

WillieStrong Foundation Impact Report

Prepared for Kevin and Claire Hughes
March 2024





Children's National®

March 16, 2024

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Dear Claire and Kevin,

As we mark five years of partnership, I extend my gratitude for your unwavering commitment. Your generous investments are instrumental in helping Children's National Hospital discover new and better treatments for childhood brain tumors.

Willie's inspirational legacy of courage and determination fuels our collective mission. His spirit reminds us of the impact we can make when we come together with purpose and compassion.

We invite you to explore the impact of your philanthropy and learn how you can continue to support our mission. Thank you for your tireless efforts to ensure that every child has the best chance for a cure.

Sincerely,

DeAnn Marshall, MHA
President, Children's National Hospital Foundation



Children's National

Urgency for Research and Discovery

William Seamus Hughes, known affectionately as Willie, inspired everyone around him.

Whether Willie was on the basketball court, baseball field, in the classroom or with his friends and family, his positive spirit was legendary.

He applied that same spirit to his more than two years of surgeries, chemotherapy and radiation and experimental therapies to treat a brain tumor.

Scientific advances had not progressed enough to provide a cure for Willie. Today, we pay tribute to him as we pursue cures for other children.



Research is vital for understanding childhood brain tumors and improving treatment options for kids like Willie.

Childhood brain cancer accounts for about 1% of all cancers diagnosed in the United States each year. Unlike many adult cancers, pediatric brain tumors often affect developing brains. This leads to unique challenges in treatment and long-term outcomes.

Current treatments, which may involve a combination of surgery, chemotherapy or radiation, can be invasive and have major side effects.

We are developing safer, less toxic therapies that specifically target cancer cells. These include innovative approaches in immunotherapy and molecular treatments.

These will offer hope for a better future for children diagnosed with these devastating diseases.



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Uniting for New and Better Treatments

For five years, the Willie Strong community has come together to help Children's National find new care and treatment approaches.

Through big fundraisers, family fun days, basketball tournaments, shopping events and more, you've united to raise money and awareness for pediatric brain cancer research.

Willie's SummerFest Gala in June 2023 brought together more than 250 people to give children a chance at healthier lifetimes. The 5th annual basketball tournament in February 2024 brought kids in grades five through twelve together for an enjoyable day to remember Willie's bright light.

Through your efforts, you've not only raised funds but spread hope to families and patients affected by this disease. Children's National is proud to partner with you as we search for cures.



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Children's National

A Perpetual Tribute

Your support established a professorship that guarantees Willie's legacy lives on in our pursuit of therapies for aggressive brain tumors.

As the inaugural William Seamus Hughes Professor of Neuro-Oncology and Immunology, physician-scientist Eugene Hwang, MD, is driven by a passion to improve the lives of young patients and their families.

Dr. Hwang joined Children's National in 2010. Since that time, he has risen to international prominence for his expertise in pediatric brain tumors. As director of the Clinical Neuro-Oncology Immunotherapeutics Program, he explores new therapies for children with brain cancer, focusing on safety and better outcomes. He became chief of Oncology in September 2023.

Dr. Hwang, who was Willie's oncologist, strives to transform big ideas into new solutions for children like him.

"Working with Willie meant fighting side-by-side with a walking inspiration," he says. "His memory fuels my mission of curing childhood brain cancer."



"I'm deeply honored to ensure that Willie's spirit and bravery live on in the promise to other families that face a devastating brain tumor diagnosis." - Eugene Hwang, MD



We were thrilled to celebrate the installation of Dr. Hwang as inaugural holder of the William Seamus Hughes Professorship in Neuro-Oncology and Immunology in May 2023.



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As the William Seamus Hughes Professor, Dr. Hwang leads groundbreaking research to improve our knowledge of cell-based treatments for brain tumors.

Immunotherapy – which uses the body's own immune system to seek and destroy tumor cells – is a new approach in cancer treatment. We don't know how well it works for children with brain tumors.

The REMIND trial, led by Dr. Hwang, is one of the first studies in the U.S. to use cell therapy for pediatric brain tumors. It enrolled 24 patients with tough-to-treat brain cancer and used special T-cells to target specific proteins in their tumors. Results are highly promising, showing better survival rates than expected. We will share findings soon with the wider medical community.

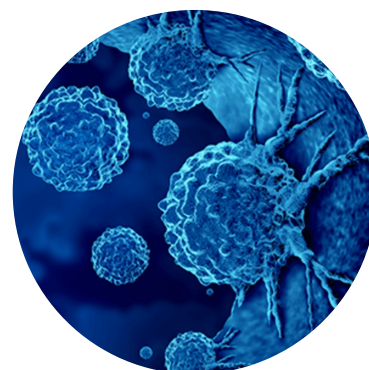
Long term, Dr. Hwang hopes this type of immunotherapy can effectively treat aggressive tumors in children without causing serious side effects.



The professorship helps Dr. Hwang push the envelope to explore new approaches for treatments. In the past year, he secured multiple grants to pilot potentially game-changing ideas.

- A Department of Defense grant-funded clinical trial combines gene therapy and immunotherapy for tough pediatric brain tumors. It will use SGT-53, a special medicine that penetrates the brain's protective barrier, to deliver therapeutic genes directly to the tumors while enhancing the body's immune response
- A new Phase I trial uses mRNA-filled particles to enhance the immune system's fight against recurring high-grade brain tumors in children
- Another study will use special immune cells called CAR cells, made from natural killer cells, to target a protein called B7H3 found on aggressive brain tumors

The pressing need for better brain tumor therapies motivates Dr. Hwang daily. *"A child diagnosed with a brain tumor today doesn't have a single day to wait for a better treatment,"* he says. *"We must do more for these kids."*



With the vital support of the professorship, Dr. Hwang engages the pediatric brain tumor community. He has become a trusted voice and respected leader in global neuro-oncology. This allows him to forge strong partnerships and push for better treatments — extending access to children in other countries. It also ensures he can mentor future pediatric specialists.

This year, Dr. Hwang continued leadership roles in five brain tumor clinical trials networks. This includes the Pediatric Brain Tumor Consortium (PBTC), where he co-chairs the Immunotherapy Working Group, and the Children's Oncology Group.

In the past year, he presented at seven national medical conferences. They included the American Association for Cancer Research Future of Cancer Research Innovation Summit and the Society for Neuro-Oncology annual meeting.

Dr. Hwang and his team also shared important research and expertise to help the broader medical community enhance patient care. In the past year, he published a book chapter, several manuscripts and contributed to four scholarly publications.





Children's National

Powering More Progress

In 2023, the Willie Strong Foundation contributed \$110,000, your biggest direct donation ever.

This gift will help us complete the REMIND trial and support research merging two exciting new methods for the first time: immunotherapy and focused ultrasound. Cell immunotherapy helps the body's defense system fight cancer. Focused ultrasound guides treatments to the brain using sound waves. The study aims to determine the most effective combination of these treatments for the best outcomes.

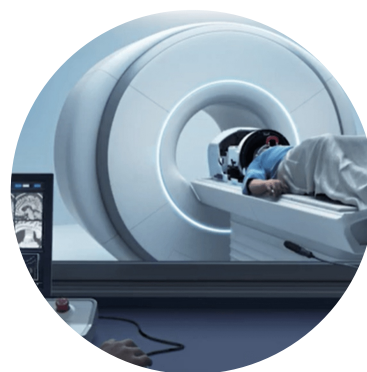


Scientists use T cells with chimeric antigen receptors (CARs) to find and destroy tumor cells, but it is sometimes difficult for the T cells to penetrate the protective barrier around the brain. We will use focused ultrasound in this study to temporarily, and only in the region of the tumor, disrupt this barrier — allowing the attacking T cells to precisely target tumors without surgery.

Children's National is the first to merge these technologies. By combining them, we aim to enhance CAR-T cell therapy's effectiveness while protecting healthy tissue.

Your philanthropy is helping test this powerful combination with pre-clinical laboratory studies and advanced imaging. We hope this will pave the way for a future clinical trial, leading to better and more precise treatment.

This is another important step in creating therapies that could greatly benefit kids with DIPG, and ultimately those with other brain tumors, helping them lead more comfortable and fulfilling lives.



Children's National experts feel a tremendous responsibility and urgency to find new and better ways to treat childhood brain tumors.

We invite the Willie Strong community to join us in supporting this groundbreaking research aimed at enhancing CAR-T cell therapy for children with DIPG.

Your contribution will increase hope for patients and families confronted with this devastating condition. Our aim is to swiftly transition promising treatments to clinical trials and, eventually, achieve cures.

Join us now at ChildrensNational.org/Willie

Together, we will help more kids like Willie and Jace, whose story we share below.



Visit your website at <https://myimpact.childrensnational.org/cnh/2023/williestrong>

Jennifer, a parent at Children's National, reflects on the brave journey of her son Jace.

Our son Jace was born healthy and energetic. As a toddler, he wanted to explore everything. He discovered the path in our backyard that leads to his grandparent's house at 3 years old. He would take off, and I'd find him helping his grandfather in the garden or throwing a ball for the dog. Jace always looked for joy and found it wherever he went.

One Saturday, when Jace was 4, we noticed him dragging his left leg intermittently. Sunday morning, he was holding his left arm close to his body. On Monday we took him to his doctor who ordered a CT scan at the local hospital. Brain tumor. Just like that, our lives stopped.



Doctors at Levine Children's Hospital in Charlotte, North Carolina, diagnosed Jace with DIPG. Care providers said we should bring him home, enjoy his last few months and make special memories. But Jace was a fighter. The oncologist told us of a clinical trial underway at Children's National that might help. When we met with the DIPG clinical trial team there, they earned our trust quickly.

Roger Packer, MD, director of the Brain Tumor Institute at Children's National, Dr. Eugene Hwang and Lauren Hancock, NP, treated us with great compassion. They were also wonderful to Jace. Dr. Packer's hand puppet and the toys in the waiting room comforted him.

They also developed a treatment plan. It started with eight weeks of radiation therapy administered at the hospital near our home that had diagnosed him. Physical therapy helped Jace to walk again. The day he took his new first step was a great day.



We traveled back and forth from North Carolina to Washington, D.C., for testing and evaluation until we could begin infusions. When the tumor progressed, Jace kept fighting despite losing his ability to walk, talk, sit and breathe. He fought for 347 days. He passed away not long after his 5th birthday.

Just like Jace and his team, we will never stop fighting. Jace's mantra throughout his 347-day battle against DIPG was, **"Can't Stop Me!"** We will continue his fight!





Your giving makes the critical research and extraordinary care for children possible. On behalf of the team at Children's National, thank you for all you do to give new hope to our patients and their families.