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NICHOLAS & CHRISTOPHER PILON
FOUNDERS OF DIGITAL BROS CREATIVE STUDIOS

PERSONAL STORY BY NICHOLAS & CHRISTOPHER PILON

GROWING UP WITH PNKD



TWIN BROTHERS FACING A RARE DISORDER & DISCOVERING THEIR TRUE CALLING

In a world where uniqueness is often celebrated, there are forms of uniqueness that come with challenges few can understand. We are Nicholas (Nick) and Christopher (Chris) Pilon, twin brothers who have spent our lives navigating the complexities of a rare neurological disorder known as Paroxysmal Non-Kinesigenic Dyskinesia, or PNKD for short. This journey has been anything but straightforward, punctuated by numerous medical tests, sleepless nights, and unavoidable disruptions in daily life. Yet, it is a journey that has not only shaped who we are but has also inspired us to turn obstacles into opportunities. In the face of adversity, we've discovered our passions, founded a digital storytelling business, and committed ourselves to advocacy for those battling with Diabetes through a partnership with a cause close to our hearts.

In the following article, we aim to share our experiences—both the struggles and the triumphs—as we coped with PNKD while also forging our path in the world of digital storytelling and advocacy. From early consultations with medical experts to emotional hurdles and eventual breakthroughs, we invite you to join us as we recount a life story where challenges became the stepping stones to our dreams.

Early Life with PNKD

Childhood is often described as a carefree time of exploration and discovery, but for us, it came with its own unique set of challenges. Diagnosed with Paroxysmal Non-Kinesigenic Dyskinesia (PNKD), we faced an uphill battle that many our age couldn't fathom. This rare neurological disorder manifested itself through unpredictable episodes that interrupted our daily lives, affecting each of us in distinct ways.

Our parents, realizing the importance of documentation for both medical and personal insights, meticulously recorded these episodes. From capturing video footage to maintaining detailed journals, they left no stone unturned. These records served as crucial evidence, not only for our medical evaluations but also for helping specialists understand the nuanced ways PNKD manifested in each of us.

Seeking answers and treatments, our family didn't hesitate to go the extra mile—quite literally. From consulting local healthcare providers to flying across the country to Washington, D.C., we met with an array of specialists who performed numerous tests to better understand our condition. The gamut of medical evaluations included MRI scans, tests measuring brain activity, and consultations with neurologists specializing in movement disorders. Nick faced intense and often violent episodes that predominantly occurred at night, disrupting his sleep and well-being. On the other hand, Chris experienced episodes that were generally less intense but occurred throughout the day, causing frequent interruptions during school hours.

Though the journey was tough, hope shimmered on the horizon. Doctors speculated that remission could be a possibility as we entered our teenage years, providing a glimmer of optimism that punctuated our otherwise challenging daily lives.



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A Journey to Understanding: Specialists and Breakthroughs

As we navigated the intricate maze of PNKD, finding the right medical guidance became an imperative quest, one that led us to the doors of various healthcare professionals. But of all the specialists we met, one stood out—not only for his expertise but also for his human touch—Dr. Kip Chillag at the Helen DeVos Children's Hospital.

Dr. Chillag was more than just a neurologist to us; he was a beacon of understanding in an often confusing and stressful healthcare journey. He took the time to demystify our disorder, walking us through the intricate neural pathways and explaining how each episode was triggered. It was an eye-opening experience that not only helped us understand the science behind our condition but also armed us with the knowledge to better manage our symptoms.

What set Dr. Chillag apart was his ability to make complex tests and treatments relatable and less intimidating. We no longer felt like mere subjects in a medical experiment but like individuals who were actively participating in our own healthcare journey. His demeanor turned what could have been a nerve-wracking experience into something more manageable, even comforting.

Our collaboration with Dr. Chillag led to multiple breakthroughs in our treatment. Nick ended up going into remission in early 2005—a landmark moment that provided much-needed relief and a renewed sense of optimism. Chris, although he continued to experience episodes until the summer of 2009, benefitted from more effective management strategies that were developed in consultation with Dr. Chillag.

This transformative journey with Dr. Chillag didn't just help us medically; it also laid the foundation for a proactive approach to life's challenges—an approach that we've applied in other areas of our lives as well.

Personal Challenges: Chris's Struggle

While Nick's episodes were severe, mostly occurring during the nighttime, Chris's battles with PNKD presented differently. His episodes would unpredictably interrupt their days, instilling a caution that weighed on both his mental and physical well-being. The unpredictable nature of these events led to frequent pauses in their routine, with Chris's educational journey from 6th to 8th grade bearing the brunt of these interruptions.

In a context where consistency and predictability play pivotal roles, Chris's irregular episodes started to cause significant disruptions. Often, he found himself confined at home, disconnected from his peers and the typical cadence of school life. This separation not only hindered his academic achievements but also inflicted emotional strains.

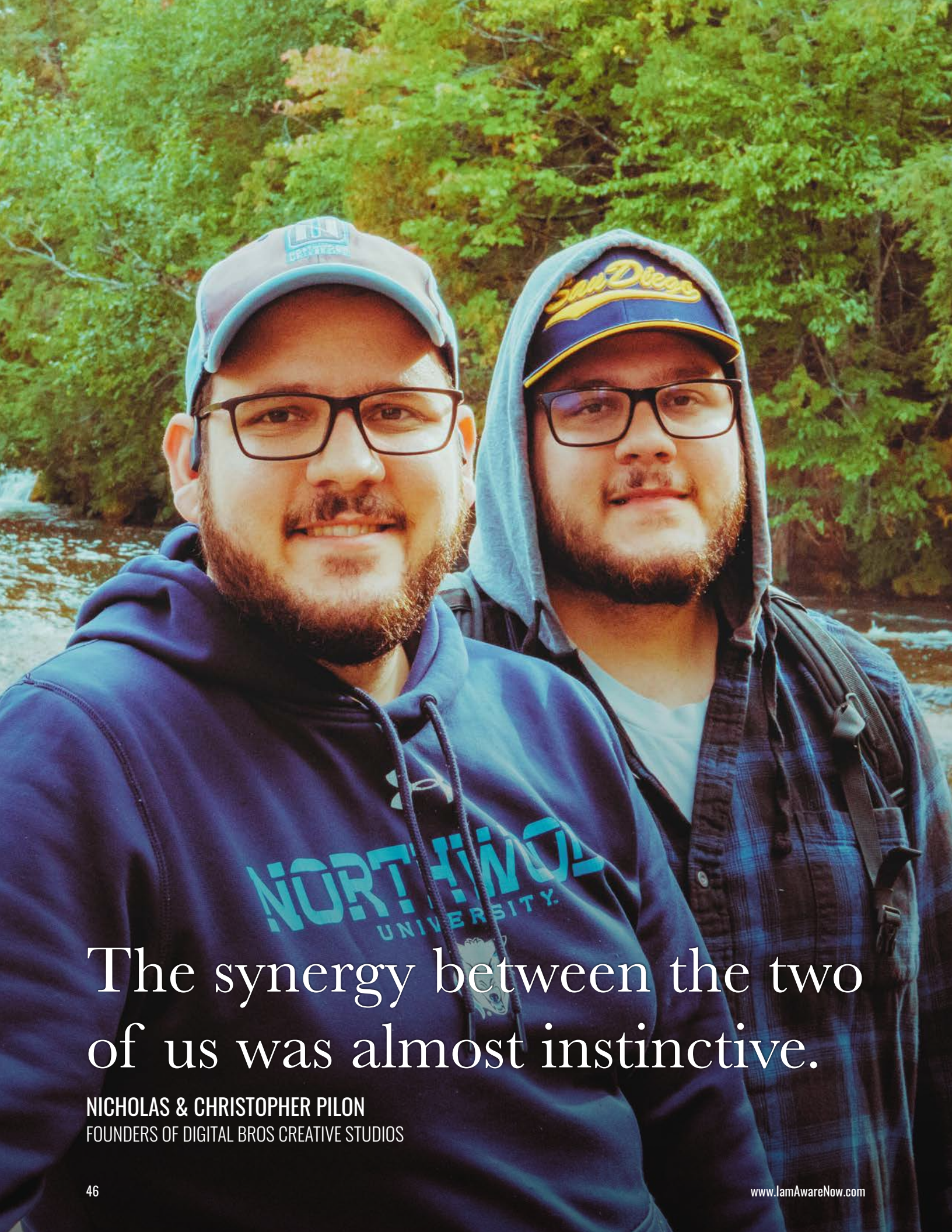
The confines of home life paved the way for mounting mental health challenges, especially depression. As he grappled with the episodes, the accompanying sensations of solitude and detachment intensified. The persistent dread of missing out on pivotal life moments—a fear made even more poignant when witnessing his twin, Nick, engaging in activities that seemed beyond his reach—added another layer of emotional distress.

Although these trials were challenging, they also catalyzed Chris's journey of self-exploration and the development of coping mechanisms. This path towards self-improvement became clearer when they were introduced to Dr. Jen Edwards at BRAINS in Grand Rapids, Michigan.

Seeking Help: Introduction to Dr. Jen Edwards at BRAINS

As we faced the mounting challenges of managing PNKD episodes, it became increasingly evident that Chris needed specialized expertise to guide him toward effective coping mechanisms. Their search led them to Dr. Jen Edwards, a neuropsychologist at BRAINS in Grand Rapids, Michigan. Recognized for its individualized and holistic approach to mental health and neurological challenges, BRAINS became a beacon of hope for Chris.

From the outset, it was clear that Dr. Edwards offered a different perspective. Instead of only addressing the physical symptoms of PNKD, she delved deep, acknowledging the emotional and psychological facets of the condition.



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Under Dr. Edwards' guidance, Chris learned specialized breathing exercises, which proved invaluable. These techniques significantly curtailed the duration of his episodes, allowing Chris to reclaim a semblance of control during those distressing moments.

Adding depth to their therapeutic relationship was Dr. Edwards's personal history. Having herself faced challenges with epilepsy and being a mother to twins, she offered an unparalleled understanding of Chris's journey, forging a deep empathetic connection.

Beyond the physical strategies, Dr. Edwards provided Chris with a safe space to confront his feelings of loneliness and the "fear of missing out." Through their sessions, he found ways to articulate and navigate the emotional labyrinth associated with PNKD.

Their time together was not merely a series of medical consultations. It marked a pivotal moment in Chris's journey, equipping him with the insights and tools necessary to handle the complexities of PNKD with renewed confidence.

Remission and Moving On

As we transitioned into our teenage years, the predictions made by our doctors started to materialize. For Nick, remission graced him as early as 2005. This change wasn't just a medical landmark; it was a profound psychological relief for him. Nights for Nick transformed from being distressing battlegrounds to periods of peaceful sleep, empowering him to direct his energy toward other endeavors.

In contrast, Chris experienced a more extended journey toward remission. His episodes remained a defining part of his daily life until the summer of 2009. As he stepped into 9th grade, there was a noticeable shift. The episodes that once loomed large in his life began to lessen in both frequency and intensity until they eventually vanished. As the cloud lifted, Chris was enveloped in a profound sense of relief.

This period of remission didn't just signify an end to our medical challenges; it represented the dawning of new opportunities. It felt like we were handed a blank canvas, unencumbered by the shackles of PNKD, and we were eager to chart our paths forward. This newfound liberty allowed us to fully chase our aspirations. It was a time of significant personal and professional growth, leading us into our collective passion for digital storytelling, business, and advocacy.

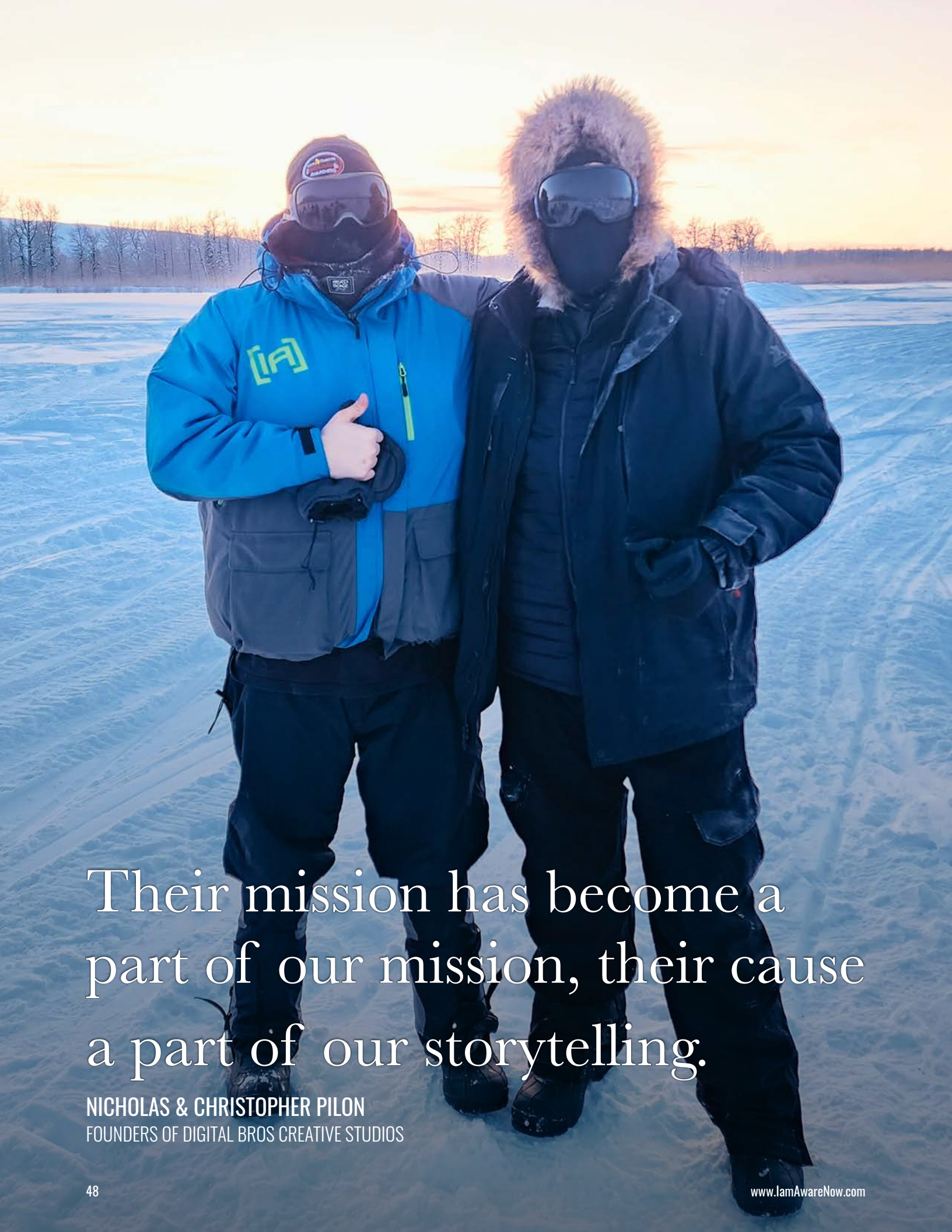
The onset of remission reshaped our lives, not just in terms of health but also in how we perceived our futures. We weren't just survivors of a condition; we were poised to etch our distinctive imprints on the world.

A Passion Unfettered: NOLIProductions to Digital Bros Creative Studios, LLC

The end of our battles with PNKD signaled the start of a new chapter where we could chase our dreams without constant disruption. One dream that burned brightly for us was our mutual passion for storytelling, especially through the medium of video. This love for narrative soon became the cornerstone of our joint business endeavor.

In the beginning, we laid the foundation for NOLIProductions, a testament to our shared enthusiasm for capturing compelling stories. While Nick honed his craft in cinematography, Chris delved deep into the intricate world of post-production. The synergy between the two of us was almost instinctive. It felt as if each had discovered a niche within the expansive universe of storytelling. Together, we could transform a mere idea into a polished masterpiece, a journey that filled us both with immense satisfaction.

As time unfurled, and our skills matured and our vision broadened, we felt the need to transition into a brand that truly embodied our evolving aspirations. This led to the metamorphosis of NOLIProductions into Digital Bros Creative Studios, LLC. With this revamped identity, our mission grew: to offer a bespoke approach to digital storytelling, addressing a spectrum of requirements from marketing endeavors to poignant messages that resonated on a global stage.



Their mission has become a
part of our mission, their cause
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But this change was more than just a rebranding exercise. The birth of Digital Bros Creative Studios was a declaration of our refined proficiency and philosophy. Through this initiative, we aimed not merely to capture stories but to craft narratives laden with purpose and emotion, narratives that could touch hearts, enlighten minds, and inspire actions.

Working with Drive For Diabetes Awareness, INC.

As our business began to flourish, we found ourselves looking for opportunities that not only aligned with our skill set but also resonated with our personal beliefs and life experiences. It was during this search that we encountered Brent Kuehl and the heartbreaking yet inspiring story of the Kuehl family. We were immediately captivated by their mission—to spread awareness of Diabetes and its symptoms in memory of their late baby brother, Rocco.

Our first interaction involved creating a promotional video that highlighted the symptoms of Diabetes, an initiative we undertook pro bono. The chemistry was instant, and what began as a one-time project evolved into an enduring partnership. Today, we proudly serve as official sponsors and advocates for Drive For Diabetes Awareness, INC. Our roles have expanded to include maintaining their website and occasionally crafting content for their social media channels.

One of the most meaningful projects we embarked on was capturing the journey of Lacy Kuehl, a young woman on a mission to honor the memory of her baby brother and contribute to the cause. Her commitment led her to participate in the Jr. Iditarod in Alaska, a grueling dog sled race that she completed despite the odds. Our documentary, filmed after 38 days of her intense training, not only chronicled her physical journey but also shed light on her emotional and psychological experiences. It served as a testament to her resolve and the impact Drive For Diabetes Awareness aims to make.

Our collaboration with the Kuehls isn't just professional; it's profoundly personal. Their mission has become a part of our mission, their cause a part of our storytelling. As filmmakers, we don't just see ourselves as service providers but as storytellers with a purpose, amplifying messages that can change lives and make a difference.

Our Most Recent Project: Driven—Florida Driver to Alaskan Musher

In the realm of storytelling, certain narratives transcend mere entertainment or information; they inspire, ignite passions, and leave an indelible mark on the audience. One such narrative was our recent project "Driven—Florida Driver to Alaskan Musher," a documentary that captures the compelling journey of Lacy Kuehl as she transitions from being a race car driver in Florida to a musher in the unforgiving terrains of Alaska.

Our journey began after 38 days of Lacy's rigorous training for the Jr. Iditarod, a dog sled race that pushes the limits of endurance and determination. We weren't just there to document her physical feats but to delve deep into the emotional and psychological aspects of her journey. Lacy wasn't merely racing for sport; she was on a mission to spread awareness about Diabetes, in honor of her late brother Rocco and in memory of Mark Torkelson, a legendary Iron Dog winner who had passed away from complications related to Diabetes.

Our documentary aimed to capture not just the beauty of the Alaskan wilderness but also the strength and resolve it takes to compete in such a challenging environment—all for a cause that resonates deeply with families affected by Diabetes across the globe. The film served as a window into Lacy's world, reflecting her grit, her challenges, and the poignant moments that made her story so incredibly inspiring.

As storytellers, the project touched us on multiple levels. It wasn't just a creative endeavor but a deeply personal one, mirroring our own journey of overcoming medical challenges to pursue our passion. "Driven" became more than just a film; it became a testament to human resilience, the power of storytelling, and the impact one person can make in the lives of many.



Conclusion

Our lives have been a tapestry woven from threads of challenge, resilience, and aspiration. From our early days grappling with Paroxysmal Non-Kinesigenic Dyskinesia (PNKD), to our transformative encounters with medical specialists, and onto our ventures in digital storytelling and advocacy, each phase has added a unique hue to our palette. While the struggles of living with a rare neurological disorder have undeniably shaped us, they haven't defined us. Instead, they have given us a distinct lens through which to see the world—a lens that values empathy, determination, and the transformative power of storytelling.

As we reflect on our journey, we can't help but feel grateful for the constellation of people who have guided us—our parents, Dr. Kip Chillag, Dr. Jen Edwards, and the inspiring Kuehl family, to name a few. They have been instrumental in turning what could have been a story of limitations into a narrative of boundless possibilities.

Today, as co-founders of Digital Bros Creative Studios, LLC, and as advocates for Drive For Diabetes Awareness, INC, we continue to channel our experiences into avenues that resonate with who we are and what we believe in. Our most recent project, "Driven—Florida Driver to Alaskan Musher," is more than just a film; it's a symbol of what can be achieved when passion meets purpose.

As twins, we've always shared much more than just our DNA. We share a drive to overcome, a passion to create, and a mission to inspire. And as we look ahead, we are excited about the countless stories that are yet to be told, lives that are yet to be touched, and challenges that are yet to be overcome. In a life characterized by both struggles and triumphs, we choose to focus on the triumphs—and in doing so, we find our truest selves. ■

Learn more about Digital Bros Creative Studios: www.digitalbrosstudios.com