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With Gratitude for the JDJ Charitable Foundation Spring 2022

Thank you, James, for your generous contributions in support of brain tumor research through the JDJ Charitable Foundation. We are pleased to share a report that details the impacts made over the past year within the Children's Brain Tumor Network (CBTN) at Children's Hospital of Philadelphia (CHOP), and beyond. It has been a landmark year, with significant progress toward open, collaborative data-driven research, and we are grateful for your generous support of our work. This has allowed us to expand our footprint and reach, positioning CBTN to be shovel-ready for the new X01 funding opportunity, and in turn tomorrow's advances and brain tumor precision treatments are now within our reach. Thank you for your generosity and commitment to driving this innovative work. We hope you are equally inspired by the work to date and our opportunities in the year ahead to make an indelible impact in the lives of children with cancer.

WHY CBTN

Bringing the Brightest Minds Together to Advance Brain Tumor Research

As you are aware, brain tumors are the leading cause of disease-related death in children in countries around the world. The median age of death is only nine. Despite the high occurrence of this disease, no drug has been developed specifically to treat pediatric brain tumors. Brain tumors affect children and adolescents differently than adults, as their brains are still developing, and the treatments developed for adults often result in more substantial and permanent side effects. We needed a new model of research that serves children now.

With this goal in mind, the Center for Data Driven Discovery in Biomedicine (D3b) at CHOP launched the Children's Brain Tumor Network a decade ago to form a union of forces between clinicians, scientists, patients and foundations from across the globe. What began as only four member sites devoted to data sharing in 2013 is now a global consortium of 26 institutions throughout Europe, Asia, Australia and the U.S., who together are establishing a new standard of care for patients by sharing data, resources and expertise to accelerate and improve discoveries. Together they created the first, and now largest, clinically annotated biorepository with real-time query abilities. It is also the largest genomic data generation effort of its kind for pediatric brain tumors.



**Children's Brain
Tumor Network**
Until every child is cured



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CBTN continues to pioneer new digital platforms and exciting ways to approach vast amounts of genomics-based clinical data; they are tireless advocates for pediatric brain tumor research. Their progress to date is a testament to a shared core belief in the power of collaboration and the idea that open access to data fuels innovation and discovery.

OPPORTUNITIES ON THE HORIZON

Critical NIH Support

As we discussed, CBTN received [exciting news](#) in September 2021 that the National Cancer Institute's Children's Cancer Data Initiative will cover the expenses of molecular profiling for the remainder of all remaining subjects in the CBTN biobank. Once processed and analyzed, this will quadruple the size and scale of the Pediatric Brain Tumor Atlas (PBTA) and empower translational research for scientists worldwide, making precision treatments a reality for children with brain tumors. The sequencing of these 4,500+ specimens represents the largest effort of its kind in the history of the NIH's data generation program and will be released without embargo. This new information will empower translational research for scientists worldwide, enabling them to identify new treatments and generate hypotheses about how existing treatments might be improved. As all CBTN subjects are tracked longitudinally, clinicians in the future will be able to compare the molecular analyses of their patients with those already in the PBTA, giving them the ability to understand what worked or didn't work for patients with similar tumor biology and making precision treatments a reality for children with brain tumors.

Engagement

CBTN's Annual Investigator Meeting in May 2021 was our highest attended gathering, despite being held virtually due to the pandemic. More than 230 attendees across three continents participated in the event, including researchers, clinicians, NIH partners, patients and families, foundation partners, and others interested in accelerating pediatric brain tumor discoveries. Over the two-day gathering, attendees engaged in 26 presentations given by physician scientists, bioinformaticians, lab researchers, data engineers, research advocates and patient families. During the first day, presentation topics included new collaborative initiatives, emerging areas of research and national advocacy opportunities. The Investigator Meeting also included an inaugural presentation of the CBTN Champions & Impact Awards. This addition honors investigators who have accelerated the pace of scientific discovery by being champions for each of CBTN's guiding principles: open science, pioneering spirit and global inclusion. We are grateful to you for sponsoring this event, which continues to inspire the brightest minds.



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Building a Diversified Model

Looking to the year ahead, we are diligently working to pursue a sustainable and diversified business model that includes a combination of:

- Philanthropy
- Government funding
- Commercial partnerships
- Institutional investment

We have tangible opportunities on the horizon related to these streams, including new NIH support, an invited proposal for consideration as a CHOP Frontier Program (which was just accepted as a finalist), and a corporate commercial partnerships strategy and leads, among others. While we have a sustainability strategy in place, our immediate need remains to accelerate our work and capabilities in line with the X01 opportunity. The risk with not scaling up, simply put, is that our efforts will take longer, and we know that the children we are striving to serve do not have time. We know that answers are contained within the data, so our goal is to move as fast as possible to sequence and translate this information in real time, both through hiring new staff and by resourcing partnerships with bioinformaticians elsewhere. While this range of concurrent work is taking place, we also remain focused on maintaining the infrastructure and global partnerships built over the last decade. Your philanthropic support is helping us to mobilize quickly without missing these valuable opportunities, and to continue this momentum and progress in the coming year to capitalize on this new influx of data.

WITH GRATITUDE

We sincerely thank the JDJ Foundation for your longstanding partnership with CHOP and engagement across so many facets of the hospital. We are fortunate for your commitment to the children that we serve in Philadelphia and beyond. We look forward to engaging in the Miracle Mustache Campaign, and to sharing the milestones in the coming year that are possible thanks to your philanthropic support for CBTN.

We will continue to accelerate the development of new therapies for the children and families who depend on us, advocate for open science and data sharing, and bring children around the world diagnosed with a brain tumor closer to a pathway for customized treatment. Thank you for your incredible partnership.

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