

***“A must-read”***

**—JULIE DUSSLIERE, CHIEF OF PARALYMPIC SPORT  
U.S. OLYMPIC & PARALYMPIC COMMITTEE**



**PURE**



**GRIT**

**Stories of Remarkable People  
Living with Physical Disability**

**LILY COLLISON & KARA BUCKLEY**

## Praise for *Pure Grit*

*Pure Grit introduces us to individuals who have helped to redefine what is possible. Their stories are educational, inspirational, and aspirational. This book reminds us that what makes us different is a strength — not a liability. I highly recommend it.*

—**DR. RAY BROWNING**, CO-FOUNDER AND CEO OF BIOMOTUM, INC.

*Pure Grit is an authentic and raw look into the life of disability. Collison and Buckley shine a light on the array of misconceptions that people with physical disabilities are forced to endure, while also showcasing a world of unlimited possibility by normalizing disability in a way that is rarely done. The book is a must-read.*

—**JULIE DUSSLIERE**, CHIEF OF PARALYMPIC SPORT, U.S. OLYMPIC & PARALYMPIC COMMITTEE

*Pure Grit is about being determined, but also about being believed in, taking opportunities, having and using support networks, and most importantly, driving social change. Being visible and successful opens a world of possibilities for those who are, and for those who are not, disabled.*

—**DR. CHRISTINE IMMS**, APEX AUSTRALIA CHAIR OF NEURODEVELOPMENT AND DISABILITY, UNIVERSITY OF MELBOURNE, CO-EDITOR OF PARTICIPATION: OPTIMISING OUTCOMES IN CHILDHOOD-ONSET NEURODISABILITY

*Pure Grit will encourage our son to own his disability and be all that he is meant to be. A book that also encourages us, as parents, to be bold and brave in how we raise our children. I loved it and can see an immediate difference in how I see and respond to life's challenges.*

—**NICOLA BRASSEY**, TEACHER AND MOTHER TO A CHILD WHO HAS CEREBRAL PALSY, UK

*The stories in Pure Grit are a testament to human achievement no matter your ability. Sports have always been a reflection of our world, and it speaks volumes that so many of these incredible stories are from Paralympians and athletes around the world. An extraordinary read.*

—**CASEY WASSERMAN**, CHAIRPERSON, LOS ANGELES 2028 OLYMPIC AND PARALYMPIC GAMES

*Wonderful accounts of individual journeys, sharing unique challenges of physical disability, fuelled by remarkable determination. The horizon of unlimited possibilities for achievement is communicated modestly. One can only be motivated by the unlocking of potential that is highlighted. A compelling read with universal appeal.*

—**DR. JANE LEONARD**, MEDICAL DIRECTOR, CRC, DUBLIN

*Pure Grit highlights the lived experience of remarkable individuals, who collectively demonstrate that growing up with a disability brings strength, perspective, and resilience. Importantly, it tells these stories through the lens of the empowerment model rather than the deficit model, demonstrating that disability is a natural, and beautiful, element of diversity and the human experience.*

—**DR. CHERI BLAUWET**, ASSISTANT PROFESSOR OF PM&R, HARVARD MEDICAL SCHOOL; BOARD OF DIRECTORS, U.S. OLYMPIC & PARALYMPIC COMMITTEE AND BOSTON ATHLETIC ASSOCIATION; RETIRED PARALYMPIC WHEELCHAIR RACER.

*This remarkable book changes my understanding of the world around me. The personal stories are told with an honesty that gets to the nub of our shared humanity.*

—**TOMMIE GORMAN**, IRISH JOURNALIST WHO LIVES WITH CANCER

*The authors have a unique ability to meet the storytellers where they are at. Every story is told with an authenticity that gives the reader an opportunity to change the many assumptions they might hold about disability without pushing or instructing them to do so. Each of the nineteen stories is superb in its own right, and as a collection this book is a joy to read.*

—**RACHEL BYRNE**, EXECUTIVE DIRECTOR, CEREBRAL PALSY FOUNDATION, NEW YORK

*Pure Grit is a compelling book that takes the reader into the hearts and minds of some extraordinary individuals. The biographies are deeply immersive, often very personal and engaging, yet move the reader to reflect on how lives — who we are and where we are — are so profoundly contingent on our relationship with each other and the culture we inhabit.*

—**DR. EMMA PULLEN**, LECTURER IN SPORTS MANAGEMENT, LOUGHBOROUGH UNIVERSITY, UK

*Inspiring! And beautifully told. Every chapter filled with a heart-warming, life-affirming story.*

—**JOHN D. MILLER**, FORMER CHIEF MARKETING OFFICER OF NBC SPORTS GROUP

*Many clinicians have recognized the value of learning from the experience of disabled youth and adults. Pure Grit provides that information ... Interviewees recognize that parental, family and community attitudes and the physical environment generate barriers or opportunities to fulfillment in careers and personal life. I highly recommend Pure Grit to audiences who are rooting for diversity in all its richness as well as those focused on health and disability studies.*

—**DR. KATHERINE D. SEELMAN**, PROFESSOR EMERITA, UNIVERSITY OF PITTSBURGH; FORMER DIRECTOR FOR U.S. NATIONAL INSTITUTE ON DISABILITY, INDEPENDENT LIVING, AND REHABILITATION RESEARCH; AND MEMBER OF THE INTERNATIONAL PANEL FOR THE WHO WORLD REPORT ON DISABILITY. SHE HAS A HEARING IMPAIRMENT.

*Pure Grit is a necessary read for anyone looking to further disability representation in various storytelling mediums. Not only does it provide helpful insight on how to do so, but more importantly it centers disability within a conversation about the universal truths of how to live a purposeful and fulfilling life. Ultimately, if there is one takeaway from this book, it is: follow your passion.*

—**ASALLE TANHA**, DIRECTOR OF DEVELOPMENT, ORIGINAL SERIES AND MOVIES AT CARTOON NETWORK STUDIOS, LOS ANGELES

*This book thoughtfully captures the breadth and diversity of disability in a way that reminds us that disability is an important part of the human experience. Loved the book.*

—**BRYAN STROMER**, MARKETING PROFESSIONAL WHO LIVES IN THE U.S., AND WHO HAS CEREBRAL PALSY

*This remarkable book prompts us to have courage in the pursuit of our own dreams, and also, to have courage to support others to achieve their life aspirations too — even when challenges are significant. Written in an engaging and accessible format, this book will resonate with and inspire readers, from all walks of life, around the world.*

—**DR. ELAINE KINSELLA**, LECTURER IN PSYCHOLOGY, AND RESEARCHER IN HEROISM, LEADERSHIP, BRAIN INJURY, UNIVERSITY OF LIMERICK, IRELAND



**PURE  
GRIT**



# PURE GRIT

**Stories of remarkable people  
living with physical disability**

LILY COLLISON & KARA BUCKLEY



*All information contained in this book is for educational purposes only. For specific medical advice and treatment, please consult a qualified health care professional. The information in this book is not intended as a substitute for consultation with your health care professional.*

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## PREFACE

**IT'S INTERESTING HOW THINGS** sometimes happen in our lives by chance.

I've known Kara, coauthor of this book, for a number of years. Kara suggested to me that I might like to read *Struggling with Serendipity*, a book written by Cindy Kolbe about life following a car accident that left her fourteen-year-old daughter Beth paralyzed. Beth later graduated from Harvard University and represented the U.S. at the Beijing 2008 Paralympic Games. Beth applied to Harvard only after catching sight of a billboard on the side of a highway — the billboard showed a Harvard student in a wheelchair wearing a graduation gown.

For Beth, that billboard shined a light on what is possible.

I have personal experience of people growing up with physical disability — my youngest son, Tommy, has spastic diplegia, a common type of cerebral palsy (CP). This led me to writing the book, *Spastic Diplegia—Bilateral Cerebral Palsy*. In writing it, I read many academic papers, but one, written by a Dutch research group, made a lasting impression on me.<sup>1</sup> It showed that compared with the general population, people with spastic diplegia (also known as bilateral cerebral palsy) have lower rates of employment, relationships, and having children. Research from other countries also bears out this



finding. It really bothered me that people with just a mild/moderate physical disability with no cognitive impairment (as spastic diplegia generally is) have lower rates of participation in society.

An Australian initiative, CP-Achieve,<sup>2</sup> aims to address the health and social inequities of adolescents and young adults with cerebral palsy. Learning about the great work they were doing, I felt there was a need for role models — people living with physical disability who have achieved in different areas of life. Just one example is Daniel Dias, a Brazilian Paralympic swimmer who has won multiple medals. In an interview, he credited fellow Paralympian Clodoaldo Silva for getting him into the sport: “I only began because I saw Clodoaldo swimming on television. I didn’t know people like me could swim, could do any sport at all.”<sup>3</sup>

Another is Justin Gallegos, who is the first professional athlete with cerebral palsy to be signed by Nike. He shows what is possible when living with a disability.

Within a month of Kara recommending that I read Cindy Kolbe’s book, I suggested to her that we cowrite this book. Beth, Daniel, and Justin are just three people featured in it; sixteen others tell their stories, too. The aim of the book is to shine a light on remarkable people living with physical disability.

—Lily Collison

...

When I asked the chief of U.S. Paralympic Sport, Julie Dussliere, to recommend a biography of a Paralympian, she suggested I read *Struggling with Serendipity*. The book had a major impact on me, as both a mom and a sports executive. I recommended the book to Lily, and fed off her enthusiasm

when we later spoke. She stressed the need to tell more stories about people who grew up with disabilities to serve as “that billboard” for others. During our conversation, she raised the idea of us cowriting this book.

I was immediately interested. The idea of writing such a book aligned with one common thread that has been constant in my career — working at the intersection of human perseverance and excellence in sport, to be a champion for athletes regardless of their individual challenge, be it due to age, gender, nationality, or physical disability. Previously, when I was working at Visa, I pioneered the Rio 2016 acceptance campaign supporting all ten athletes on the Refugee Olympic Team. Today, one in three athletes I work with has a physical disability, and one of my goals is to democratize athlete access to opportunities, especially between Paralympians and Olympians.

While we have made a lot of progress within the Paralympic Movement, there is still room for improvement. For example, in the United States, several elite feeder programs exist for Olympic sport, but there is often no clear path for many children and teenagers with physical disabilities to train for the Paralympics. Through the stories in this book, I saw the potential to focus more attention on developing a path for young people with physical disabilities to pursue sport.

In the recent Netflix documentary *Rising Phoenix*, Paralympian Ellie Cole talks about having her leg amputated as a young child — she explains that she didn’t have any role models to look up to until she learned about the Paralympic Games. This comment on lack of role models mirrors conversations I’ve had with other Paralympians.

Lily and I both share the philosophy of living with a growth mindset and a spirit of optimism: that you may not be able to

control what happens to you in life, but you can control how you react.

I soon realized how a book like this could be useful.

**–Kara Buckley**

...

Together, we wrote the stories in this book by doing background research and then both of us interviewing each participant over Zoom. We Zoomed around the world from Campinas in Brazil to Sydney in Australia to Reykjavík in Iceland, having a lot of fun connecting across time zones.

In telling each story, we have respected each individual's preferred disability language — some prefer “disabled person,” rather than “person with disability,” and “nondisabled person” rather than “able-bodied person.”

No conclusions are drawn — we leave it to you, the reader, to draw your own.

We've also included two appendices with further information and context: Appendix 1 provides resources to learn more about physical disabilities. Appendix 2 contains information on Para sport.

We hope that the stories in this book might nudge all of us — disabled and nondisabled — to reflect on how we are living our lives. The stories shine a light on boundless possibility whatever our individual challenge.

**–Lily Collison and Kara Buckley**

# INTRODUCTION

**THIS BOOK TELLS STORIES** of remarkable people living with physical disability — adults who have grown up with a physical disability from birth or acquired one during childhood or adolescence, and who have achieved much in their individual fields.

An estimated two to three percent of children and adolescents grow up with a physical disability,<sup>1</sup> which is a different experience from acquiring one in adulthood, when one is already established as a person. For the child and adolescent with a physical disability, the challenge of their disability is added to all the “regular” challenges of growing up. It is worth noting, though, that as people progress through adulthood, they may acquire physical disability through, for example, accident or illness. Disability is a reality for fifteen percent of people *across the lifespan*. A billion people worldwide have a disability.<sup>2</sup>

The people in these stories are remarkable in different ways — they are successful across fields such as business, sport, medicine, dance, tech, and politics. The sports stories are varied, but a number of them feature swimmers (reflecting the popularity of swimming as a sport of choice for people with a physical disability).

These are stories of people with different types of physical disabilities. Since cerebral palsy (CP) is the most common

cause of physical disability in childhood,<sup>3</sup> several stories feature people with this condition — and where known we have specified the type (spastic diplegia or hemiplegia). These stories also address physical disability alone, acknowledging that some physical disabilities also have associated cognitive challenges.

Although the stories are diverse, some common themes emerge. Many tell of parents being given poor predictions of their child's life soon after birth. "Won't." "Can't." "Never." These words were often heard.

But these people have lived out a different story. These remarkable individuals are not *overcoming* disability — they are accommodating disability in their lives while pursuing their dreams. Many tell of influential people they had early in their lives, and all offer rich insights on disability. For instance, just because a person has a disability doesn't mean they are exceptional, special, or inspirational — they are ordinary. It is what they *do* in life that makes them remarkable.

Athletes talk of wanting to be recognized for their sporting achievements, not to be given inspirational awards merely for participating. Others emphasize that the environment (physical and attitudinal) is often more limiting than the disability itself; that sometimes, nondisabled people are uncomfortable around disability simply because they don't know any disabled people. Giving disability visibility is important.

Perseverance is the one characteristic that all the people in these stories share — they all display *pure grit*, which is what inspired the title of the book. In her story, Ila Eckhoff says, "Grit is one of those things that we don't quite know how to measure. Grit has been proven to have much more of an impact on goals, objectives, and achievement — even more than intellect . . . a person with above-average grit is

going to go a lot further than somebody who's super smart with zero grit who, once they get stopped, doesn't know how to get back up." Everyone profiled in this book knows, or has learned, how to get up again.

And while many of those featured in these stories don't see themselves as role models, they are. Role models, as most people understand, have a useful place in society, and a growing body of research supports their importance.<sup>4</sup>

Success in life is to some extent additive — later success builds on earlier successes and failures. The remarkable people featured here vary in age from their twenties to seventies and are at different stages of success. For example, in Paralympic sport, one athlete has just made the qualifying time; others are world-leading multi-medalists.

Taken together, the stories shine a light on unlimited possibilities. Success is what *you* want it to be. Success is achievement at any age. Success can be in the quiet of your own home as equally as on a world stage. Success takes effort, success takes resilience, and indeed, sometimes success takes failure. Success can bring satisfaction, and success "breeds success."

Reading this book will make you laugh and sometimes cry. The book goes a long way toward dispelling the lingering myth that disability is something to be pitied, that it leads to a "less than" life. When reading these stories, pity is not likely the emotion you will feel — more likely it will be awe and, indeed, sometimes envy of these amazingly fulfilled and vibrant lives.

Marian Wright Edelman, the American activist for children's rights, coined the phrase: "You can't be what you can't see." We hope this book will help people *see* in order *to be*.



# LEX GILLETTE

*No need for sight when you have a vision*



Lex is a U.S. Paralympic long jumper.  
He has been blind since childhood.





**LEX GILLETTE STEPS OFF THE SCHOOL BUS**, feeling the firm pavement under his feet as the warm spring air hits his face. A backpack in tow, he steps up onto the curb of the familiar sidewalk, walking straight. He reaches the grass line, feeling the soft padding beneath his shoes, his cue to turn right. Because Lex cannot see, his daily journey home from school is guided by his other senses.

Lex arrives at the stairs, counting the steps — one, two, three — before taking five steps forward. He then has a choice: he can turn right toward his front door or, even better, he can turn left, to the ledge.

That beloved ledge represents freedom to this young boy from Raleigh, North Carolina. Lex drops his backpack, picks up his pace, and runs. His arms spread wide as he pushes off the edge, jumps, and starts to fly. Gravity draws him three feet down, landing on the soft grass below.

Lex was not born blind. He still remembers the sight of flowers blooming and birds flying in his neighborhood. It wasn't until he was three years old that he first lost vision in his left eye due to a detached retina. He still had vision in his right eye though — until things started to go murky at age eight.

Once again, a detached retina was the culprit. When Lex got into the bathtub one night, he saw lines blurring his

vision, and the next day at school, teachers noticed that he was bumping into things in the classroom. Lex had to wear an eye patch for several weeks and began a series of new operations.

“After the tenth operation (I endured thirteen starting at three years old), ophthalmologist Dr. Brooks McKewen talked to my mother. He said to her, ‘Ms. Gillette, we have tried everything. Your son will eventually go blind. I am sorry, but there is nothing else we can do.’ Questions rattled around in my head. ‘So, now what?’ I wondered,” Lex later wrote in his memoir.<sup>1</sup>

His mother, Verdina, had already instilled her own approach to navigating disability into Lex’s hard drive. She is also visually impaired, having a form of glaucoma that grants her some usable sight. She was Lex’s role model early on.

“She was a really good example,” says Lex. “I think the biggest thing is that she let me go, at the end of the day. She let me go outside and discover and continue to explore after I lost my sight. Although I couldn’t see anything, it was about learning the neighborhood from my other senses.”

With his mother’s blend of expectations and aspirations, Lex quickly learned how to navigate independently. Verdina expected Lex to have the same responsibilities as any other kid: washing the dishes, doing his chores, and finishing his homework. She aspired for him to gain autonomy, encouraging him to learn how to navigate life among his sighted peers.

“It was literally my mom who kept me growing, allowing me to go out there and figure out the world from all aspects, minus the visual,” says Lex. “She told me ‘This is your life. I want you to be able to go into the world and do amazing things. I want you to achieve everything you see within your mind, and it doesn’t matter what anyone says or the obstacles

that lie in your path. You have what it takes internally to overcome all of those things.”

Verdina never cocooned or overprotected Lex. She let him try new things. Other people would come over and see Lex outside, doing cartwheels and jumping, and say, “Oh my gosh, he’s going to kill himself!” But his mom would defend the freedom she allowed, countering that she had to let him.

Her penchant for encouraging Lex’s independence came from a core truth: that without sight, he made up only a small percentage of people in the world, and she never wanted him to be completely separated from the larger population. She knew that when he went out into the world, especially as an adult, the majority of people would be able to see. So, she wanted to keep him embedded in mainstream society — participating, interacting, and working alongside sighted peers.

Verdina made a deliberate decision early on to keep Lex in public school, integrated with sighted children. It took Lex a year to learn braille in elementary school. He was given textbooks in braille and began using a braille writer, much like an old-fashioned typewriter. Homework took longer for him to do than it did for his peers. Fortunately, Lex didn’t experience much bullying as a child. Kids joked, but he quickly learned to joke as well. By dishing it back, he showed kids he wouldn’t put up with it, and they stopped picking on him. He kept things as light and friendly as possible.

Every summer, Lex attended programs at a local school for the blind, which offered courses on independent living and mobility. There he learned how to care for himself at a young age — how to iron his clothes, do laundry, clean the house — a host of practical skills that he still uses today. In elementary school, Lex also started working with a mobility specialist, John Higgins, who taught him how to use a cane to “see”

his surroundings in place of his eyes. Higgins created three-dimensional maps so Lex could read directions: gluing down sticks to paper so he could feel the roads with his hands, and using braille to name each street. The map pointed to Lex's favorite restaurant, T.J. Cinnamons, with a reward of cinnamon buns for navigating the neighborhood autonomously.

As he did in his lessons with Mr. Higgins, Lex learned from his mother an important philosophy: there is a difference between sight and vision. While his sight was limited, Verdina maintained a strong vision for the wonderful, independent life her son could — and would go on to — have, though never imagining the level of success he would find in sport and public speaking.

...

As he was when jumping off the ledge, Lex is freest while in motion. On summer breaks from school, he enjoyed that freedom riding bikes with his cousins during visits to the countryside where they lived.

They never focused on the fact that he couldn't see anything. Instead, they adapted and made accommodations to include Lex. At that age, no one deliberately thought about "inclusion," but of course, as humans, kids figure it out.

As Lex would pedal down the road with his cousins, he could hear the gravel crunch beneath his tires. He followed the similar crunching sound from the bike ahead — his cousin leading the way down the rural lane in the July sun. The smell of pine trees enveloped Lex, with a humid heat radiating from the ground. Hearing his cousin take a right, Lex would mimic the movement, and the path would audibly change. A soft, smooth sound indicated they were now on the dirt path heading back to the house.

“Every aspect of life has a certain sound to it,” says Lex. “I knew that if I was in line with where they were, then that would keep me in a really safe space.”

Lex got creative when navigating other sports too. It was basketball that changed his life.

In North Carolina, basketball is a religion. Lex was a huge Michael Jordan and Tar Heels fan, so it was a no-brainer — of course he’d play the game, too, shooting hoops in his childhood bedroom, with a Nerf net hung on the back of his door. Lex oriented his room around that net, knowing the position of his bed and dresser relative to the door, so he could envisage where it was located. He spent hours shooting basket after basket, and it got to the point where he literally felt like he could see what was going on.

“I knew that if I could shoot this basket — something I couldn’t see — I could shoot for anything else in life,” says Lex. “I transferred that same type of energy to my outlook on life. It really helped me to put the rubber to the road. I think that’s a very important lesson nowadays, that to achieve things it does take hours and hours of practice.”

That net became a symbol for Lex. It signified a goal he had set for himself and taught him a lesson in confidence: that with determination and practice he could achieve great things, despite being blind.

In high school, he joined the track-and-field team and quickly progressed to international competitions, going to his first Paralympics in Athens in 2004. Lex competed in the long jump and won his first silver medal there at age nineteen.

...

In the long jump, Lex’s guide, Wesley Williams, stands at the end of the runway, clapping and shouting to direct Lex.

When Wesley begins to clap, Lex heads in his direction at full speed, and starts counting his strides. After Lex plants his foot on the sixteenth step, he hears Wesley shouting, “Fly, fly, fly,” as Lex leaps in the air. Lex’s feet leave the pavement and come down together as he lands in the sandpit. In competition, medals aren’t just awarded to the athletes competing — guides also receive a medal.

In Paralympic sport, Lex is classified as T11 — T for track events, and 11 to indicate vision impairment and its level. All T11 athletes are required to wear eyeshades to ensure a fair competition, since some have reduced vision while others have no vision at all. The irony, of course, is that in Lex’s case, he has shaped his entire career on the fact that his blindness is *not* an impairment. Through sport, and lessons from his mother, Lex has found that he is no longer imprisoned by what is and has instead gained the ability to see what could be.

...

Lex attended East Carolina University, a massive campus with 20,000 students. There he learned how to use the help offered from Disability Services and other resources to ensure his academic success. In those life transitions, Lex learned how to advocate for himself. He no longer had his mom to speak up on his behalf.

“It was a totally different situation. I had to be vulnerable and verbalize the types of assistance I needed,” says Lex. “I was still dealing with different insecurities about my blindness, wondering if I was looking toward someone when I was speaking to them, or if people were looking at me weirdly.”

He got over those feelings of awkwardness by learning how to push through. Lex came to understand that by having the courage to open himself up and ask for what he needed,

he could get over his nervousness. Whenever he took a step forward, the feelings started to dissipate. He realized he didn't get hurt, nothing crazy happened — and he was able to achieve what he needed. It encouraged him to keep going.

When he was younger, Lex had observed his mother push through similar tough situations. As a single mom, Verdina was the model of the characteristics that she wanted to pass on to Lex: warm, hardworking, and meticulous. Money wasn't plentiful, but Lex never lacked in family love and support. Although Verdina and Lex's father were no longer together, his mom encouraged Lex to have a relationship with his dad. The two of them spent every summer together, and when Lex's dad passed away in 2010, Lex found peace in their relationship and the knowledge that his father was immensely proud of him.

Lex's relationship with both of his parents taught him to be attuned to habits that develop strength and resilience. Once he was on his own, he used that same power of observation to his benefit: how to pick and choose habits from other people. Lex saw how people balanced certain aspects of their lives, and he adopted the habits that worked for him.

One of the habits he rejected from the get-go was expecting instant gratification. Growing up, Lex saw many wonderful advancements for visually impaired people, like Aira, an app that he now uses to connect with a sighted person via his smartphone camera anytime he needs extra assistance.<sup>2</sup> But with such advancements also comes a shift in how we all operate and think. We have all become programmed to expect immediate results.

"In a way, success is challenging because people look at opportunities and the trajectory of life in the same way," Lex says. "People need to understand that success takes time.



And it's going to take some falling down to figure out how to get back up."

Lex has learned that nothing can be achieved alone. In long jump, every competition requires teamwork. Lex knows that the first step in winning is realizing that you need other people in order to transform your vision into reality.

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On a warm, summer day in London, Lex kicks his leg high into the air, touching his toe to his fingertips. Finishing his warmup, he walks into the holding zone and takes a seat. He hears the familiar sounds of his competitors: lilts of Portuguese among the Brazilian team, stochastic tones from the Chinese delegation. Officials check Lex's bag, ensuring his spikes meet competition standards.

Suddenly it's go time. Lex rises and is escorted into the tunnel. As he walks forward, he feels the concrete beneath his shoes begin to incline. The people speaking in foreign languages around him hush as the group progresses toward the mouth of the stadium, feeling a contagious sense of mounting anticipation. Lex quietly reflects on his preparation — Every. Single. Day. — for the previous four years, all leading to this point.

In the same instant that Lex feels the sun hit his face, he feels the rubberized mondo track under his feet. In a dramatic flash, tens of thousands of people surround him — screaming for him, screaming against him.

The London 2012 Paralympic Games feel like home.

"I started clapping my hands. The next thing you know, 85,000 people started clapping their hands in the exact same rhythm. That was the essence of unity," says Lex. "At that

moment, we all had the same heartbeat. I could relive that moment over and over again.”

Lex’s career in sport is full of impressive accomplishments — most notably, as the best totally blind long and triple jumper in the history of the U.S. Paralympic Movement. In addition, he’s the current world record holder in long jump, a four-time Paralympic medalist, four-time long jump world champion, and eighteen-time national champion.

It doesn’t stop there. Lex is also musically gifted: playing the piano, singing and even recording his own songs. He published his first book in 2020, *Fly*, a memoir. Lex Gillette Day is celebrated on September 25 in both Hagerstown and Washington County in Maryland. And he is in high demand as a motivational speaker, talking to audiences about the difference between sight and vision.

Lex uses the lessons he has learned in sport to create analogies that apply to business and leadership. He takes his experience of leaping blindly into the sand and repurposes that into helping other people leap into new opportunities in their own lives.

His legacy is already in motion. Lex is a mentor for children through Classroom Champions, an organization that pairs elite athletes with classrooms to teach kids important lessons. He remembers how important it was to have his own role models at a young age, and he provides those same lessons he learned — about goal setting, perseverance, and healthy living.

“A lot of us want change, but it has to happen within ourselves. There’s a lot that we personally have to do as we push forward in life,” Lex says. “And a lot of the change we want to see in the world depends on how we raise the future generation.

“And so, working with Classroom Champions and being able to equip these kids with great skills is about wanting to build this world that I feel will produce a lot of success.”

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Lex finds motivation in knowing our time on Earth is finite. His ultimate goal is to exhaust every aspect of his entire being. He wants to soak up every opportunity in life so at the end, he can say that he didn't leave anything in the tank.

He's also driven to leave something on this Earth that wasn't here before. A big part of that legacy is his definition of vision — and our ability to see things before they exist. He wants to open people's eyes and minds to the potential that lies within. And he wants to pay it forward, using everything he's been blessed with to share opportunities with others.

“I want to break down barriers for the next person,” says Lex. “Especially when we look at the Paralympic Movement. Since I started in 2004, I've seen how it has evolved, driven by all these pioneers. I want to help too. The next athletes that come along shouldn't have to fight the same battles. I want to clear up some of those bottlenecks now, to make their lives easier and help keep the Movement flourishing.”

Lex says one of the challenges in the U.S. is a lack of understanding about Paralympic sport. A big part of that is getting mainstream media and corporations to put the Paralympics at the forefront, showing the amazing athletic talents across a variety of sports — from swimmers to wheelchair rugby to sitting volleyball. He sees the Los Angeles 2028 Paralympic Games as an opportunity to change those perceptions and make things explode in a positive way.

“All of these sports have these amazing athletes. When you start to dig deeper, you learn about who they are as humans, and the things they do off the field of play,” says Lex.

“These are the things people need to see. Yes, we have a disability, but that doesn’t inhibit us from any other aspect of life. We’re still successful. We hold down jobs, and support families. We have kids.

“I want the public to see how we’re participating in life.”

Lex knows that to evolve public perception, he must start with his vision for change — an image, a belief, a dream for how the world sees Paralympians. And with that vision, he can change the world.



# JAN BRUNSTROM-HERNANDEZ

*Meant to live*



Based in Texas, “Dr. Jan” is a pediatric neurologist specializing in cerebral palsy care. She has spastic diplegia.



**AN ANNUAL CONFERENCE** at Pacific Lutheran University (PLU) in Tacoma, Washington, brings alumni back to talk with current students. The 2015 keynote speaker, Dr. Jan Brunstrom-Hernandez, a 1983 graduate, walks to the podium to deliver her presentation, titled Meant to Live.

She tells the audience that she has cerebral palsy because she was born three months early, weighing a little over three pounds. Her parents had previously lost multiple pregnancies through both miscarriages and premature births.

Doctors had told her mother that she would not get pregnant again. When she did, the doctors said the pregnancy would not go to term. When Jan was born, doctors said she had no chance of survival. After she did survive, they said that she would never walk or talk.

Dr. Jan Brunstrom-Hernandez, or “Dr. Jan,” as she’s affectionately known by her patient families, is a pediatric neurologist and an internationally recognized expert in cerebral palsy. Dr. Jan understands cerebral palsy because she has been both a researcher and clinician in this field. She also understands it because she has lived with cerebral palsy and has defied each one of those early predictions.

Dr. Jan has the spastic diplegic form of cerebral palsy; it mostly affects her lower limbs, but she has some upper limb involvement.



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Dr. Jan was born in Seattle. She has a sister who is just six weeks older who was adopted at birth. Her parents had pursued adoption before her mother became pregnant with Jan. At that time, one couldn't adopt if pregnant, but a court case allowed the already-initiated adoption process to continue, since the expectations for the pregnancy to reach viability were so low.

Her dad, who always traveled a lot for work, didn't leave the city once for the entire time Jan was in the hospital after her birth. "He came to see me every day and took movies with a reel-to-reel camera through a glass partition." She explains, "When, as an adult, I asked him why he went to all the trouble to take movies of me when he was told I had zero chance of survival, he said he wanted to document that he had a baby girl."

Her mother, on the other hand, couldn't bear to come to the hospital because she didn't want to get attached to another baby the doctors predicted would die. She had had too many losses, including a baby boy who was born prematurely and died the day he was due to be brought home from the hospital. Dr. Jan believes that fear of loss had a lifelong effect on her mother, and on their mother-daughter relationship.

The pregnancy losses over a decade took a toll on both her parents. Of her dad, she says, "The thing that was stuck in his heart, even as I grew to be an adult, was hearing doctors say I had zero chance of survival. That caused such an incredible heartache and sadness in him, which I'm not sure he has ever been able to let go of."

"When I eventually came home from the hospital around two months old, I was not developing normally and was stiff

as a board. Nobody would tell my parents what was wrong. Everything was blamed on my being premature.”

Her parents were overwhelmed. “Thankfully, my grandmother stepped in saying, ‘I’m going to stand her up; I’m going to do stuff with her.’”

When Jan was still a baby, her dad’s job took the family initially to England and then to Australia. England was where Jan was diagnosed, when she was eighteen months old, when a doctor, who was treating her sister looked at Jan’s mom and said, “Do you know that the child sitting on your lap has cerebral palsy?”

Dr. Jan says, “My mom’s reaction was, ‘thankfully, somebody has finally told me.’”

Now armed with a diagnosis, her mom was determined to find ways to help. “She encouraged me to do a lot of standing. She insisted that when I fell down, I would always pick myself up. I had piano lessons to help my weak left hand. She was very against surgery, because she was terrified of anesthesia and also because she feared a bad outcome,” Dr. Jan says. “My mother was strong and very determined, but I don’t ever remember her hugging me as a child.”

Jan attended the Spastic Centre in Perth (one of the locations of Spastic Centre Australia, an organization she would in later life collaborate with as the renamed Cerebral Palsy Alliance). It was there she received both therapy and schooling. Though Dr. Jan doesn’t remember this, her mom credits a teacher there who clearly looked at the whole child — a teacher who believed in Jan and who taught her to read at age four.

“My mother was also a teacher, but because of what everybody had told her about cerebral palsy, she thought I was cognitively impaired. It would be many years later, when I was

graduating from high school at age sixteen, first in my class, that my mother, crying, told me she was very sorry that she didn't fully believe I was okay. Right up to the moment when she found out I was first in my class, she still had her doubts."

Her mom says she should have known better when Jan came home reading at the age of four. But as Dr. Jan points out, "Just because teaching is your profession doesn't mean that you take your blinders off and see your own child objectively."

When Jan was seven, the family moved back to the U.S. Her parents had difficulty finding a school that could provide appropriate education and therapy like they had found in Australia. They tried public school, but ended up sending her to private school.

Her parents went on to adopt two more children. When Jan was sixteen, her parents divorced. Her dad later remarried, and she has a brother from that relationship.

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Jan wanted to be a doctor from the time she was six years old. She started down that path at just sixteen, enrolling in PLU to study for a bachelor of science in biology. She succeeded, but it wasn't all plain sailing. An early academic advisor suggested she "go home and grow up; you're way too young to be in college."

She ignored this advice.

During her senior year in college she applied to medical schools. It was 1983, and discrimination raised its head at one interview. Given her physical disability, she was questioned about her suitability to be a doctor. Would she risk a baby's life? What if she dropped a baby while walking? Her calm and well-reasoned reply to the questions about her disability ensured she passed that particular interview.

Dr. Jan graduated from Virginia Commonwealth University in 1987 and then did her pediatric neurology training at St. Louis Children's Hospital and Barnes–Jewish Hospital, neighboring hospitals in St. Louis. She went on to complete a postdoctoral research fellowship in developmental neurobiology at Washington University School of Medicine, in St. Louis, before joining the faculty there in 1995.

During this time, she married and had a son. She spoke of her joy in motherhood in her 2015 presentation at PLU: “I got to have a baby, even though all the doctors said that I would never have a baby. Why? Not because there was anything wrong with my insides. It was because I had cerebral palsy. When you have cerebral palsy, there's this big box and everything that goes wrong with you gets dumped in this box and people make assumptions. I did have a baby and I gave birth to him in the regular way, and I'm happy to say he is perfectly healthy.”<sup>1</sup>

Dr. Jan's son, Ian, now in his mid-twenties, is a professional musician. Dr. Jan says, “My son is a very good musician. I mean, I'm biased but he's very talented.” She herself is musical, and if she hadn't become a doctor, she says her career choice might have been in the music business. She adds with a smile, “I live vicariously through my son.”

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In 1998, Dr. Jan founded and became the director of the Pediatric Neurology Cerebral Palsy Center at Washington University School of Medicine and St. Louis Children's Hospital, a position she held for over sixteen years.

She had been initially reluctant to start the clinic, despite strong and continuous encouragement from her colleagues. She confesses she struggled to accept her own disability. She

has said that “The biggest reason I didn’t want to start a clinic was because I was too uncomfortable around kids who were like me. I’d gotten so good at ‘forgetting’ my disability except when I fell down and things like that. I also tried to protect other people from my disability . . . I would try to make it okay for them not to feel uncomfortable.”<sup>1</sup>

She freely admits now that the clinic — and especially the children — changed her life. Learning from her patients and families, she grew to accept herself and make peace with her disability. She says, “When I started the clinic, I was working very hard at trying to be good enough. Meanwhile, I had these patients and their families saying to me, ‘Thank you, Dr. Jan. We love you Dr. Jan.’ They would give me hugs and I wasn’t feeling very huggable at that point. They would say things like, ‘You’re so great. You’ve helped us so much.’

“All I could think was — if you really knew me you wouldn’t say that because I’m the crippled kid that nobody ever wanted to go out with, that nobody ever wanted . . .

“I was mad at the world because I felt I had to prove myself all the time and at a different level than typically developing people. I had not only to prove myself academically to be able to be a doctor, but I also had to prove to myself that I could be even better because they’re all looking at my disability. I was this bitter, angry person, but most people couldn’t tell this because I was always putting on a smile.

“But they broke down the wall. They cracked through the veneer. The kids and their families taught me that I can be okay the way that I am — even if I never walk better — even if I never walk perfectly. They taught me unconditional love and acceptance of myself exactly the way that I am. I didn’t have to be one iota better to be loved by them. It was because

of these children and their families that I started to heal and become a real person capable of loving someone else.”

Dr. Jan is quick to point how much, even to this day, she learns from her patients and their families. She is also very quick to acknowledge the wonderful staff who worked at the St. Louis clinic, adding that treating kids with cerebral palsy is a team effort.

As well as the clinic staff, Dr. Jan also acknowledges the great support she received from other colleagues in St. Louis and around the world.

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One of the remarkable aspects of the St. Louis clinic is its sports program for children and adolescents with cerebral palsy. The program offers a wide range of sports — martial arts, swimming, dance, tennis, baseball, volleyball, soccer, and basketball. Camp Independence is the intensive summer sports program, but there are activities year-round. The program is run by a physical therapist, and family members (of both patients and staff) are enthusiastic volunteers.

Dr. Jan says that getting kids with cerebral palsy into sport is very important. “Sport is really great therapy. Learning to play sport themselves also got the kids playing with their family and friends. Sport really opened the eyes of these kids and changed their lives.”

Getting the chance to participate herself in sports was a bonus for Dr. Jan, as she had never played sports growing up. In her forties, she learned to play basketball, water-ski, and dance, and she discovered that certain dance rhythms reduced her dystonia. She got her first bike, a recumbent model, and experienced for the first time the pleasure of riding with her son, and the joy kids get from going fast on a bike.

She emphasizes that “older people with cerebral palsy can also learn new motor skills.”

For the work she did in St. Louis, Dr. Jan was named Outstanding Missourian of the Year in 2007. And two months before she left Missouri for her next career challenge, the mayor of St. Louis proclaimed October 1, 2014, as Dr. Jan Brunstrom-Hernandez Day.

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Dr. Jan now resides in the Dallas–Fort Worth area in Texas, where she moved with her second husband, Ruben, a Texan, to set up her own cerebral palsy treatment center — 1 CP Place. This was the realization of a dream of hers to set up a freestanding clinic with the mission to help young people with cerebral palsy “live their very best, healthiest lives.”

With the help of a very committed team, Dr. Jan coordinates the care of the children and adolescents with cerebral palsy, many whose photographs adorn the clinic hallways. Ruben, who made Dr. Jan’s dream his dream, manages the technology and office administration. (Unfortunately, for now, COVID-19 has curtailed the clinic’s sports program.)

Dr. Jan won’t listen to any negative predictions about any kid with cerebral palsy. She’s realistic and knows that they won’t all do wonderfully, but she says, “I promise you that every single child, every single person can do much better than the negative expectations that have been leveled at them, so that’s what I was put here to do.

“My job is to find all the available information and do a very thorough examination of each kid and figure out what the problems are, what the strengths are and what we can do to help them right now.”

Families have different reactions to learning that their child has a disability. “Some have this ability to accept their child exactly like they are right now,” Dr. Jan says. “They’ll explain, ‘We love our child just like they are. You don’t have to fix everything, but if there’s something you can do to make their quality of life better . . .’ There are also parents who want you to pull out all the stops and make their child perfect. In some ways, I could relate to the latter type because for a long time I worked to be perfect myself — it wasn’t going to happen.

“Parents want predictions from me all the time, ‘Are they going to walk?’ My answer is, ‘Well, we’re sure going to try,’ or if it looks really tough, I say, ‘We’re going to try, but here are the obstacles they’re up against,’ and I explain, ‘Your child will let you know. We just have to wait. We just have to give it a little bit more time and then we will see.’ You have to give the parents time to come to grips with it, and you have to give the child a chance to show what they can do, because the motivation of the child counts for a lot.”

While her priority at the clinic is to treat children and adolescents, Dr. Jan also treats adults, acknowledging the lack of care for adults with cerebral palsy.

In addition to treating all her patients, she considers it her job “to go nag and poke and push all these other doctors and scientists and smart people to do their very best so that we can have more options and more treatments and that, some day, we will have cures!” To that end, she herself has contributed to the research as coauthor of over twenty publications. She has also written chapters for a number of books.

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Dr. Jan speaks directly to others living with a disability, sharing her wisdom from what she has learned herself from having cerebral palsy and later life challenges. She knows that the biggest limitations with having a physical disability are not physical environmental things like curb cuts or inaccessible buildings: “It’s the inaccessibility of most of the world’s minds about what people [with disability] can and cannot do.”<sup>1</sup> She advises people with disability to “just don’t take no for an answer.”

She understands that “everything takes longer. It takes me more time to do the daily life stuff, so I have less time. For example, I’m slower walking, getting dressed, and typing.”

An added challenge for her has been the diagnosis of rheumatoid arthritis, which came when she was in her forties. She says, “It took two years to diagnose because I kept being told that it was due to my cerebral palsy.” It was a hard lesson for this very independent woman to admit: “I finally had to let someone help me. I finally had to say I can’t do it all by myself.”

Through it all, she’s learned a lot of lessons and grown in wisdom:

“Find *your* calling,” she says. “Identify and play to your strengths to be the best *you* that you can be; make the biggest contribution you can to this world, to help people for generations to come.

“It’s not about being ‘perfect physically’ because that’s almost never possible; it’s about being physically fit, healthy, and pain free.

“Live a full life. That includes trying and failing at relationships; going after a dream and risk failing; not having stuff given to you just because you have a disability.

“Never feel shame for something you have no control over. Never feel you can’t be beautiful just because you walk funny, like I do. Beauty comes from within. It’s okay to want to change, it’s okay to want to do things better, once it comes from a place of acceptance, of having made peace with your disability.”

She recalls a time from her childhood that she has never forgotten: “I was around seven and the principal at the school videotaped all the kids at school to show at a fundraiser. I could never truly run, but I could kind of move fast and do this waddling kind of movement. The video clip showed me trying to run down the hall grinning from ear to ear, I’m very happy in the clip.

“When the video was shown, the auditorium erupted in laughter at the scene with me in it. I sat in that auditorium feeling only shame. I stopped trying to run that day, but I never stopped wanting to run.”

The moral of that story is, “The value of a person is not defined by what they look like or how they move.”

Dr. Jan asks, “How do we teach that? How do we teach kids to be strong when they are mocked or bullied? In a world of social media messages going viral, how do we teach them resilience?”

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Dr. Jan has defied the many negative predictions ascribed to her. In helping kids with cerebral palsy and their families, she has found her calling.

*She was meant to live.*

