Circadian Dysfunction, to better understand how the body may use that in responding to medicine and disease, and ecDNA (extrachromosomal DNA), for its potential role in driving cancer development, progression, and drug resistance. Our donors trust us to use their resources to advance science in the most impactful ways, and we are proud that each of these projects has the potential to improve many clinical trials in the future.



PROGRAMS

Noah's GIFTS

This program allows us to cover a portion of the travel expenses for families who enroll their children in cancer related medical trials far from home. Your support gives hope to families of children affected by recurrent pediatric cancer who have not responded to standard treatment options. Families eligible for Noah's GIFTS have a child who is entering treatment at a Children's Brain Tumor Network or Pacific Pediatric Neuro Oncology Consortia institution.



When Maria Newman was told her daughter Brittany had brain cancer, her immediate questions about what to do and who to contact were met with less urgency than she would have expected. The truth is, this type of cancer is relatively rare in children and doctors don't often feel the need to direct a patient to the kind of resources to help plan treatment options for children. In the worst moment a parent can experience, the situation is compounded when there isn't a clear direction from the medical professionals tasked with treating your child. Many doctors are ill prepared to help parents navigate the complex issues that arise from a cancer diagnosis for their child so it's hard to lay blame.

Thankfully, the Newmans discovered how Noah's G.I.F.T.S. (Giving Initiative for Treatment Support) and Dragon Master Initiative have already helped other families just like them. Amanda and Dragon Master offered hope and support when the Newman's needed it most, provided guidance and connections to ensure they could make educated decisions about a treatment plan that gave them the best chance to overcome the diagnosis.

Aside from assistance covering the travel expenses, Noah's G.I.F.T.S. offered additional resources and support while the Newman family sought treatment for Brittany's brain tumors far from home. Noah's G.I.F.T.S. filled a need that might otherwise cause undue hardship for a family already dealing with seemingly insurmountable obstacles on the road to health and happiness.

With generous support from our donors,
Dragon Master Initiative helps fund programs like
Noah's G.I.F.T.S. and provides invaluable insight for
parents as they struggle to find suitable treatment for
their child.



ACTIVATE THE COMMUNITY

Working toward a cure requires outreach with the public to generate the funds necessary to continue research, development, and support for organizations promoting collaborative processes in cancer research. Dragon Master Initiative has been active in this regard with several public events and marketing outreach to gain awareness.

Disney Races

Walt Disney World® Marathon Weekend and other running events remain a big part of our community outreach. We use these running events to generate donations which in turn help us promote the sharing of information and seek to make research more effective by empowering collaboration.

Dragon Derby

In addition to supporting families that travel for care, Dragon Master Initiative hosted other "fun" projects throughout the year. Creating entries in our Dragon Derby fundraiser for the kids gives the families a personal stake in the outcome of the race, and so far, we have had kids with cancer win prizes each year of the event.

Inflate Awareness

Inflate Awareness is a new initiative aimed at bringing some joy to children with cancer. The idea behind it is simple: create a display in a visible place that will help show kids with cancer that people are rooting for them. The more silly and fun the display, the more potential joy it could bring! We saw people create social media posts with balloons, run around town in inflatable costumes, and set up inflatable lawn decor to show kids they are not alone.

Other Community Fundraising

Dragon Master Initiative is always looking for ways to connect and build community support around kids facing cancer and other rare diseases. In 2023, we held our first CureQuest, an online gaming adventure that inspired teams of people to band together to give to help find cures through collaboration and technology.





A DECADE OF DETERMINATION

In 2023, Dragon Master Initiative reached its tenth year as a 501(c)3 nonprofit charitable organization that champions cures for kids with a mission to eliminate childhood cancer and advance the way scientific research happens.

Dragon Master Initiative has marked the occasion with a year-long observance. The foundation was co-founded in May 2013 by Amanda Haddock because of a request made by her 18-year-old son David Pearson shortly before he passed away from glioblastoma, an aggressive brain tumor. David wished that no other child would have to suffer from cancer. This tragedy brought the need for better research tools to Haddock's attention.





As Dragon Master Initiative moves forward, it is focused on tactics that strengthen the usefulness of data already available to researchers:

- Develop visualization tools that make it easier for researchers and clinicians to understand and explore massive amounts of data efficiently.
- Convert the analog parts of patient records to digital data to be computed for research.
- Activate natural language processing.
- Simplify database tools to elevate usability by clinicians. This allows practitioners to treat individual patients more precisely.
- Educate patient families to better use and understand research data.

David was an amazing force for good.

We remain deeply committed to fulfilling his wish over the coming years to ensure that no child need endure the horrific cancer journey.

If you'd like to keep up with our progress, sign up for our e-newsletter at dragonmaster.org.





HELP

Volunteer/Fundraise/Advocate/Shop/Share/Donate

GIVE

Strength in Numbers

By investing monthly, you give financial assistance to parents so they can spend time focusing on their child. And, you empower researchers to collaborate and advance progress toward cures. Through a steady flow of financial support, you help accelerate breakthroughs and provide hope.

In-Kind Giving

Every contribution counts. Did you know you can support Dragon Master's mission through gift cards, airline miles, hotel points, toys and games, artwork, or auction package gifts?

SHOP ONLINE

When you shop online, you can donate a percentage of your purchase to support Dragon Master, a 501(c)3 charity. Check out and give at eBay, iGive, Kroger Community Rewards, and others.

Dragon Master Merch

Shop our store and declare your support for kids with cancer. When you purchase Dragon Master merchandise, all proceeds directly benefit our work.

CONNECT (f) (5) (8) (in)









dragonmaster.org #BeADragonMaster

Dragon Master Foundation, dba Dragon Master Initiative, is a 501(c)3 public charity, FEIN #46-2847688. Donors can deduct contributions under IRC Section 170. Dragon Master recommends that you consult with your tax adviser or the IRS to determine whether a contribution is deductible in your situation.





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