



Glowing Hearts III

MOTHER & CHILD

CO-WRITTEN BY
*Jeffrey Tiessen &
Kimberly Tiessen*

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“The moment a child is born, the mother is also born. She never existed before. The woman existed, but the mother, never. A mother is something absolutely new.” – Rajneesh

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No Day But Today: Kimberly Tiessen

Storm Trooper: Kimberly Tiessen

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FOREWORD

“God couldn’t be everywhere so He (or She) invented mothers.”
- Unknown

As a child psychiatrist on staff at the Hospital for Sick Children and Holland Bloorview Kids Rehab, I have spent the past 37 years working with children with all kinds of disabilities and/or chronic illnesses and I know how terribly important great role models are to them and to my work. Textbooks and lectures have taught me about their medical conditions, their “pathology”, but not about how to promote resiliency and strengths: this I learned from the incredibly resourceful families I have had the privilege to work with over the years. That’s the first reason why I love the *Glowing Hearts* book series and am particularly excited about this *Mother & Child* edition.

The second reason is that I grew up with a brother with Down syndrome and remember vividly the tears in my mother’s eyes each time someone would stare at Dany as we walked down the street, which happened a lot, as most babies with Down syndrome were institutionalized when he was born, in 1952. If only my mother could have met any one of the amazing moms featured in this book, her journey would not have been as difficult, nor as lonely.

Much has changed in the field of advocacy and disability in the past 60 years, but what hasn’t changed is the fact that young families raising children with disabilities also need great role models to inspire and guide them. There are many, many different ways of fostering self-esteem and autonomy in children with disabilities, as you will read in this remarkable collection of interviews!

“One good role model is worth a thousand shrinks” and the *Glowing Hearts* series is a treasure trove of terrific role models.

Arlette Lefebvre, MD, FRCP, OOn, CM

Staff Psychiatrist,

Hospital for Sick Children and Holland Bloorview Kids Rehabilitation Centre



*“Do not fear the winds
of adversity. Remember:
a kite rises against
the wind rather than with it.”*

- Unknown

INTRODUCTION

“I have experienced a mother’s love twice, the first was my mom and the second was the mother of my children, and I pray to know it twice more in the mothers of my grandchildren.”

When I first heard of Disability Today Publishing’s book series called *Glowing Hearts*, which premiered its first title *Play to Podium* in conjunction with the 2008 Beijing Paralympic Games, I really thought that it was too cliché, all warm and fuzzy, too much like a Disney film.

Most of the youth that I have known over my 30+ year career of coaching athletes with disabilities were equally familiar with *broken hearts*... almost qualifying for the team, finishing second or just out of the medals in fourth, or struggling to survive on piece-meal funding while pursuing their athletic dreams. Or finally finding that perfect stride or stroke only to be derailed by an injury. The perfection to which they aspire lives on a tight rope, and is only attained by maintaining the fine balance between too much and not enough in an extreme training regimen. *Glowing Hearts* was just too pretty of a term.

However, Disability Today’s publisher is a professional of the highest quality and four years after the launch of the first installment in the *Glowing Hearts* series comes the third... *“Mother & Child”*. I’m not surprised really. I know this guy pretty well. He survived losing both of his hands and still found a way to rise to prominence as a writer, a publisher and a Paralympic athlete. Just getting on with life would have had people admiring him and telling him how courageous he was and what a motivational force he was regardless. But that’s not his nature and his story isn’t for Disney. It’s up there somewhere between RUDY, Chariots of Fire and Apollo 13.

He is tough, but after his injury at age 11, he had to find a path back to a life he envisioned for himself when his only compass was his heart and the hearts of those who loved him. Maybe there was a “Glow”, maybe a spark that couldn’t be extinguished even by a catastrophic injury... a spark that could only burn brightly if kindled by parents and siblings who had to be as tough as he was. Their strength and courage and motivation could help him find a new path, maybe a path that could lead to excellence.



Maybe that is worth writing about, I thought. Who are these moms, the ones who wield such love that they forge paths where none exist? The ones who see far beyond their child's impairment or limitations, and into the land of limitless potential that exists within every child. The ones who foster growth, and skill development and happiness with a vision of what is possible, not what is not. I've met these moms. In fact, several of the moms celebrated in this book I have known for decades. Their love and support and discipline is unrelenting. A fire burns in their chests too, often so intense that others can feel its energy. Can those stories be told? You be the judge, but I knew if anyone could do them justice it was Jeff Tiessen and his co-author, and sister, Kimberly.

None of these remarkable stories is about a quick fix. There have been no simple answers. Never a battle won to end the war. Always one triumph leading to another; for example, at school to home to the community gym, pool or arena... one small victory led to another.

Either mothers on their own or families who learned to stick together, one thing was the same: they celebrated achievements that most others could never understand. How hard it must be to watch a child fail one hundred times learning to do it themselves when it would be so much easier to do it for them. To see a child heartbroken when simple inclusion and accessibility was denied to them. What was it like when their own brand of excellence was first achieved and recognized? Was it when some form of personal independence was achieved?... like dressing themselves, feeding themselves or riding a bike long after their peers had mastered these basic skills. Was it in a swimming pool or on a basketball court? Was it when they realized that their dreams were possible? Was it when a mom, or a dad of course, resolved to believe that their struggles were not only worthwhile, but essential for success?

The stories you will read in *Mother & Child* will inspire. But most importantly, they will encourage a new generation of mothers and fathers, teachers and coaches, to realize that the battles they fight can be won and the victories, most rewarding.

Joe Millage

Coach. Mentor. Advocate.



AUTHOR NOTE

“Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next.”

– Gilda Radner



Writers tell stories. Other people’s stories. I’ve told a thousand of them. It’s a charmed trade really, inviting yourself into the lives of others like a long-lost relative who’s just arrived back in town. It’s a special title, a freedom to pry where no stranger otherwise would have the right. And it’s an important craft, actively listening, correctly interpreting and sharing precisely what you heard. Sometimes it’s easy and sometimes it’s hard.

This book was both easy and hard. Easy in the sense that its inspiration has been in me for 35 years, ever since my own mother joined the sorority of special needs moms. Easy in the sense that in my work, never am I so moved and motivated than after an honest-to-goodness exchange with an extraordinary mother of a child with a disability.

And easy with respect to the fact that this book was inspired by the overwhelming response from parents to the first two books in our *Glowing Hearts* series, and so with *Mother & Child* we depart from our “for kids” format to serve up an enlightening resource for moms (and dads) raising a child with a disability.

But it was hard too, a unique challenge and an ultimate responsibility to do justice to the most personal and heartfelt anecdotes shared with us. We were expected and trusted to do so. And I truly believe that we delivered a collection of inimitable stories, each with constants and contrasts, that reverently celebrates 10 magnificent moms through their triumphs, trials and tribulations, joys, fears, hopes and dreams.

“Our” moms, like all moms, celebrate accomplishments and relish in their child’s smiles. But with a constant eye fixed on the next challenge ahead of them, they are most inclined to cherish the smallest of victories. Incredible women. Remarkable stories.

How would I sum up this anthology? Many things have changed for parents of kids with a disability over the last three decades. But one thing for certain has not, and that’s the impact of attitude. To borrow fitting words from evangelical pastor and author Chuck Swindoll: “We cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude. I am convinced that life is 10 percent what happens to me and 90 percent how I react to it.”

Thank-you mom.

Jeffrey Tiessen

Son. Advocate. Author.



AUTHOR NOTE

“Being a mother is learning about strengths you didn’t know you had, and dealing with fears you didn’t know existed.”

– Linda Wooten



It’s not hard to sum up what I’ve taken away from contributing to this book. I am a mother too, and I would do absolutely anything for my child. I’ve had to make some really tough decisions in my life that, at the time, protected her from things that scared me. And then there were times that I had to let go of that fear so she could blossom.

Being a mother is one of the most difficult and rewarding jobs all wrapped up into one. The responsibility we hold as their guiding light is overwhelming at times, and very much worth it at the end of the day. I know I have taught my daughter to be kind and considerate and that the world is made up of people with all kinds of differences. Some look the same as us, some do not. I’ve taught her that if everyone on earth were the same, how boring would life be. I have taught her not to be afraid of people who are different but to embrace their uniqueness and accept people for who they are.

The mothers whom I have had the pleasure of interviewing for this book are amazing people. The devotion of each, in their own special way, is their gift to their children. I thank all of the mothers in this book for the gentle reminder of the precious souls we hold in our hands every day.

What I found most fascinating about these stories is that the underlying messages from each account were identical... a mother’s love is unlike any other, and mothers of children with disabilities desire the same things for their kids as any mother. We all hope for them to experience the best life possible, with ample opportunities for emotional, physical and social growth. We strive for them to be happy, loved, kind to others and above all else, accepted. In simple terms, as one mother suggested: “You get what you give.”

I know for certain that the twists and turns that one’s life takes along our meandering journeys of discovery have purpose. People weave in and out of our lives for good reason. It’s evident from the narratives in this book that these remarkable women, for the most part, didn’t accomplish what they have in their children alone. There were “angels” along the way, as my mother shared so appreciatively, who supported them. The opportunity to contribute to this very special book was a gift for me. I trust that you too will recognize aspects of yourself within these pages, and find comfort in it, and be encouraged to always celebrate your gift.

Kimberly Tiessen

Mother. Photographer. Author.





Guiding Light

She is her son's eyes. She is his guide. His teacher. His friend. A mother of three. She praises those who help her. She walks away from those who won't. She's made mistakes. She's found solutions. One day at a time. This is how she did it.

There is a calm about Cheryl Hampson that does not befit all that life has given her to worry about. There is a gentle smile and a soft, gracious voice that lulls one to believe that this forty-something stay-at-home mom has not yet met real adversity in her life. Pragmatic and ceaselessly positive, life for her is good, is the impression she hands you.

Life for Cheryl Hampson is good. She has made it that way. In fact, in a wrench of fate, adversity itself showed her the way. And make no mistake, this mom of three teenagers has accepted more than her fair share to agonize about.

Robert Hampson is the middle child of Cheryl and husband Philip. On the day of his younger brother's birth, his parents learned that their second child was losing his vision. Robert, at age four, underwent major surgery and came out blind as a result of a brain tumor.

Life, in an instant, had ushered into the Hampson's home uncharted challenges apart from the obvious of a new baby, a newly blind child and the effects on a six-year-old sister. Guilt, resentment and fear pulled up a chair.

"There were times when Robert needed so much attention," Cheryl remembers. "It seemed like the baby took all of the rest. I felt so guilty that there was little or no time left for Robert's older sister. She needed lots of time too."

While many parents feel that there were things they could have done to prevent or lessen their child's disability, Cheryl included, she describes how she moved past that guilt. "I just don't think about how I could have done things differently anymore. What really matters right now is what I am doing today and what I am going to do tomorrow."

One of the things she wished she would have done differently was to find a way to balance the needs of all her kids more quickly. Robert received different attention and his older sister could not help but feel resentment toward her younger brother.

CHERYL HAMPSON'S DARING JOURNEY FROM DARKNESS

That delicate balance of making sure each child got the attention they needed was difficult. A lot of work had to be done later with their eldest child, when there was more time, to show her they loved her just as much. In time, she did a complete turn around and has come to really admire Robert.

"There were years when we just weren't that fantastic as parents," Cheryl concedes matter-of-factly. "There was no parenting manual for us. If it takes a village to raise a child, the same goes for parents of kids with a disability. In time we realized we needed to learn from others." Her advice to other parents: "Reach out for help right away."

Cheryl acknowledges that Robert's growing up with a disability has in some ways been very good for his siblings. Her daughter, for instance, volunteered for a one-year humanitarian sojourn in Africa and Peru, teaching and helping in crowded healthcare clinics. "Both of Robert's siblings have a heightened sensitivity, understanding that there are people in this world with greater needs than theirs that they can help." Philip and Cheryl's parenting mantra was always "keep it positive and foster regular sibling relationships."

Shortly after Robert lost his sight, his mom watched him climb up onto the kitchen counter when he thought no one was looking. He was determined to sneak a cookie snack before dinner. It was an epiphany moment for Cheryl who struggled with her instinct toward being over-protective of this child. "I suddenly realized that he was still just like any other kid in many ways and needed to be treated that way. I still have to work very hard not to be over-protective," she confesses. "There will be enough barriers in his life... I don't want to make more for him... but it's a balancing act between keeping him safe and giving him the help to succeed, and backing away so he has opportunities to solve problems himself."

One of Cheryl's most difficult decisions was backing away from the formalized education system. School wasn't working for Robert. It wasn't working

"I was so young that I didn't understand what it meant to be blind. I asked my mom when morning would come. I asked my dad to turn on the lights. I went outside. I just couldn't understand why it was dark all the time. I bumped, crashed and ran into a lot of things - brick walls, metal poles, doors and trees. I fell downstairs, tripped over curbs and walked off the end of our dock at least three times. But I never gave up. These days nothing stops me. I use my hearing to see."



academically and it wasn't working socially. Cheryl couldn't stand the thought of the indelible scar this could leave on her son.

A very bright young student Robert was, but the school system frustrated him. He didn't get the stimulation he needed. He was bullied and teased. He got into trouble. He'd test his specialized education teachers and their means of punishment by tossing objects to the floor. Twice Robert was tossed to the floor with arms clasped behind his back in consequence – once after throwing a banana – an adult reaction that Cheryl to this day believes would be unimaginable in any regular classroom.

“At first I tried to change the system,” she recounts. “But I was spending an enormous amount of energy for only incremental gains. My husband suggested that those hours would be better served by giving them to Robert.”

She agreed. “I decided I didn't need either of the schools we tried and left. “I learned Braille, and with the support of the school system in the form of getting the curriculum from the school board and a weekly visit from an itinerant teacher who was a Braille specialist, we did it. It wasn't perfect but we were successful.” Cheryl allows that her approach is not for everyone. “I hesitate to advise other parents to do the same because not everyone has the opportunity to do that – fortunately I did.”

Cheryl declares making some mistakes herself in Robert's early education and learning from them, wisely taking a new tack with his return to school in grade nine.

“Go in as a friend and not an adversary,” she recommends. “That's a big mistake I made in the past. It never helps. Even if the educators agree to work with your child under confrontational conditions, how will they treat your child afterward?” Cheryl understands that a gym teacher, for example, who suddenly has a child with a dis-

ability in their class may feel overwhelmed. “I always go in with the approach that ‘My son is a great kid. I will help you in any way I can. Let me know what I can do for you.’ When they know they have my support and know that I understand that we all make mistakes, and can fix them, it'll be a better experience for all.” Sometimes however, you do have to be more assertive, Cheryl offers, “but pick those battles carefully. And without fail,” she adds, “thank those who have done a great job for you.”

Robert's physical health has always been a priority for the Hampsons as well. It doesn't take much imagination to envision how the loss of sight limits physical play opportunities – running activities primarily. Cheryl and Philip spent four years searching out programs for Robert. But even in Toronto, the big city that it is, there is a very small population of kids who are blind, and so, experiences with those kids where sports and recreation activities are concerned are very minute too.

Cheryl could find nothing for Robert. Wheelchair sports were not an option. Some community programs wouldn't accept a child who is blind. Others insisted that the Hampsons bring their own assistant for Robert, even though they accommodated kids with a disability. A decade removed from those frustrations, Cheryl says things have changed for the better with many more programs now being inclusionary.

The Hampsons' exhaustive search did turn up a perfect match for Robert, and he's never looked back, or elsewhere, for that matter. Variety Village in Scarborough, Ont., had a different approach... come one, come all. This fully accessible sports and recreation facility did not discriminate among its members – able-bodied members of the community were welcome too. It is a great community melting pot for kids and adults of all abilities. At age eight, Robert decided to join the Variety Village Flames swim team.

“I will never forget that moment he walked onto the pool deck with coach Vicki Keith, a renowned marathon swimmer,” Cheryl tears. “That was the day his life changed forever. The other kids were so excited he was there. He was treated so kindly and respectfully. And he had so much fun!”

Every success, no matter how small, is recognized at Variety Village. In the pool, Robert was no longer the kid being teased, being bullied, or the one finding trouble. Robert was a swimmer, the pool his “worldly oyster” and a child with goals and dreams before him.



Achievements came fast and furious and Robert celebrated them.

He shared his life through Variety Village's Ambassador Speakers Program. "Social skills are so important for people with disabilities who want to fully integrate into the community," Cheryl has observed. "You can talk your way out of a lot of things," she laughs.

But more than the social experience Variety Village has afforded Robert, and his siblings who join him there regularly, the program has motivated him to dream bigger and reach higher. He quickly tasted a new-found freedom, and hungered for more. He was confident he could do a lot more and although sports like basketball and soccer proved too formidable, he discovered skiing, cycling, rock climbing, sailing and ropes courses, goalball, judo and wrestling. He learned to scuba dive, water-ski and sky dive.

Robert has accomplished more before his 19th birthday than most adults have in their lifetime. But that sated scorecard is less about the Hampsons' adventurous spirit than it is about their pragmatic conscience. "We just get it done... there were times when we just didn't know if we'd have that chance again," Cheryl reluctantly shares. "Robert may not always be with us and that's a very sensitive issue for our family. How do we cope with that? Denial has worked really well," she jokes. "Actually," she chimes without pause, "you just make sure every day is really great... we really do live that way. If there's something Robert wants to do, we don't wait until next year, we do it now."

Cheryl maintains that they were once the average family, but Robert has made sure they are not.

"Robert has given us such a different perspective on things and we're doing things we never imagined."

But as Robert matures into a young man, new sets of problems need his attention. "He's always recognized that he has obstacles because of his blindness but couldn't understand why anyone would think it would stop him," reveals Cheryl. "But he's seeing the light now, so-to-speak, that things like... driving a car... isn't in his future - at least not legally," she chuckles nervously.

He also understands that being a person with a disability, and a minority of one in his high school, comes with dubious celebrity. "We both understand - like it or not - that the minute he walks out our front door he is an ambassador for



every person with a disability, particularly those who are blind," explains Cheryl. "Robert realizes that he always needs to be on his best behaviour because those who come after him will be judged based on what people think of him. It's a burden, but at the same time you can take that burden and flip it around. We're taking this golden opportunity to educate people one person at a time, removing the fear of the unknown and putting them at ease." Cheryl is quick to qualify that a smile and a lot of patience are required for this voluntary job, just as hard hats and steel-toed boots are fixtures on a construction site.

It's still all about one day at a time for the Hampsons, but their thoughts do slide toward Robert's future more and more. "I believe that Robert's ability for social interaction will make him the happiest in life and give him the most opportunities," professes Cheryl. "Friends. Sleepovers. Self-advocacy. There will be letdowns. But I see myself as always being part of his life." His Guiding Light.



MY BEST DAYS By Robert Hampson

The most amazing thing happened to me last year! I went to swim practice at my school. This may not seem amazing to you, but it is to me. Maybe I should start at the beginning.

I had to learn how to do everything without sight – walk around without bumping into things, get dressed, read and write, use a computer. Imagine putting on a blindfold and eating a spaghetti dinner? Remember! No peeking.

Another thing about being blind is that it can be hard to get enough physical activity each day. There aren't many places that you can run full blast without getting hurt. You have to be innovative.

My parents had a hard time finding sports leagues for me to join. But when I was eight, one swim changed my life forever. My goal was to swim across the lake at camp. It took me two and a half hours. I was so dizzy when I got to the other shore but it was so worth it! I was so proud of myself.

I told everyone about it. Then someone told me about a famous marathon swimmer named Vicki Keith. She had a team for swimmers with a disability at Variety Village.

My first day on the swim team was one of the best days of my life! I couldn't believe it! The other kids were all calling out to have me on their relay team. Nobody at school had ever wanted me on their team. I was so nervous. Vicki treated us all with such respect. This was one of the first times in my life that I had found a place where it didn't matter that I was blind.

I love swimming because I don't have to feel for things in the pool. I know that I won't trip over any rocks or walk into any trees. But most of all, I love feeling strong and fit.

I enjoy a lot of different sports now. I downhill ski all winter long. Someone goes behind me and calls "right, left, right, left, tree, hill, woops, SORRY!" In the summer I canoe, kayak, sail, boogie board and do archery (yup, bows and arrows). I rock climb. No fear of heights... the ground doesn't look that far away to me! I water-ski and scuba dive. I've even gone sky diving once.

That sounds like quite a story doesn't it? Maybe it's important to tell you that by the time I was 12 years old I had spent four and a half years of my life

in chemotherapy. My tumor grew back three times. That meant about 1,000 needles, 25,000 pills and three operations. I've had more of each since. Sky diving just didn't seem all that scary to me after all that.

It's still amazing to me how small things in life can make a big difference. Like respect and kindness. Do you know what I want most in life? It's to be treated just like everyone else.

The most amazing thing happened to me last year! I went to swim practice at my school. That may not seem amazing to you, but 10 years ago I probably wouldn't have been allowed to join.

When I arrived at my first practice the coach said: "Glad to have you on our team. Is there anything you need or anything you would like us to do?" That was one of the best days of my life!



“Life’s challenges are not supposed to paralyze you; they’re supposed to help you discover who you are.”

– Bernice Johnson Reagon



Mother's Intuition

“My strength and my willpower come from my mom. Everything I’ve learned about standing up for myself comes from her. She’s a rock. She’s my best friend. I kiss her hello and I kiss her goodbye. I don’t care that my buddies think that’s not cool for a 21-year-old. She gives me trust and freedom and room to make mistakes. She encourages me to be my best and never quit. She’s my inspiration. She is why I am who I am.”

A touching tribute from a son who needed his mother’s unwavering strength in ways far beyond what most find imaginable. Accolades born out of a mother-son bond that has been cemented by tumultuous times and shared triumphs. Homage to a woman who has been both mother and father to him, balancing nurture and nature on their remarkable journey to here.

Who is this mom? She’s Shayne Smith’s mom, a selfless identity and place in the world that attests to her parenting success. A mother who nearly lost her only child at just six months when his body was ravished by Meningococcal Septicemia, an unforgiving bacterial infection in his blood. The doctors saved his life but not the ends of three limbs and part of his one remaining hand. A mother who raised that child as nothing more or nothing less than a regular kid, only to watch an extraordinary child ripen into a compassionate young adult.

Who then is Shayne Smith’s mom? She is Jo-Ann Milner, a single parent and driving force not only in her son’s life but in the lives of other mothers, and fathers, with kids with disabilities. Resolute in her opinions and fearless in her resolve to express them, she has soldiered through medical hazes and school mazes for her child, leaving a path behind her for others to follow. She credits her son wholeheartedly for the woman she became.

“As strange as it might sound,” Jo-Ann admits, “Shayne was always just a regular kid and my philosophy was always to be grateful for that. Parents ask me all the time how I coped, how I managed. Honestly, Shayne made it much easier for me. He was always happy. Never complained and woke up every morning with a

JO-ANN MILNER LEARNS TO TRUST HER INSTINCTS

smile on his face.” She’s quick to qualify: “Don’t get me wrong; we certainly went through rough patches during puberty and the teen years.”

The outside world was not so affable. It unfailingly reminded Jo-Ann that her child was not a regular kid at all. Instinctively, she couldn’t help but become blindingly aggravated with the gawking, the intrusive questions, and the tears in strangers’ eyes. “I often reacted in a negative way. I couldn’t help it. I’m a mother and mothers want to protect their child. But Shayne would comfort me... ‘It’s okay mom,’ he’d say. Shayne would show the most patience,” she continues. “He’d take time to answer their questions and always end with ‘...and I’m happy to be alive.’ My son taught me how to handle these situations with courage, patience and kindness.”

Jo-Ann recalls a conversation with one of Shayne’s teachers that served as a defining moment in her attitude and perspective as to who her son was to those who actually knew him. “I remember complaining at one point about how many birthday parties he was invited to,” she confesses regrettably, adding that as a single working mom with a child with a disability, time and patience were often in short supply. The teacher told her to stop complaining. “Some kids have never been invited to a birthday party,” the teacher said.

That conversation gave Jo-Ann a lot of strength to let a lot of things go, but not the tight grip one would have expected her to have on Shayne’s childhood. While there is a strong tendency for parents to treat their child with a disability with kid gloves sometimes, that was never Jo-Ann’s approach. “I’ve actually always pushed him to be very physical,” she shares. “I didn’t want to hold him back. And I wanted to ensure he’d push himself, especially with physical activity.”

Shayne Smith is unique. Look past his physical differences – absence of most of three limbs and part of the fourth and the distinct scars on his face – and you see an engaging, confident, socially mature young man with an “old soul” as one popular TV news anchor reported. He has enjoyed several long-term relationships with wonderful and beautiful women, worth mentioning only because many would believe that such physical differences would preempt others from seeing him as interesting or attractive. Shayne proves to be both.





Being born and raised in South Africa, Jo-Ann has always loved and played sports and wanted the same for Shayne too. “We were fortunate to have integrated programs in our city [Toronto] affording Shayne swimming opportunities, horseback riding, adapted tennis and ultimately sledge hockey and wheelchair basketball, his first love,” she details. “When he’s playing competitive sledge hockey or wheelchair basketball or play fighting with his cousins, I’ve never had the temptation to run to his aid when he’s fallen... and with only one hand to brace himself, he falls hard!”

“My mom has been burdened with having to play the role of both my mom and my dad,” sees Shayne. “The mom might want to run out onto the court, but her dad role forces her to sit tight.”

His parents separated shortly after he got sick as an infant. “When Shayne got sick his dad could not cope in the hospital,” she offers with no contempt. “I knew Shayne was in for a long journey, so I told his dad that we weren’t coming home to him. We were done. I had a sick child and I could not take care of a sick adult too. Shayne and I moved straight from the hospital in with my mother.”

Shayne attended regular school. The school system ultimately adapted to him, but not without struggle.

“When you have a child with a disability you have to fight for everything,” Jo-Ann maintains. “The school system certainly taught me that. Literally, it was a battle every step of the way. I can’t count how many schools we went to that either didn’t want him or weren’t accessible or whatever, until we found one that was very accepting.” Even so, there was a teacher in that school who left her position there when she heard Shayne was going to be in her class. “This was fifteen years ago, and ADD and ADHD were the catch phrases of the day,” she recounts. “I’m sure she had dealt with behaviour issues. All that she was getting with Shayne was a great kid missing a few limbs.” Jo-Ann told the principal, simply and as a matter of fact, that “missing out on having Shayne in her classroom is her loss, not ours. She can go on her merry way.”

Jo-Ann acknowledges that she’s never been reserved about speaking her mind.

“I open my mouth, question things and dig for answers. I’ve learned that you need to push and push for what you want.” But she also recognizes that there are parents of kids with disabilities who can’t bring themselves to do that. “There are parents who are absolutely terrified to take one step in the wrong direction for fear of compromising the services or funding that their child is receiving,” she observes. “They are grateful for that funding and don’t want to do anything that could jeopardize it. I sit on several Parent Advisory Committees so I can help those who are not as vocal as I am.”

She informs these families that no one is going to take anything away from them because they asked questions. “The health care system is daunting for anyone. If you can’t do it yourself,” she advises, “get someone who will speak for you – an advocate, another family member or your minister for example. Or go to disability-specific organizations like the spina bifida or cerebral palsy associations for help. You have to speak for your child,” she adds. “When they’re little they can’t do it for themselves. You cannot be afraid. Sometimes you have to be a thorn in someone’s side to get something done.”

When Shayne was first in the hospital, 20 years ago, parents weren’t allowed to stay in the room with their kids overnight. “I simply said ‘I’m not leaving so get me a cot.’ I said, ‘Hello, there are eight kids on this floor and two nurses.

I'll be here to ensure my child gets attention when he needs it." Today, Sick Kids Hospital in Toronto has family rooms with permanent bunks in the rooms for parents.

Jo-Ann's advocacy for other parents is in part the product of help she benefited from during the acute period of Shayne's trauma. "If it were not for the War Amps of Canada I would have floundered for who knows how long wondering, 'Oh My God, how am I going to get through life?'" she remembers. "I heard that they offered peer support to parents of amputee children. I contacted them and told them straight: 'I'm going through a very traumatic time. I need to meet a family that is very gentle. I don't need some rough and tough bunch right now that'll tell me that everything's going to be all right, and whatever.'"

The War Amps sent a family to visit Jo-Ann in the hospital to share what life was like for them. Their son was born without limbs and was older, which wasn't exactly the same situation Jo-Ann and Shayne were in, but they talked about regular school, regular lifestyles and regular relationships with others. It was a glimpse into the future for her. "And they simply said... 'you'll see, it'll be the same for Shayne too,'" Jo-Ann recalls, and then recites their departing words. "As long as you act like he's a regular kid, other people will see that he's a regular kid."

Jo-Ann joined the War Amps in a program now known as Matching Mothers as a way to return their favour to other moms, new to being a parent of a child with a disability. "Shayne does all the work actually," she admits. "In he comes into their homes and their lives as a fun-loving, active kid, bouncing from the floor to their couch with so much zest and life. He empowers the kids we meet and their parents are so happy to follow suit."

When asked about mistakes as cautionary tales for other parents, Jo-Ann doesn't hesitate in pinpointing a lingering regret. Her concern for her son's education, coupled with his learning disabilities, provided Shayne with a classroom assistant. "My biggest mistake was fighting to keep her with him through each school year all the way to grade eight," Jo-Ann declares. "It made it too easy sometimes. It would have served Shayne better if he would have had to muddle through on his own at times." Shayne admits his assistant was a big help in doing the tough work that came with the latter grades of elementary school, a habit or pattern that grew out of their familiarity with one



another. And when high school came and she was gone, he was lost and some failing grades followed. "I wish I would have seen him struggle earlier on is what I'm saying," she qualifies.

Jo-Ann sums up her parenting journey thus far this way. "There's a maternal instinct to be overprotective. All parents can be overprotective, but the tendency is greater when you have a child with a disability. You have to let them fall down and pick themselves up. You just have to. They know you're there for them. But someday we won't be. Let them go."





Battle Tested

There comes a time, a calling, in some people's lives when enough is enough. A time that either anxiously calls for action, or comfortably assures that all that could be done has been done. Thirty years ago Donna Trella could bear no more. It was prejudice, segregation and frustration that pressed her into battle. And she never retreated, until now.

Donna Trella's corpus of service to the disability community, specifically kids with special needs and their families, spans three decades, book-ended by her own call to retreat from the not-for-profit world. But make no mistake... it was a career not nearly as serene as it may sound. Inexhaustible, Donna was always more entrepreneur than advocate, more radical than conventional. She departs her post as the only executive director her organization has ever known and, as one of the most prolific fundraisers Canada has ever known. Since 1983 Donna has spearheaded nearly \$65 million for kids with disabilities through her charity, Reach for the Rainbow. Such an encompassing devotion however, did not come without expense - war-wounds - for her and her family. And yet for Donna, this legacy is not veiled in any regret: "I did it for Dove," she shares.

"Let me tell you about Dove," she initiates. "She's a beautiful girl, with a wonderful spirit, who engages everyone with her captivating smile. She can only walk when someone is holding her hand. She can't feed herself, dress herself, brush her teeth or comb her hair. She can't tell me when she's in pain or when she's unhappy. She lives with life-threatening seizures, and I have come to accept the fact that there is always a possibility that she will not come back to me at the end of an episode."

Dove was born in 1979. A difficult delivery resulted in physical and developmental disabilities, but Donna envisioned her daughter growing up with the same opportunities available to other children. She was wrong.

"Those were really different times," Donna explains. "They were segregated times and your life really belonged to the hands of the professionals. Children with

DONNA TRELLA PIONEERS FIGHT FOR INCLUSION

disabilities were undervalued, shunned, hidden or institutionalized. They were referred to as mentally retarded, profoundly handicapped, and other derogatory terms identified by disability,” she laments. “Parents of a child with a disability were not encouraged to have an opinion. We were told what was best for us. More often than not we were told that institutional care was the answer. Parents were not encouraged to raise their child with a disability at home. The battle was just beginning.”

Donna knew how to be a mother of a child, but admits that she didn't know how to be a mother to a disabled child. Not by her own shortcomings, but by what was being dictated to her. “It was my vision that my angelic child who I put to sleep at night was going to be able to wake up to greet the next day like every other child. But that wasn't the case. She was forced to go to a ‘special school’ for children like her – a segregated nursery school. That directive was given to me with Dove's diagnosis in the hospital setting. Dove was labelled. Those were my orders.”

Although Dove had a developmental disability from birth she didn't display any immediate signs, and at first attended a regular day care. But repeated seizures exacerbated her disability and left residual damage in its wake. Now a single mother, Donna and Dove's daily destinations alternated between day care and hospital care. And once the formal diagnosis was made, and the official words “mentally retarded” were applied, Dove was “kicked out of ‘school’



“When I was young, an only child for nine years, I wanted a brother or a sister. I was blessed with a sister. Everything was cool for the first months, but then my sister had her first seizure and everything we knew as normal changed. It was tough. All of a sudden she was not only the centre of attention, but needed all of the attention. I remember doing my homework in her hospital room night after night. I remember how sad I was when I couldn't do something fun because Dove was ill. I remember how tired and scared my mom was. But I look back and see what that experience taught me. My sister had a profound effect on everyone she met. Things were hard, but because of it, I'm more compassionate, more tolerant and more understanding. Looking at the world through Dove's eyes makes a hard day much easier. She's an amazing spirit. I'm proud to be her brother.”

at the tender age of three,” Donna derides, “and told to go to a school for children *like her*.”

Donna was devastated. Dove's new day care was populated with children ranging in age from 18 months to 14 years. “The only thing it didn't have was bars on the windows,” Donna describes with disdain. “It felt to me like a prison cell.” Her breaking point, her enough is enough moment, was looming.

Dove loved Ronald McDonald, the fast food chain's iconic clown. Donna set about orchestrating a “Golden Arches” party for Dove's fourth birthday, her first to be celebrated anywhere other than Toronto's Sick Kids Hospital. She called the school to share her big plans and ask for addresses



for her invitations. Nothing came. She asked again. The director told her that the addresses were confidential. Agreeably, she provided the invitations to the school to be sent home with the kids. Not one family replied. The invitations, in fact, were never sent home. Donna wanted answers, only to be comforted with: “Look Donna, Dove will never know the difference. Just have a little party with her family around her.” Donna was distraught. “I was despondent,” she remembers. “To me she was perfectly normal. Even though she had a diagnosis, I didn’t know what that meant or what to expect of it. There was no internet and there weren’t a lot of books; and support groups were all ‘woe is me.’ My glass was still half full.”

A breakthrough came with Bill 82 – an education act mandating the right to mainstream classrooms for all Ontario children. Up until that point, segregated schools were the norm. There were integrated schools, but only for those who were higher functioning. You would never see a profoundly autistic child in an integrated classroom. Or a child that was severely physically challenged. That was incomprehensible. “With Bill 82 came war,” Donna recalls. “Nobody knew

what to do with it. Everyone was up in arms. You could not pick up a newspaper without an opinion piece that resonated resistance like: ‘I don’t want a group home in my backyard’ or ‘I don’t want these children in my classroom.’ The only voice that our children were going to have was our voice. So we as parents had to be very militant, very vocal and very in-your-face.”

It was a historical crossroads that Donna hopes is not lost on the generation of special needs parents that have followed her and her contemporaries, a generation that prospered from the inclusionary pioneers of the 1980s. “Parents need to remember that they are part of a bigger picture. What they have today wasn’t given to them on a silver platter.”

Armed with Bill 82 and the promise of integration Donna reached out to her school board. She felt as if she’d be thrown a life line. Dove would go to a regular school. Could it be that simple? She quickly found out that “they had put the cart before the horse. The compassion was there,” she recognizes, “but nobody really knew what to do with the children.” Nonetheless, Dove was going to regular school.

Then came the altercation. “Not appearing typically ‘disabled’ Dove got into a bit of a situation with another child,” as Donna puts it, “at a popular city park.” She was four. “The dad reprimanded me for not reprimanding her. I explained but he didn’t understand. I explained, in the vernacular of the day, that she was mentally retarded. His response? ‘Well lady, if your kid is retarded why do you have her here?’ It was the first time I’d actually cried.”

That was the start of Reach for the Rainbow. “I was driving home with Dove and wondered what she would say if she could speak. Would she say ‘Mom, what are you doing throwing me to the lions; no one wants me there.’ That’s when reality occurred to me – you can’t legislate attitudes; you have to change them one person at a time. And that’s what I went about doing.” Dove was the spark, but it was one parent’s rebuking of her daughter’s right to participate that fuelled Donna to embrace this exclusionary attitude as a challenge.

Donna and a friend approached Ontario Place, Toronto’s premier cultural, leisure and entertainment parkland, during its zenith of popularity in 1983 to suggest ‘a day of integration’ that would raise the awareness of children with

disabilities... a celebratory day for thousands of families, including those raising a child with a disability, to come on Victoria Day to enjoy all of the inclusive festivities. Mountains were moved to ensure that all needs were met, including most importantly, positive and welcoming attitudes. For seven more years Reach for the Rainbow Day became a magical day – when it seemed that disabilities and exclusive values were parked at the front entrance of Ontario Place. Donna gives the facility top marks. “Politically it was a good thing for them to do, but it was a contentious issue.”

From Donna’s dedication and guidance grew an organization determined to bolster awareness and to expand inclusive programs in Ontario. In 1987 Reach for the Rainbow (RFTR) introduced its integrated summer camp programs. Rather than design another children’s camp, RFTR worked to support and modify the structure of established camps to provide inclusive opportunities for children and young adults with disabilities. In turn, parents are able to enjoy much needed family respite, knowing that their child is growing and learning in a typical setting, with enriched care. On any given summer’s day almost 2,000 hours of respite is provided for families, with an annual value of some \$2 million dollars. Since its inception, RFTR has advocated for legislative change for individuals with disabilities, promoted public awareness, developed a tangible model for effective integration and family respite, and impacted hundreds of thousands of lives.

As much as this agency has given to so many, it has taken some away from Donna. She admits that 80-hour work weeks in the beginning, and a 24/7 mental commitment, although all part and parcel of being an entrepreneur in the non-profit sector, inconsiderately borrowed time and energy and attention from other things that mattered.

“I am the kind of person that doesn’t look at my situation as a choice,” she explains. “I didn’t see it as something terrible; I just saw it as what I had to do. It was exhausting but when you are living it, you are in the moment. That was how my world evolved.” If she could do anything differently, she suggests that she probably would have tried to bring more balance into her journey as a family rather than being hyper-focused on certain facets. “I didn’t have to be the best at everything; I could have settled for a little bit less, which would have afforded us as a family a more well-rounded lifestyle. My life

evolved around the charity and subsequently my children’s lives did too.”

Her son, Dove’s older brother Derek, had to grow up too fast. “As a 10-year-old he had to be the man of the house. He was a star athlete and a stellar student. He took a few wrong turns. I was a single parent, and had no one, not even family close by for help and support. I couldn’t get him to the hockey games – Dove or the charity always came first. And when I wasn’t there for him there was the peer pressure and the bullies. We went through a rough time. He had an incredible amount of love and affection for his sister but in the end I have to admit, he must have felt like he always came second. He needed and deserved more of me. Could I have kept my son closer? I have questions more than regrets.”

Donna also questions whether she could have put more heart and soul into Dove’s toilet training. “She’s still in diapers and I tried so hard,” she discloses. “To this day I ask myself if I could have been more consistent if I had had a normal 9-to-5 job. You can’t go through a process and not wonder. I think we all think we could have been better parents. It’s natural.”





And she wishes she would have told more people off. “I have a list,” chuckles Donna. “When I think of how much control I gave doctors, or times I walked out of a room with my tail between my legs because I was intimidated by them or something they said...” she pauses. “As much as it is a different world, we must make sure we don’t go back there. There are still pockets of prejudice. I don’t want people who do not see the goodness, the greatness, in Dove in her life or mine.”

When asked about her legacy Donna is adamant that Reach for the Rainbow is Dove’s tribute. “I can’t accept the accolades; they belong to her. She’s the one who matters, who touches the lives, who has changed lives. I am just her instrument. I have never asked ‘Why me?’ I’ve always felt blessed, so lucky. I would never change a day of her life for me... for her yes. It is sad that there are many things in life that she will not experience like having

a baby, or walking down the aisle. But for me she has been more of a joy than I could have ever imagined.”

As Donna leaves her everyday role with her organization, she hopes that today’s parents of special needs kids always remember that the light should always burn for their children, that they are their voice, their arms, their legs and their ears. “They can achieve and they should be encouraged to go after the light.”

Time has not been Dove’s friend, something Donna acknowledged years ago. As a young girl, Dove was one of the most popular kids in school. She wasn’t isolated. “She was always surrounded by kids at communion or school pageants or birthday parties,” Donna remembers. “She has swam with dolphins and been to Africa. Summer camps have been a huge part of her life. She had a normal life. Now she’s in a group home and it’s different. Her friends from school have gone by the wayside. I don’t know what will happen. Will the group home she is involved with convert to a home for seniors? I can’t get answers about the what-ifs. My spirituality comes into play and I have to turn her over to that. She has friends in her group home. She has her life there. She has her role in life, and her needs are so simple and her love is unconditional. She’s happy.”

Dove goes back and forth between Donna’s home and the group home. She regularly comes into the office and helps with paper shredding. Tuesdays are date night... nothing stands in the way of time together!

“The easiest thing to do is to look at your life as half empty,” Donna professes. “But that child will teach you more about life, living, who you are and where you have to go than you could ever hope to get on a psychiatric couch. Look at the world through their eyes and you’ll see a world most people ignore.” Is enough ever enough?



*“When you are a mother,
you are never really alone
in your thoughts. A mother
always has to think twice,
once for herself and
once for her child.”*

- Sophia Loren, Women and Beauty



All Things Equal

Sometimes you just shouldn't question why; sometimes just accepting what is given to you will provide the answer. Waiting for the results of any medical test is excruciating, but as a mother, when it comes to your baby, it's a pain unlike any other. That's how motherhood began for Marilyn Jang.

At first she refused to believe it. The doctors admitted they couldn't tell for sure. They would need to do a test. A simple blood test would confirm if baby Kathleen carried the one chromosome that caused Down syndrome. But it would be days before they had the results. Marilyn decided right then and there that if the test was positive, then positive was the way to go.

"We cling to the hope that everything is fine," Marilyn says. "The waiting was the worst, your mind is everywhere and nowhere." She knew that she had a baby to take care of - with or without Down syndrome - that needed her mother's love, and acceptance. Marilyn still held out hope that the doctors were wrong and when her OBGYN came for a congratulatory visit, she didn't do Marilyn any favours. When Marilyn shared the news about Kathleen, her instant reaction was "Oh that's nonsense!" Hope was still afloat as Marilyn's trusted doctor sounded so convincing.

The results came back positive. Looking back, Marilyn is glad that she never knew and grateful that she never got the test done while pregnant. She confesses that she really doesn't know if she would have terminated the pregnancy or not, but is comforted by the fact that it was never an option. "Until you start your journey, it's human nature to question 'why me,' but now I understand that this is what was meant to be." Marilyn proudly boasts that having Kathleen changed her as a person... a better, stronger and kinder human being.

In the face of the challenges of raising a child with Down syndrome, Marilyn and her husband Arthur decided to stay the course of their family plan and have two more children. "Of course I was worried that I would have another child with Down syndrome, but both times I had the tests done and thankfully never had to make that dreadful decision to terminate the pregnancies." The couple welcomed their

FOR MARILYN JANG, YOU GET WHAT YOU GIVE

second daughter Laura two years after Kathleen and two years after that came Kevin. And happily ever after could begin.

Marilyn and her husband were always very close and having a baby born with special needs brought them even closer. They are opposites. “My husband is a calm and steady rock, my rational side,” Marilyn reveals. “Our core values have always been on the same page. You get tested when you become parents. Luckily for us, our test made us stronger. You have to choose your battles.” She also advises letting go of what other people expect. They decided to take their children’s milestones in stride, never leaning on textbooks for direction, or over-reacting if Kathleen wasn’t walking or potty trained *on time*. They let go of society’s expectations and lived day to day.

When it came to advice from others, particularly public health nurses and doctors, the discerning twosome employed their own 3D method: discuss it, dissect it and decide if the suggestion tallied with their parenting regimen which begins with the principle that all rules are set for all three children and are to be followed by all. No one got special treatment or special rules, not even Kathleen. Many parents would question the fairness of such a precept, or if it was even realistic. For this family, it was realistic and it was about respect.

Marilyn admits to being a Type-A personality and is convinced she would have been a competitive and aggressive mother had it not been for Kathleen’s disability. Easy-going, and brimming with a love for life and family time together, her children were afforded the freedom to learn and play at the expense of the perfect home. She believes wholeheartedly that a child’s toy is their work – tools to teach them how to maneuver their way through life and learn coping skills. Her house is filled with toys, instruments, art painted by her kids, music sheets, puzzles, pictures and poems. She believes that her home reflects her dedication as a mother and her willingness to let it be as it may.

As experts tell us, every child observes and learns from the behaviour and actions of their parents. Marilyn agrees. “They are sponges and you get what you

A high school graduate, Kathleen looks forward to a life of volunteering and mentoring other kids with disabilities in her community. She is a sports fanatic, her bedroom a shrine to all of her beloved teams. She has a black belt in Taekwondo and is a budding Special Olympics Swim Team star. She loves music too, plays the drums and piano and adorns her bedroom walls with posters of her ‘husband-to-be’... Justin Bieber.





give,” she professes. Marilyn remembers the dark tunnel she found herself in after her first-born daughter’s diagnosis. She remembers too when a door would open and let light in, in the form of a knock at the door from a public health nurse. The nurse gave her the courage to accept that the outlook was bright for Kathleen. She dismissed the worst case scenarios of institutions of days gone by and gave her the strength and resources to carry on. She remembers consenting: “Okay, this is our new normal. We have a child with Down syndrome. Now we have to find our way through.”

Kathleen’s life would not be just appointments with her doctors and therapists. It would be much more than that. They were able to enroll Kathleen in wonderful preschool and city programs. “Without them,” Marilyn admits, “Kathleen would not be where she is today.” Marilyn feels fortunate to have had these programs at their disposal and sympathizes with mothers who embark on this journey in rural areas. “Rural areas can add the stress of having to be a very creative and resourceful parent.” Marilyn loves to include Kathleen, now 21, in any conversation and encourages her to speak her mind. The bond between them is undeniable. It extends to all three of her children. They have a pact as a family: what one child wants to learn as a new sport or musical instrument, they all must learn and partake.

Marilyn has always instilled confidence in her children with a discerning eye on Kathleen, constantly reminding her daughter that it doesn’t matter how long

it takes her to learn or grasp something. Repetition is key. Trying her best would ensure that she would be just fine. “It may take her longer to absorb something,” she explains, “but it’s never beyond her reach because she knows there are people who believe in her.”

Kathleen learned to write and do math at a Montessori school alongside kids who did not have special needs. After successfully completing grade eight, Kathleen went on to a Catholic high school in her neighbourhood, one that included eight other students with Down syndrome, and one that embraced all children as equals. Kathleen thrived happily.

As her children matured, a sibling rivalry grew between Laura and Kevin. Her son sought any attention he could steal away from her middle child and Laura resented him for it. There were tough years but Marilyn vowed to give them the space needed to work through it, never interfering too much. The struggle endured but the younger set have managed to find common ground as young adults. The common ground that eventually bonded Laura and Kevin together, was their protectiveness over Kathleen from the beginning.

Kathleen’s first teenage temper tantrum is remembered by her parents quite fondly, and actually celebrated. “I thought it was the greatest thing!” Marilyn exclaims. “Kathleen getting so mad, and slamming her door, instantly told us that if something or someone was bothering her, she just wasn’t going to take it. She was capable of fighting back and not be a victim. It was a great moment for me as her mother.” It was a milestone both triumphant and frightening at the same time; the moment Marilyn knew she had done her job well. Kathleen spread her wings and maybe, just maybe, she could fly on her own.

As Marilyn reflects on the years of triumphs and tribulations, it sometimes saddens her how hurtful people can be. She recalls when Kathleen was first born. Passersby would look at her and glance away. When Laura was born Marilyn was astounded at how brazen people could be. “Strangers would come over to me and comment on how cute Laura was, and look at Kathleen and say nothing at all,” she shares with a pause. It pained her to understand why people would even bother and it took years for her to find peace with such thoughtlessness. Maybe it was that insensitivity that propelled Marilyn to always insist that Kathleen be treated like every other child. Not in the sense that she felt the need to defend her daughter, but

rather the opposite. Marilyn would linger at Girl Scouts or other activities to make sure that no one was giving Kathleen special treatment. Extra or special attention was not an option in her eyes. Kathleen would do things the fair way and the right way. She made a point of ensuring that others saw and heard how she spoke to her daughter, guaranteeing that Kathleen was not invisible and was very capable. “She may not be vocal or verbal because she’s so focused on what she’s doing,” tells Marilyn, “but she can be a part of a group.”

Some have accused this astute mom of being pushy or harsh, but it was her way to be sure Kathleen was being included.

It also helped others feel comfortable being around someone who was different. Marilyn defends her hands-on approach: “In a very indirect way, a program has to be a two-way street. Kathleen has to fit in just as the program has to fit with her.” She sought out “angels” for her daughter, “people who believe in what they do, for everyone, and are passionate about doing it. Those are the people who are going to make a difference in your life.” Marilyn instilled a message of possibility in Kathleen, and those who worked with her, to allow her the freedom to learn. She removed obstacles for others whose reservations were based on fear.

There was an incident at a park with Marilyn’s son when he was young. A boy who knew no boundaries nearly broke Kevin’s spine with a stick. Instead of confronting the boy’s mother, Marilyn thought about her own teachings to her children. “All my life I preached to my kids not to hit, not to fight. Use your words,” she shares. “It suddenly dawned on me that some people don’t play by those rules.” So instead of assuming the role of victim, Marilyn flew into action. “I announced to my family that we were all enrolling in a Taekwondo program.” Marilyn and her three kids joined the program and all four learned confidence, and grew stronger as a unit.

Marilyn has always advocated an inclusive philosophy whereby when her kids wanted to learn something new, she happily came along for the ride. She wasn’t a proficient swimmer and the kids wanted to take swimming lessons, so she took swimming lessons too. She refuses to be a back seat parent and by learning alongside of her kids she can encourage them and relate through her own experiences. “If we learn side by side,” Marilyn proclaims, “we can learn from each other. It becomes a reinforcing circle.” Marilyn and Kathleen earned their black belt together,

and now assist other special needs kids in achieving the same, teaching them techniques and tips that enabled them to excel in their sport. “That’s how we teach... repeat and reinforce and retain high expectations,” instructs Marilyn. “Too many people in life take short cuts. Some special needs kids are too used to taking short cuts.”

As for mistakes, Marilyn is quick to reach for one or two that stand out in her memory. With little hesitation she maintains that her family’s school experience was a mistake and not only for Kathleen but for all three of her kids. She felt that the teachers in the public school system were not adequately trained to educate kids with special needs. Secondly, she no longer assumes that people are always telling you the truth. A piano teacher once promised that he would teach Kathleen to play the same way that he taught all of his students. It turned out that he resorted to pasting the notes on the keys for Kathleen, offering her a short cut. From those simple life lessons, Marilyn learned to ask questions and follow through. “Stick around and make sure people are doing what they say,” she advises.

Marilyn never plans, she reacts. She doesn’t believe in a five-year plan and doesn’t ruminate on what the future holds.

As she and her husband age, it’s not quite clear what they intend to do when it comes to Kathleen. She hopes her daughter will one day have the courage to live on her own and become self sufficient. She would be completely content if Kathleen had a place of her own and spent the weekends at home with her family. She skirts around the question of what happens when her and Arthur can no longer take care of Kathleen. It’s clear that they’ll cross that bridge when they get there. Marilyn defaults to her life’s motto: Live your life and believe that anything is possible and you’ll be amazed that it is.





Keeping the Faith

She has felt the weight of the world. It was crushing her. She felt as if she had lost everything. There was no hope. An acquired brain injury sustained by her teenage son was devastating. But today that weight is gone. Through faith and family, and the healing power of paint, she has persevered. Today, reshaped by his troubles, her son is simply a different Benjamin.

The effects of loving someone who has suffered an acquired brain injury is a very intense, emotional journey. It begins with the prognosis. “Your son will never walk, talk, play the piano, or experience emotion again,” the surgeons informed Anita Sloetjes. Naturally, she was overwhelmed, as any mother would be, by uncertainty for the future. “I was scared for my son, myself, wondering if I could be there for him in the way I knew he would need me,” she remembers.

Energetic and affable, Anita does not speak in subtleties. Ten years of care giving for her adult son Benjamin has washed away any pretense or pretending. Life is what it is. They manage. She’s happy. He’s happy. It’s God’s will.

It’s hard to imagine this resolute woman any other way. It’s easy to surmise that she’s always been this way, that her fortitude is not a byproduct of a world that crashed down upon her when her son’s car plunged down on him.

“I’m a fighter,” she asserts. “I remember standing in the hallway while Ben was still in the ICU. I felt like vomiting. I’m talking to myself, out loud I’m sure,” she smiles. “I asked myself: Do I believe in God or not? All my life I’ve believed, I answered. I must still believe, I rationalized, or otherwise I would be like all of the other people coming into these cramped crisis rooms yelling and screaming. I was calm, comforted in knowing all my life that God’s love is in my life for some good reason. I trusted that He would give me the strength to get through this.”

Several days after her hallway affirmation, Anita had to meet with the doctor. She admits to being numb and frozen. She doesn’t temper his cutting words even a decade after he uttered them. “If he survives he will be in a vegetative

ANITA SLOETJES, GUIDED BY HER SPIRITUALITY

state, deaf and blind.” The mere suggestion of taking Ben off of life support fuelled that fighting spirit without an inkling of flight. “Three times you revived him,” she barked, “and any of those three times God could have taken him home. If God wants to take his life He will but I won’t.” She hurried to the chapel to pray. “I told God that if He wanted to give Ben back to me then I would accept him however he was.” Her acceptance process began right there and then.

Ben was 18. He’d been fixing his car on the edge of the driveway at his home. It wasn’t jacked up properly and heaved downward, directly on top of Ben. Anita was home and heard the unusual noise and ran to him. “I knew right away because he wasn’t responding to me,” she says. “I went back inside to call 911. It was so hard leaving him alone under the car. The last thing I said to him that day was, “Ben, if you can hear me, I love you, but I have to leave you alone while I go inside to call for help.” Anita had to remain on the phone until the emergency vehicles arrived, but was never allowed to go back outside to be with her son. Her living room began to fill up with neighbours to be with her. A police officer came in to speak to her. She asked “he’s gone right?” With a very grave face, he said he wouldn’t answer that, but they were going to try to land a helicopter in the backyard to take Ben to Sunnybrook in Toronto. “I knew he had a head injury and immediately asked if Benjamin could be taken anywhere closer to home. They agreed and flew him to the Hamilton General Hospital.”

When asked about her healing, Anita quips “I didn’t have time to grieve.” It’s probably true. “When I started to go through this,” she explains, “I was everything to everyone in my family, including my mother who was struggling with dementia.” Relying on a familiar passage from the Bible – “God doesn’t sleep or slumber” – Anita found meaning in it as she lay awake in bed at

His mother remembers Benjamin, the middle child of five, as the funny kid, strong-willed. Stubborn. Computer smart. Lots of friends. He was musical, good with his hands and loved to cycle. Today a different Benjamin, she portrays him as very content. Relaxed. A joy in every sense of the word.



midnight, night after night. “Well, I’ll call my friend in British Columbia because it was only 9 p.m. there,” she figured, “and if I’m still awake at 2 or 3 a.m. I’ll call relatives in Holland.” It wasn’t unusual either for her neighbour to let herself in at 11 o’clock, put the kettle on, and just be there.

Anita never asked for help. It just came to her. Church friends came to the hospital in shifts to give our family a break. Finances were tight, and they helped with gift certificates and meals, and the like. “Certain types of people just know what to say and do,” she maintains. “Not until you come up out of it and look at the people who walked the road with you do you fully appreciate them,” she confesses.

Shortly after his accident, coming out of his coma, Ben did well. He was able to walk with help, but began regressing in the hospital setting. Eight months after

his accident he came home, with a rehab team in tow. “When he came home, my support system [friends and supporters] assumed that ‘Ben’s better.’” They were supplanted by therapists coming and going. “I lost all my privacy,” Anita recalls. “At night I’d go into Ben’s room. I’d put my nose to his nose and look into his eyes and ask, ‘Ben, when are you coming back?’”

Anita endeavored to find some normalcy for the two of them. Ben had been in a music band. They went to see them perform. Seeing Ben’s replacement on stage was a harsh reminder for Anita that life as they knew it was no more. They went to what should have been Ben’s graduation, sitting in the back watching all of his classmates receive their



diplomas. “I went because I wanted to go,” she clarifies. “I wanted to deal with it. Those were his friends. I knew them. But when they spoke about him in the valedictorian speech, and I saw the standing ovation for Ben, I cried. It was hard.”

Of all the friends and family that came to Anita’s rescue, it was a stranger who helped right their drifting ship and set them sailing on a new course. Two months after his accident, Anita still didn’t have a lawyer. A friend from church met a new neighbour at a Sunday afternoon hockey party. The woman was a Speech Pathologist for people with brain injuries. She gave him a business card to give to Anita. “I must have had hundreds of cards. But that Monday morning I was at a place in this journey that was very dark, and was sitting at my kitchen table wondering what I could do, and I pulled out her card and called her. She asked me if I had a lawyer. I told her I didn’t. I didn’t need any more stress. She told me I needed one and that she would have the best lawyer in Toronto call me. She said if he didn’t call in 15 minutes she would call the second best in the city. Within 15 minutes Bernie Gluckstein called.

Gluckstein & Associates, a personal injury law firm, advocated for Anita and Ben, first securing a case manager and then a settlement. An incredible burden was lifted from Anita’s shoulders. Ben was able to come home and thrive in his own environment while undergoing intensive therapy. An accessible home was built right across the street which they moved into five years after his accident. “Because of Gluckstein’s advocacy for my son, we were able to tap into many different resources that we never would have known were available. Under their watch, my son was not just another statistic. He was a human being who deserved the best shot at life possible. When they believed in him, I realized that I was capable of believing in him too, and that together, we could conquer brain injury.”

That belief has translated into Ben now touching the lives of others through his gift of artistic expression. He paints abstract installations that are reproduced as large format wall hangings, as well as small format greeting cards. It all started with a walk in the park. “I took my mom and Ben and two grandchildren to a park,” Anita begins, “where a tent was set up for kids to create their own greeting cards. So I pushed Ben up and he made one. That gave me an idea. He could do this. Five years after his accident we celebrated!

We sent out invitations to everyone we could think of who had been part of our journey. I rented a tent and 400 people came. We sold Ben's cards." Today, his art has been recognized by the Hamilton Health Science Group, St. Michael's Hospital in Toronto, the Canadian Art Society and by the Lieutenant Governor, with displays.

And except for the mess, Anita loves painting with Ben. "It's cathartic for me," she admits. "Ben's disability goes away while we paint. It's just mom and son. We close the door and it is one-to-one. He is exhausted after he's done, but smiles after each painting is finished. He loves them. He smiles even more when he gets money in his hand. Prior to his accident Ben had a real entrepreneurial spirit."

When it comes to advice for other parents of kids injured as a teenager, Anita knows you can't just tell people that they need acceptance, and once they find it life will be a lot better. It's not that easy. So what does she say? "I ask them if they have a good lawyer. I preach that. And I tell them that they'll need a really good support system. You lose some friends, but you make new friends."

As straightforward as she can be, Anita is careful not to minimize other people's stress. "You need to show compassion to others. You can't wallow on your own stuff. I always told my kids that they needed to speak up if they thought they were being neglected. I didn't want them to think all of my efforts went to Ben. I've tried very hard not to do that. He's always on the front burner, but there are times when my family comes in, my other kids, grandkids and he goes to the back burner - it's not his turn to shine. And on respite weekends, I go out with my other adult kids. They all love Ben, but sometimes it's nice to have me to themselves. But either way, we'd take him too, but some focused time is good."

It is not today that worries Anita anymore. It is tomorrow. The future frightens her. "What happens when I'm not here," she wonders. "This is what wakes me at night. But I know God has been there for me, and He will be there for Ben. But I don't want my other kids to be responsible for him. I don't want Ben in an institutional setting." Anita has dreams for their home and nine-acre property so that their home in the future will always be home for Benjamin.

Anita remembers a solemn day, just three days after her son's tragedy, sitting in a little restaurant in the hospital forcing down some soup. "I saw a mom with a son in a wheelchair and it made me cry watching the way she cared for him and



loved him with kisses. I thought to myself that I would never be able to do that; Ben's not going to be in a wheelchair." She pauses before offering her point. "I became that mom. And what's more ironic," she contends, "is that I'm happy to be that mom. God picked me to take care of him. I don't ask Him why He picked me. Of course I would want for Ben to not be in a wheelchair, but for me, not at the loss of the richness of this journey."





Moments in Time

For most parents, enrolling their children in community sports like hockey is a rite of passage. For Debbie Braun however, parent of two adolescent boys with a rare form of dwarfism that is degenerative and progressive, being a hockey mom was something she could only dream about.

Debbie's life as mother of Lucas and Zane is not made up of normal milestones. Lucas and Zane were born with the most severe form of Morquio Syndrome, a lysosomal storage disease which causes the boys chronic pain and affects their bones, spine, organs, hearing, eyesight and breathing. The disease presents itself in only one in 250,000 births. The average life expectancy for Morquio is less than 30 years.

Morquio Syndrome is an auto recessive gene, and both Debbie and the boys' father, her ex-husband, carry the recessive gene. So although Morquio is very rare, it's not unusual for siblings to have the disease... a one in four chance in each pregnancy. "When you look at the map and see that there are two cases in this town, and two cases in that town, three cases in that town, you know that the kids are usually from the same family," Debbie explains.

When the boys were first born, the Brauns really didn't notice that they were different at all until they started missing milestones... and stopped growing. Lucas was almost three years old before he was diagnosed with the disease. Zane was diagnosed just before his first birthday.

"Lucas keeps me very grounded," says Debbie. "He's very adamant about people liking him for who he is. He's very comfortable putting that out there and he's okay with the fact that he's not going to live to be very old." Debbie believes it's a natural tendency for parents like her to search for a cure but when Lucas was just five he asked her why she was doing so much research about him. "When I told him that I was trying to learn as much as I could about his disease he said, 'I hope you're not trying to fix me because I'm not broken. I'm perfect just the way I am,' he insisted."

Like any parent, Debbie has searched for answers to the 'why' questions... Why me? Why my kids? Why my family? "But when Lucas said to me 'don't fix

DEBBIE BRAUN AND HER BOYS LIVE FOR EACH DAY

me,' I stopped right then and there and promised myself that I would not go through life trying to do that and I'd happily accept he and Zane just the way they are. He slapped me right in the face with his words. He was right. He is perfect. Zane is perfect. And our family wouldn't be what it is under different circumstances... we wouldn't value what we value, and do what we do if Lucas and Zane were any different."

Debbie has been determined to provide a normal family for her four kids – the boys have two older sisters. "We don't live life like they're dying. I really do think we live like regular families, cramming work and school and activities into each day."

The Brauns hail from a small community in Ontario where there aren't many other kids with disabilities and both of the boys' sisters are very protective of them. "I often have to remind my oldest daughter to step back a little bit at school and let Lucas figure things out on his own." But at the same time the sisters have normal relationships with their brothers too. They argue with them and can find them annoying on occasion. And at times they can't help but feel a little put out that their mom spends so much time with their brothers. "My second daughter Alexa lets me know about that resentment, but she is very caring and loving of her brothers. My other daughter, Nikki, mothers them but bugs and badgers them too, just like any big sister would."

Debbie acknowledges that her daughters have probably had to grow up faster than other girls their age. "But I think our reality has helped them value what's important in life a bit more and not be overly fixated on material things." She also admits that it's fair to say that their circumstance as a family with kids with a disability led to her divorce. "Some families," she observes, "pull together and others are broken apart in such situations. I threw myself into learning more, but my ex-husband went the route of denial and started to drink. The boys have asked if their father left because they were small," she shares.

"The divorce period was very hard on all of us but in fact, it was one of the better things that happened to us. Since then,



Lucas (on right), the older brother, is the serious one, wise beyond his years. He never gives up on anything. Zane is the silly one, always making people laugh. He doesn't take anything too seriously. Lucas is the rule follower. Little brother Zane is the rebel. To a casual stranger they look a lot alike, but in most ways they are as different as night and day. Except for one striking reality, both serious and unusual, that the brothers share... Morquio Syndrome.



I have met a great guy with three kids of his own who has been very supportive and is great with the boys. He brings a lot of laughter into our lives. I think things happen for a reason. We both feel that God brought us together.”

Lucas starts high school.

He’s a real go-getter, immediately joining the chess club and enlisting as a class representative for Student Council. “I joked with him that he has to stop joining stuff, because he has to fit his school work in there too,” smiles Debbie. “Their stamina is very low so Lucas is only taking three courses with a resource class at the end of the day to give him time to do his homework. When they get home from school, they usually need to take a nap or at least rest anyway. Although they walk around at home, they both use a scooter at school because of the effort it takes to walk.” Both boys also rely on a breathing apparatus at night to help with their sleep apnoea, common to Morquio Syndrome.

However, the time came when Lucas and Zane’s disabilities became front and center for the family, with doctor discussions about health issues and life expectancies. In 2011, the boys began a 27-week drug trial at Sick Kids Hospital in Toronto for enzyme replacement therapy, sponsored by a drug company. Every Thursday, Debbie took the boys out of school and they drove to Toronto, stayed overnight in a hotel and received the treatment for most of each Friday. With the completion of the study, the drug is being funded for three years by the sponsor – a cost of \$100,000 per year per boy. The treatment is expected to help decrease the amount of lysosomes that are building up in their joints, heart, lungs, eyes, ears and other parts of the body. The treatment

can potentially increase the boys’ life expectancy as well as their quality of living.

This has brought Zane to a place where he’s questioning his mortality for the first time. His learning disability forces him to learn differently. He thinks about how sad his mom will be when she has to say goodbye to him, and hates the thought of that. Lucas tries to shelter him from thoughts about the eventuality of a shorter life than others. His biggest concern for his mother left him wondering if she could do the 400-km round-trip drive each week from their town to downtown Toronto. “I told him I would drive to the moon for them,” Debbie offers emotionally.

Enlisting in the trial had to be a family decision for Debbie and the boys. With two teenage daughters, and a partner with kids of his own, she needed a “town meeting” to make sure everyone was on board. But the ultimate decision was left to the boys. Zane usually goes along with whatever Lucas wants to do and Lucas wanted to do it to help other kids with the disease if the study was to prove that enzyme therapy was beneficial.

The hopeful outcome of the study for the Braun family is to increase the boys’ mobility and endurance levels and lung capacity. “Kids don’t die from the disease, but rather from complications from it – respiratory issues usually,” Debbie explains. “And I told Lucas that this trial is not about fixing him but just wanting him to be with us longer. If I can spend even one more day with them then all this effort is worth it.”

Lucas approaches the reality of a shortened life with a maturity well beyond his years. He’s even given thought to the song he’d like played at his funeral, a song by Johnny Reid called “If I Could Change the World.” And at a hometown fundraiser, both boys had their hands moulded in wax which they gave to their mother so she could always hold their hands, even when they’re gone.

That sentiment is at once both comforting and disturbing for Debbie. She’s happy that Lucas is okay with his fate, that he’s not worrying about dying. But she embraces each day. “We are happy for each day that we have.”

The biggest challenge for Debbie has always been a financial one. “I was a single mom for almost five years, raising four kids by myself.” A veterinarian technician, she worked part-time before her divorce and tried to up her hours after the split but found it too difficult with all of the ongoing doctor appointments. But graciously she says her ex-husband has

always paid child support. “But it was still hard while we were on our own to do the everyday stuff.”

For Debbie ‘everday stuff’ includes basic mobility equipment such as wheelchairs, walkers and ramps which is of course expensive, and not always feasible to finance on her own. “It’s very difficult having to make your children wait for the equipment that is their lifeline to being mobile and independent,” she insists.

Easter Seals has helped with some of the financial demands. “We first asked for help from Easter Seals when I needed a lift put in the house. It was a joint effort between local Kinsmen and Lions clubs and Easter Seals to install a platform lift so the boys could get their scooters and wheelchairs to our living area,” describes Debbie.

Easter Seals has also helped send the boys to camp – Woodeden near London – which has been a godsend according to Debbie, something she would never have been able to provide on her own.

“The first time they went, I cried for all 10 days,” Debbie confesses. “I had no one to look after. But it was such a great experience for them spending time with other kids with disabilities. They admired the abilities of the other campers and all that they could do. It made the boys feel like they could do anything too. If these kids could do it, so could they. It empowered them.”

Those 10 days also gave her some great mom-daughter time as well. “Too often I forget that they just don’t get the same amount of time from me as the boys do. But they are such great daughters... they understand, never complain and never ask for much.”

Another major challenge for Debbie comes in the form of others’ perceptions of her as a super-mom. “I get frustrated when I’m told ‘I’m amazing’. I hear it too many times. I’m not amazing. I do what I do because I love my kids. I do what any other parent would do. You do what you have to do. Sometimes I think you have to find something amazing within yourself because it’s not always easy to get out of bed some mornings. But you have to do it. When someone first told me that God only gives you as much as you can handle, I questioned what He was thinking?,” she chuckles. “You get what you get. You can’t send your kids back. Of course, some deal

with it better than others and at first I didn’t know if I could deal with it. Ironically, the boys were the ones who helped me learn how to handle it.”

After the boys were diagnosed, did she ever imagine that she’d be where she is today? “No. I’m in a very happy place. Back then I was devastated that I would never be a hockey mom. When you have kids, you have a dream for each one of them. My dream was to be a hockey mom at the arena cheering them on. I had to change my dream. I just wasn’t ready for that at first.”

But Debbie says she has no regrets. “We’ve spent every day doing what we can do for their health and to be a loving family that spends time together. I leave laundry sit so I can spend time with my kids. One day at a time. I hope this study gives me more days with them. Even if it’s just one more.”



Thank You Mom By Lucas and Zane Braun, and Debbie's partner Jay

Mom, we just want you to know how much we love you. You are our shoulder to cry on when we're sad and our rock when we need strength to get through our tests and surgeries. Like any good parent you have always been there for us and for that we are so thankful that we call you our mom. Zane and I are thankful for a lot of things in our life like Leafs hockey, hot tubs, Play Station, mini sticks and campfires, but we are most thankful for you and the many things you do for us. So we made up a thank-you list just for you...

Thank you for taking us to the hospital and sitting with us through all our surgeries, appointments and tests, even though sometimes I'm sure it is not much fun. You always make us feel safe and loved.

Thank you for being so brave and so strong even when some days are an uphill climb where you never reach the top. Without you we could never do what we do.

Thank you for keeping us well dressed, well fed, warm and healthy. Sometimes I think you feed me too well.

Thank you for letting us go commando.

Thank you for letting us play mini sticks in the family room even when we promise not to fight but we always do.

Thank you for getting the family a bulldog that has crooked legs just like us.

Thank you for renovating our house to give us our own toilet, sink and a lift up the stairs so when our legs hurt we can ride and we don't have to walk.

Thank you for the three-hour trips to Toronto and back to make sure we have a good quality of life and we stay as healthy as we can be. And thank you for all the new words we learned when you were stuck in traffic on the 401.

Thank you for letting me become the 2010 Easter Seals Ambassador; it was a lot of driving and time in Toronto for you but it was something I knew I could do well and you were behind me 100 percent.

Thank you for picking us up after school when we volunteer to help coach the Basketball team. We know you have just worked a full day and are very tired but you always support anything we want to do when it comes to school or sports activities.

Thank you for understanding that there is nothing wrong with us and we are not broken.

But most of all thank you for loving us and for being such a great Mom.

We'll love you forever; we'll like you for always, as long as we're living, our mommy you'll be.



*“Biology is the least of what
makes someone a mother.”*

– Oprah Winfrey



Planned Parenting

When Caroline Findlay takes her nine-year-old son Tyler to the shopping mall or the movie theatre or the park, no one knows he has a disability. There's no glaringly obvious physical disability that tempts passersby to stare or survey their every move. Tyler is just another normal little boy with the biggest and brightest blue eyes you've ever seen. But the world that exists behind those baby blues is a very different place than the world most ordinary little boys live in.

Tyler is autistic. And it was only because of his mother's insistence, her intuition, her gut feeling really, that their pediatrician agreed to investigate Caroline's growing concerns about her young son.

At age 39, Caroline was preparing like every other new expectant mom - the nursery was in perfect order, the tiny sleepers folded and set for her first baby's arrival, her dreams for her new family's future bright and hopeful. Caroline had a difficult pregnancy but trusted the hands of her doctors, hopeful that they were doing everything possible to keep her and her baby healthy. Even when she gave birth seven weeks prematurely, no one batted an eye as Tyler progressed as a healthy, happy, flourishing baby.

As days and weeks grew into months however, Caroline began to notice subtle differences between her son Tyler and other babies. She had a feeling that something wasn't right. "I have a friend who has an autistic child," Caroline starts. "I phoned him up and started asking questions." The more Caroline heard, the more she knew she was hearing what she so desperately wished she wouldn't.

Tyler wasn't like most other kids his age... he was smart, too smart. He could recite the alphabet at a very young age, but inexplicably could not connect the letters into words. "He could say Mommy," Caroline describes, "but had no idea that that was me! As a mother you long for that moment when your baby recognizes you as Mommy." It was beyond devastating when that recognition didn't come. Caroline started to monitor Tyler's growth more closely, taking note of what she felt was lacking or missing in his development. She remembers taking him to the park when he

CAROLINE FINDLAY STARTS AS SHE MEANS TO GO

was about two years old. She hoisted him up onto the slide but the simple action of aligning his body to slide down was lost on Tyler – another devastating blow and the last red flag she needed.

Tyler’s motor planning skills just wouldn’t come naturally. Caroline took him to his pediatrician only to be surprised at how hard she had to push the doctor for a closer examination of her son. “I actually had to convince her something wasn’t right,” she recalls with disbelief. After spending several hours with Tyler, Caroline will never forget the doctor’s words after her assessment. “I’m the one who usually has to tell the parents that their child has autism; this is a very unique situation.” It wasn’t that Tyler’s doctor wasn’t willing to do her job. It was that Tyler could talk. He would look another person in the eye. He was just a bit different. It seems, as Caroline observed, that Tyler’s doctor learned a valuable lesson that day: never underestimate a mother’s intuition. And Caroline reinforced a life lesson of her own: always follow that intuition and never give up until you get the answers you need.

It was now official, left there for Caroline to absorb and digest – her son has autism. It was her ever-present instincts that set their family on a new course. Caroline knew in her heart of hearts that the diagnosis was coming, but she so desperately wanted to be wrong. What mother wouldn’t. Now what?

The upside to the early diagnosis was that she had the opportunity to react right away. Caroline and her husband Paul quickly agreed on how they were going to tackle their new normal. They had to come to terms with the reality that their dreams for Tyler would have to change and face the fact that their child was different. They were older than most first-time parents. Maybe that was an asset. Maybe the couple was better equipped emotionally to get on with life. They immediately enrolled Tyler in speech therapy and he began seeing an occupational therapist on a regular basis. Things started to progress. Caroline wanted to give Tyler absolutely every chance to develop and reach his necessary milestones and would do, and pay, for whatever was needed.

When it comes to their approach to parenting, Paul and Caroline are very much alike. Both calm and not overly emotional, together they scripted a strategy. There was no pointing of fingers. Never once



Tyler is a nine-year-old little boy who goes to school, does his homework and loves basketball. He has autism, a diagnosis that came early in his life thanks to his mother’s love and intuition. He got the help he needed to attend a school in his community like every other kid. He loves to experience all the fun things a child’s life has to offer, especially swimming, sports, video games and friends.



did they blame anyone or anything. “We are fortunate that we have very similar personalities,” Caroline appreciates. Tyler having autism inadvertently brought this couple closer together. “His disability has forced us to talk about everything,” she shares. “We have to be on the same page about Tyler’s day, about how we are going to handle difficult situations, what we think he needs, and what’s new in the world of autism. It’s endless.” Hands-on parents, the Findlays wouldn’t have it any other way.

Caroline works for IBM and benefits from a flexible schedule and Paul works for a family business. “We have a great routine,” Caroline explains. “I drop Tyler off at school in the morning and Paul picks him up. We take turns on bath nights and with Tyler’s therapy appointments. It’s an equal balance of things. I think as a mom and a woman you can feel the most weighed down when saddled with having to do most everything,” Caroline presumes. “I don’t experience that. Paul helps so much.” Both involved and plugged in to their family’s needs, their foundation is solid as a rock.” But don’t get me wrong,” Caroline qualifies, “there are days when I get frustrated with Paul or with Tyler and I need to walk away from the situation to cool down.” She admits to having bad days and wishes things could be different. But for the most part, her life runs like a well-oiled machine... the only way it could work for her.

The prevalence of autism is clearly on the rise and yet there is no concrete evidence that speaks to its cause and as such, there is no cure. Caroline’s endless online research on autism has brought many suppositions to light, but nothing has been confirmed. The theory that vaccines can cause autism is plausible, but to Caroline it’s not something that carries a lot of weight. “I believe in vaccines and I wouldn’t go back and choose differently,” she maintains. She suggests, based on that theory,

that she might have chosen to go about her son’s vaccine schedule differently. Since Tyler was premature, Caroline wonders if his vaccines should have started later than those babies born to term and have been stretched out over a greater length of time. It was certainly something to ponder for Caroline but other plausible causes continue to surface.

“I survey the research online all of the time; that’s where I find the most information,” she says. “Researchers are now saying there might be a link to a gene mutation.” A recent study found a specific gene that possibly could cause autism. Caroline didn’t hesitate to pursue it. “We decided to have the genetic testing, but in the end, we do not qualify with that specific gene.” She resolves that she might just simply fall under the category of being an older mother. Caroline concedes that being older likely lends to increased risk factors for other abnormalities beyond Down syndrome – a traditional concern related to later-in-life pregnancies – but there is still no concrete evidence to prove her presumption right or wrong.

Caroline understands how important the internet is to parents of kids with special needs who are searching for answers, for help and for peer support. She thrives on supporting other parents with an autistic child and giving back to this community, the same one that provided her with much-needed guidance at the onset of her journey into the uncharted world of autism. She now volunteers for Ability Online, a renowned source of support and resources for families with children with disabilities, where she serves as the moderator for the autism forum, answering questions posted by parents struggling with a child with autism. She also relies heavily on the power of Twitter and Facebook to share information and support with other parents. “Every day I get something of interest through social media,” she tells, “like travel tips for kids with disabilities or iPad apps for speech therapy, for example.”

It’s obvious that Caroline herself finds solace in social networking. A sponge for new information and research, her aim is to maintain as much normalcy for her family each day as possible through tips and tools gleaned from her online discoveries. Unlike many parents of children with autism, Caroline does not shy away from crowds or places with other kids. She loves ushering Tyler out to expand his horizons. “We take Tyler everywhere and give him the same opportunities as other kids enjoy. We just go about it differently. We believe in growing Tyler’s world. I want him to experience things and he loves it,” she enthuses.

Unquestionably, raising a child with autism calls for unconventional considerations and concerns, but Caroline queried early on if her life really had to be that much different than other families? Tyler attends a Catholic school and is part of a regular class. He shares a full-time Education Assistant with a classmate who also has autism. Caroline is proud to report that Tyler's school is very much on top of things and extremely sensitive to Tyler's needs. She knows that she's fortunate in that regard, and lucky to have teachers who work closely with her when it comes to Tyler's behaviour and school work. In fact, Caroline constructed a behaviour chart and introduced it to Tyler's teacher who embraced it as a fabulous idea. They now work together, marrying home and school life to correct behaviour issues. For example, if Tyler cooperates in school and complies as he's asked, his take-home note for Caroline's chart logs that it was a good day. In return, Tyler gets to do his favourite activity... play basketball in the driveway after dinner. Just like any other kid, Tyler is rewarded for good behaviour.

Caroline would have loved to have had more children but that dream was mitigated by the possibility of having a second child with autism. Add to that, she felt that she was too old to have another. She wishes that Tyler had a sibling to play with, to feed off of and learn from. With a hint of regret, Caroline admits, "I see other kids with their siblings and I know how that enriches their lives. I wish Tyler had that." What she also sees in those families is that the responsibility to constantly entertain doesn't fall exclusively on the parent. However, what Caroline innocently overlooks, is that such is the case among 'normal' families as well. There are families with singletons by choice of course, and there are families where sibling rivalry has a mother tearing her hair out. A normal life is subject to interpretation, and regrets are commonplace. Caroline knows this, and has never allowed hers to manifest into resentment or bitterness.

Nonetheless, at times Caroline still gets tripped up on her own definition of a normal life. When out at a mall, or a park, and watching other moms with their little ones, she marvels at the basic instincts of mothers and their children alike. "When I see other kids reach up and take their mother's hand or follow them around a store, I wish I had that. I don't know what that's like. It's fascinating to me that a child will just automatically follow their mother." The primal relationship of mother and child is obviously not lost on Caroline, and it's easy to believe that Caroline longs for what she sees other mothers might take for granted. But she also knows that Tyler is her special gift and he is here to teach her something as much as she is teaching him.

Caroline's biggest concern today is what tomorrow holds for Tyler, something she simply cannot predict.

"I would like to know that one day Tyler can live on his own, have a job, have friends that he can trust and count on, and be able to live the day-to-day life we all take for granted." And as she ponders in silence for just a moment, she reveals her true fear as both hope and worry show on her face. "I just don't know how to make that possible right now."

From the very beginning Caroline has held her family to a certain standard, insisting that her son engage and behave like every other child. She has never allowed Tyler, or herself, to use his autism as an excuse for anything less than acceptable. Start as you mean to go, she has demonstrated... that's how this family has survived. She has not wavered from her dream of a normal family, something they strive for every day. Hard work? Yes. Harder than most families? Probably yes. "I wouldn't change a thing about Tyler," she accepts. "He's a happy, considerate and kind child. It's a joy to be his mother."





No Day But Today

To sit down and talk with Donna Frey is both calming and inspiring all at once. It's her quiet nature, but it's her bountiful outlook on life too. This retired ballet teacher's cup is always half full, if not overflowing, even in the wake of one of life's most unexpected missteps. Life can change in a split second. We all know that. But it is hard to imagine how one could ever prepare for it.

It was 1992. A loving husband in Bill, a budding career, a happy five-year-old and a baby on the way rounded out a life that Donna had scripted. Her impending newborn would complete her family and push her plans forward. Her second pregnancy gave her no real reason for concern; she knew her baby was a bit small but the doctors pointed to slow fetal growth, but the baby was sure to catch up once she was born. All of her ultra sound results appeared to be normal. Donna took comfort in knowing that her first daughter was born perfectly healthy with zero complications.

Donna never second guessed her doctors. Today she regrets not asking more questions. She wishes she would have demanded the results of her ultra sound, as is every mother's right. As life would have it though, three weeks before her due date, premature labour turned out to be her first blessing in disguise. Little Morgan's early arrival and low birth weight were Donna's saving grace.

Morgan was born missing her right hand and part of her left, her left foot above the ankle and her right foot below the ankle. Not to diminish these congenital limb differences, but there was a more pressing concern upon delivery. Morgan's umbilical cord was wrapped around her neck twice. She was born breach and lifeless.

"I remember the nurse softly asking someone if they wanted to sit down," Donna tells, just as Morgan was born. "I thought she was talking to my husband, but when I looked up and saw the doctor take a seat, and not my husband, I knew something was wrong."

IN DONNA FREY'S LIFE, YOU CAN ALWAYS GET PARTS

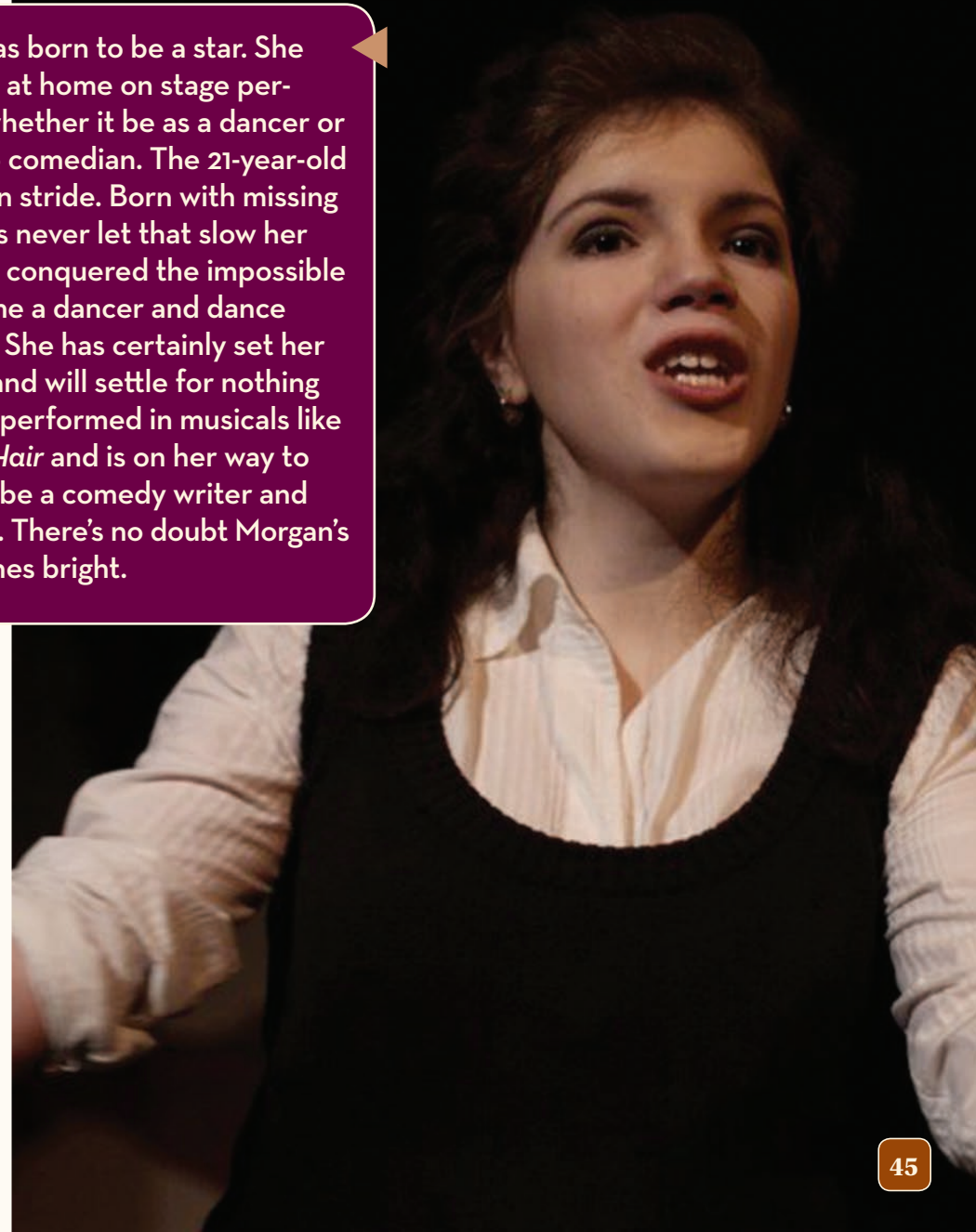
Morgan was delivered at only three and a half pounds and was swiftly whisked away by the nurses. Donna ached to hear her baby's first cry. She needed to know that she was breathing. With the help of her doctors, Morgan complied. Within minutes a nurse returned the baby to Donna, but with a caveat: "There seems to be something wrong with your baby's foot and hand." Donna didn't care; the only thing that mattered was that Morgan was alive.

Life can change in a split second. Donna had just held her baby for the first time when Morgan was wrenched from her again. Tiny Morgan faced yet another life or death situation. She needed heart surgery. She had a blocked valve necessitating an angioplasty. Donna recalls the moment she learned of Morgan's heart situation. Then and there she resolved that Morgan's limbs were a secondary issue. "They never came into the equation," she explains. "There wasn't time for that. Her heart took the focus off her limbs completely. The fact that Morgan might not live relegated her limbs to the deal-with-it-later list." Morgan's limb differences have remained in the shadows of importance ever since.

Donna believes that things are presented to us in ways that we are equipped to handle. The frantic first few hours of Morgan's life never allowed Donna to think beyond the moment. Being confronted with that much trauma all at once, something had to give, and for Donna it was the fact that her daughter was born with physical disabilities. Her limbs just didn't have a place on the priority list. "It would have seemed vain to worry about such trivial things," she confides.

Donna divulges that while gazing at her newborn baby lying in an incubator, enveloped in tubes, hour after hour, is when she became fortified to face whatever life had in store for her. She lovingly whispered into Morgan's minute ear: "Well... I guess you're not my dancer."

Morgan was born to be a star. She feels most at home on stage performing, whether it be as a dancer or a stand-up comedian. The 21-year-old takes life in stride. Born with missing limbs, she's never let that slow her down. She conquered the impossible and became a dancer and dance instructor. She has certainly set her bars high and will settle for nothing less. She's performed in musicals like *Rent* and *Hair* and is on her way to college to be a comedy writer and performer. There's no doubt Morgan's future shines bright.



How people will react in times of crisis can rarely be predicted. But Donna's calm and collected conclusion that Morgan would not follow in her footsteps as a dancer is not surprising. A defense mechanism, her brain telling her heart that it was okay to let go of her dreams for Morgan and the perfect life.

The day after Morgan was born, Donna was discharged but Morgan remained behind in the hospital. Donna was sent home with a task set out by the medical team. "They sent me on my way with one thing to do... contact the War Amps [The War Amps of Canada] and a social worker in our area." Donna believes that had Morgan been born with *just* her missing limbs, she may never have discovered the support she needed. "In the early '90s there wasn't much information available on this sort of thing," she qualifies. "The internet wasn't the 'go-to' guide that it is today. Parents were on their own and at the mercy of the professionals who sent us on our way."

She contacted the War Amps as she was told to do. A package arrived within just days. The information helped ready Donna for Morgan's home coming. While Morgan awaited surgery, Donna was forced back into reality and life at home. Her oldest daughter Katherine was in grade one and in school full time. Donna needed to maintain a normal routine for Katherine, getting her ready for school, dropping her off, going to the hospital to visit Morgan all day and back home in time to

retrieve Katherine from school. Donna was grateful for the distraction of normalcy, and routine seemed to set the stage for the Frey family's road ahead.

Morgan awaited surgery for six weeks while a social worker anxiously awaited Morgan's arrival home. It was that social worker who inadvertently gave Donna the best advice she says she's ever received in her life. "The social worker took one look at Morgan," Donna recalls, "and said 'Oh your baby is so adorable and you know... you can always get parts. Parts are nothing.'" That put everything into perspective for Donna and those words have served as the Frey's family and life motto ever since. That presumably off-the-cuff remark validated something deep inside Donna and empowered her to continue to look at life in a positive light.

Donna isn't the type to dwell on the past or what-ifs. She's a take-it-as-it-comes kind of lady. That said, she maintains that her only regret throughout her parenting journey is all the time spent commuting Morgan to doctor's appointments for the first five years. Donna regrets that the first few years of Morgan's life were spent in a car. "It's time I can never get back," she laments. "It was time I got to spend with Morgan of course, but it wasn't quality time." On top of the regular check-ups and shots that all kids get, add to that the heart specialist, prosthetist and other professionals. Mothers love to parade their babies in front of friends and family, and share stories with them, and with other new moms. Donna didn't get to do that with Morgan and the worst part was, she knew what she was missing because she did all those things with her first. She knew she was missing play dates and sing song classes and afternoon naps and strolls to the coffee shop. She knew every car ride drove Morgan farther away from "normal" but there was nothing she could do about it. Donna's regret might be as simple as crushed expectations and had Morgan been the first born, this mom might not have known any different.

In the years that followed, family life ran quite smoothly with very few bumps in the road. At nine months Morgan was fitted for her first passive hand - a crawling hand. She had feet fashioned for her out of foam because she was so tiny. And as Morgan matured she flourished, and her mother decided to take a risk that arguably may be considered the defining moment in Morgan's young life. Donna would try something that she thought Morgan could never do. She enrolled her in dance class.



“Tap dancing doesn’t involve much ankle movement, so I thought why not?” Morgan loved it. Donna then discovered that skating doesn’t involve much ankle movement either. Morgan skated brilliantly. It was a blessing too for this mom to watch Morgan succeed at things her oldest daughter could do too. It curtailed resentment and bitterness from building between the two sisters, she feels. Morgan adored her older sister and the feeling was mutual. Donna grins as she shares her favourite story of adoration between her two girls. “When Katherine was in grade eight she had an assignment that called for her to write a story about her hero - Katherine chose Morgan. But the teacher told Katherine that she couldn’t have a hero that was younger than her. I was furious. That’s the only time we really needed to step in and be an advocate for Morgan in that sense. Katherine wrote about her younger hero and to this day still feels the same way about her sister.”

As for Donna and Bill, their biggest challenges came with the school system. Morgan never really experienced bullying beyond the norm. She had a good group of friends and lived and played as any other kid. But by grade three, her school wanted to label Morgan as *handicapped* and Donna couldn’t understand why. Donna had been in the classroom over the years to ensure Morgan could function and get to and from where she needed to be. They always took it upon themselves to visit Morgan’s classroom every September and talk to her classmates and teacher about her disability. It was an approach that encouraged the children to ask questions and feel comfortable and accept someone who is different. So when the school offered Morgan a full-time aide Donna dug her heels in and outright refused.

Donna and Bill’s steady proactive approach was abruptly aborted when they felt the school was using their daughter’s disability to play the system. “We decided at that point to pull Morgan out of the public school system,” Donna bemoans. “We felt that they were using Morgan’s physical disability to get an aide for other children. I know those positions are hard to come by, but not at my daughter’s expense.” Morgan was enrolled in a private school and never looked back. Morgan thrived in that environment, with her new school encouraging her to do and try things she never thought possible. “I walked in one day,” Donna chuckles, “and Morgan was knitting. I never thought I’d see that happen.”



Morgan’s love of dancing and performing blossomed in her adolescent years and with her mother’s encouragement she once again exceeded expectations. Morgan has immersed herself in the world of dance and has risen to heights that not many would have ever imagined. Today she is a certified dance instructor, a job and a platform for her to share her message about “endless possibilities” with other kids. A few years ago, it didn’t surprise Donna that Morgan wanted to audition for the musical production *Rent*. Morgan had the guts to try anything and was so inspired by her own courage to audition for a role, she commemorated the occasion with a “no day but today” tattoo on her forearm... a permanent reminder that life is short, so live it to the fullest. She got the part. A star was born and Morgan was off to Humber College to study Comedy Writing and Performance. Donna marvels at how at ease Morgan feels when she’s on stage and how there’s no doubt that her daughter has found her calling. “The greatest thing about her comedy,” she describes, “is that Morgan doesn’t make fun of the obvious. She doesn’t talk about her limbs. She makes fun of herself in every other way but that.” Another Frey family motto: “if you can’t laugh at it, then it’s really tragic.”



Looking back now, Donna believes there were things that happened throughout her pregnancy that for whatever reason were silently or subtly preparing her for what was to come. At 38, she was considered a geriatric expectant mother in her community. Her doctors encouraged her to have an amniocentesis to see if the baby had Down syndrome but beyond that never provided her with the care or attention an older expectant mother would be guaranteed today. Having the option of the amniocentesis test gave Donna and Bill the chance to contemplate the outcome. “I remember Bill saying to me that he supports any decision I make, but he couldn’t imagine feeling life inside and then have to make the decision to terminate the pregnancy.” Donna was glad to hear that and knew she could never end her pregnancy either. Whatever she was given she would trust was meant to be. Even during her final ultra sound, the technician went and got a doctor to take a closer look, but Donna never thought to question why. She trusted that if something was wrong her doctor would be notified and she would deal with it. “I would certainly tell expectant mothers today to always go with your gut and if you have questions – ask, ask, ask!”

Donna smiles proudly, “we realized a lot of things through Morgan too. She’s been a real eye-opener her whole life.” Donna’s intuitive nature was right about another thing... a hero is not defined by age. Morgan has overcome much adversity, ploughed through obstacles with dignity and grace, and has come out on the other side with a sense of humour and a dream. That is heroic, but calls out the hero in all of us.

As Morgan prepares to leave the nest and head off to college, she leaves one more assumption lingering in the air for her mother to contemplate.

Morgan turned out to be Donna’s little dancer after all. Morgan is proof that anything is possible, especially when fuelled by the courage and love of a strong and steady mother.

Donna’s attitude and love for life certainly constructed the foundation for this family’s approach to what life had in store for them. So, is the cup half full or half empty? No need to ponder that question when it comes to Donna and her daughter’s take on life... there’s no day but today, and if all else fails, you can always get parts.



*“Mother love is the fuel
that enables human beings
to do the impossible.”*

– Marion C. Garretty, quoted in
*A Little Spoonful of Chicken Soup
for the Mother’s Soul*



Storm Trooper

For a woman who wondered what she could possibly contribute as life advice for other mothers with a child with a disability, her compelling story of survival reads like it is pulled from the pages of a battlefield diary. Hilda Tiessen is a survivor.

A first-generation Canadian – born in Austria – she grew up in a small town in the most southern part of Ontario. Married at 18, fresh out of high school, a mother before her 19th birthday. She had never left her county, never traveled on a train or in a taxi cab, until 30 when she had to face her greatest of fears and tote her newly disabled son to the big city of Toronto. How she would muster the courage to survive it she couldn't fathom. But she did. A mother will do anything for her child.

It was 1977, on a sunny but cold February Sunday afternoon when her three kids, along with a boyhood friend of Jeff, her eldest child at age 11, ventured out for some tobogganing fun after an infamous snowstorm in that part of the province. Hilda, and her husband Vic, were raising their family on the dreamy shores of Lake Erie. Residing on a private street perched high above the water below, their home overlooked the town's water filtration plant, a neighbourhood fixture since the town was built, and never a cause for worry for Hilda.

With the snow piled tall around the perimeter of the building's fencing, the most curious of her children, her eldest, was free to climb into a forbidden area. Jeff was playing where he shouldn't have been. He tumbled off of a snow drift and reached for the first thing he could grab. The transformer sent 27,000 volts of electricity through his body. A deafening sound and flash of fire rang up the shoreline. In an instant, the lives of countless people were changed forever.

Hilda and her husband were washing the lunch dishes when the lights flickered. Hilda had an overwhelming and ominous sense of doom. She had only a few minutes to shrug it off before Jeff's friend came dashing up the sidewalk with a desperate call for help. Vic raced out of the house. Hilda stayed behind. Nothing could ever have prepared her for what her husband was about to find. "I remember it taking such a long time," recalls Hilda. "A crowd began to gather which was odd.

KINDNESS OF OTHERS WAS HILDA TIESSEN'S LIFELINE

We lived on a quiet dead-end street. Then I saw Vic pulling Jeff up the hill on a toboggan and my heart sank.”

There was no time to wait for an ambulance. “I will never forget the sound of my son’s voice all the way to the hospital,” she tells. “He was disoriented, in shock, and moaning over and over ‘it hurts so bad, I wish I was dead.’” To witness her child in such a state was the worst kind of torture. She crinkles her face and delicately spills out the words, “and there was this horrible smell of burnt flesh. I knew it was really bad.”

Their small-town hospital served only as a brief layover. “I’ll never forget the looks on the doctors’ and nurses’ faces; utter shock and disbelief,” she recalls. This was more than the hospital was equipped to handle and her son was whisked away by ambulance to the nearest city centre – Windsor. Doctors would be waiting for his arrival.

Now what? Hilda had two other children who had just witnessed a horrific accident. They were left at home with their grandparents wondering if their brother was dead or alive. She had to get to them to see if they were alright. The frantic couple stopped at home to find their two small kids huddled with their grandparents – one looking no less frightened than the next. Still, no one really knew how her son got hurt and she turned to the accounts of the young siblings. They were despondent. Jeff needed her most right then, and she needed to get to him. Knowing her two little ones were safe in the arms of her parents, Hilda and her husband raced away from life as they knew it.

“We ran into the emergency room and there stood the two surgeons, pale like ghosts, waiting for us at the door,” Hilda cites. “They were just standing there waiting, like they had nothing to do. We didn’t know the situation; we didn’t understand what being electrocuted meant.” Electrical burns take their time in revealing their full damage. It was now a waiting game... a game no one wanted to play. Waiting and wondering was excruciating.

One week after the accident the doctors finally concluded that it



Jeff’s life took an unexpected turn when he lost both arms in an electrical accident as an 11-year-old boy. He chose to survive and thrive in spite of society’s perception of people with disabilities in the late 1970s. A Paralympic champion and world record holder in the 400-metre event, husband and father of two, Jeff founded an acclaimed publishing company as a vehicle to educate and advocate on behalf of countless others with a disability, always promoting acceptance of those with differences.

was time. “They said they would try and save his elbows,” remembers Hilda. “But his hands would be taken.” It’s striking how Hilda refers to his hands as being ‘taken’ with an underlying connotation of being or feeling robbed of something. Jeff’s life as she had envisioned it had been taken. Jeff’s hands were taken like some sort of punishment.

“We just wanted to get on with things,” offers Hilda. “The damage was done; we had to find a way to accept that. He wasn’t going to grow his arms back.” Hilda was thrust into a completely foreign world. She was a young, sheltered, stay-at-home mom with three happy, healthy children. Changes and concessions were imminent. Acceptance eluded her. But perhaps it was her young age and naiveté that ultimately proved to be her blessing and saving grace all at once.



Multiple surgeries and life-threatening infections ensued. Skin grafts and ice-packed baths followed. Pain and agony. Hilda witnessed it from a front row seat. She could do nothing for him but try to help her son understand this would save his life... despite his oft-repeated wishes otherwise. This was Hilda's greatest agony. It turned and twisted her inside out. She wished she could trade places with him to ease her child's pain.

Every day, for three months, Hilda was at her son's bedside, a 45-minute commute from home each way. Every day she rallied to present a steady and strong attitude for her son. But as time slowly crept along, the couple became more and more frustrated. They pushed for their son's release in the spring but doctors were non-committal. The burn unit was becoming too much like home for him, too safe, with doctors and nurses too much like family. Hilda knew that it was time to leave the comfort of that nest and learn to fly on their own. "I wanted to know what was next for him. He lost his arms but no one was moving in any direction toward rehabilitation or prosthetics." Granted, it was the late 1970s and the doctors admittedly, didn't know what to do next. You just couldn't "Search" for doctors or prosthetics or resources or rehabilitation centres at that time. The internet was still a decade away. But Hilda was ready to face what the world had in store for them.

Jeff left the hospital exactly 100 days after he arrived, with two stumps and a mother sewn to his side. "I had to feed him, bathe him, use the bathroom with him, put him to sleep, get him dressed." She relied on every member of her family for help, including her two younger kids. They became caregivers too. "The hospital basically sent us on our way with best wishes," expresses Hilda. "No referrals. No suggestions, no direction, no hope." Today, she understands that burn units deal with burns and quickly comes to the defense of the doctors and their decisions. "They did their job. There was nothing left for them to do."

Comfort awaited in the arms of her community. The townspeople enveloped her family, assisting in any way they could.

She would get calls from friends of friends and daughters of this person and cousins of someone else. One such overture led to an appointment with a specialist in Toronto. Hilda would now face yet another terrifying fear - this one a very personal one. She'd never before left her small community; she'd never been anywhere on her own let alone a city subway or hotel room. Pushing those fears aside, she packed her bags and headed east to see what was next for her son. An unforeseen reality met her there.

"When I walked into the rehab centre for the first time," remembers Hilda, "I wanted to turn around and flee." When she saw rooms full of children with all kinds of different disabilities, she could not relate. She didn't belong there, she rationalized. Reality bowled her over. She wanted nothing more but to scurry back to the accepting bubble of her community. "This wasn't our world. We wanted to be normal."

But they stayed, deciding to accept the help that was offered. Things now slowed to a pace that afforded Hilda time to reflect on her new reality while her son was in rehab all day... no parents allowed. She began to grasp how many lives had been changed, including her own. "The world was smaller then," Hilda remembers, "and I truly believe that that laid the brick work for Jeff's new road in life." She found solace in recollecting how many times she walked into Jeff's hospital room in Windsor to find countless people waiting to meet him - NHL players, baseball and basketball stars, and even Bill Davis, the Premier of Ontario, would wait patiently for her permission to visit her son.

It was with incredible foresight that these young parents resolved to welcome anyone who wanted to visit Jeff and granted them access. It demonstrated to both

them and their son that people cared and wanted to help. It comforted them to know that they were not alone and at the same time, it empowered visitors to find whatever they were searching for in the company of their brave son. Jeff accepted and appreciated everyone's visits until one day he walked a middle-aged, double-arm amputee, just like him. "Jeff didn't want anything to do with him. He wanted him out of his room and never to come back." As if Hilda could read his mind, she saw and felt what her son was feeling and began to question their choices. "I took one look at that fellow, disheveled, somewhat uncouth, and drenched in the smell of cigarette smoke, and thought this wasn't our story, this wasn't our life," Hilda judges. For Hilda and her husband, they conceded that acceptance was still an issue for them. "We still envisioned our child having hands - not hooks." For Jeff it was not that at all. Simply, he couldn't relate to this man, and Hilda now realizes that arguably, that ruffled, well-intentioned, well-wisher had the most influence on her son of all. Jeff was determined that that was not who he would become.

"Jeff's story was on and off the front page of the local newspapers for months," recalls Hilda. "It's a different world today for sure. People have access to all sorts of sad stories on the internet. Maybe it's harder today to stop for a moment and see how one tiny gesture can change someone's day, or better yet, their life." Ironically, her son was inadvertently doing this for others in his own time of need. Hilda remembers a local newspaper cartoonist, a regular visitor, who would come and sketch his drawings at Jeff's bedside. "I would walk in and there he was," Hilda smiles, "waiting to find inspiration in my son. He would quietly sit there sketching his daily submission. Then one day he just stopped coming," she continues. "Turns out he found whatever he was looking for, quit his job and travelled around the world for a few years before he died. You just never know when or how people touch one another's lives or if we are fortunate enough to even recognize it with our own eyes."

There was one person in particular. "Sitting in the waiting room one day," Hilda starts, "was this odd, diminutive, frizzy-haired man named Cam. He was from a very wealthy family in the area, and at the time the Reeve of a small township in our county. He read about Jeff's accident and wanted to see how he could help. He basically never left." Cam became a friend, a perfectly-timed gift in Hilda's life. He brought his gift of humour back into their lives when there was none. "He was my Guardian Angel," she proclaims.

"He was definitely sent for me." Cam found purpose in his new friends as well. "He was being tested in his life too," Hilda qualifies. "I guess misery does love company." Cam risked it all with the Tiessens when he shared with them, for the first time in his life, that he was gay. He feared they would abandon him. They did not. Hilda now knew what it felt like to desperately seek acceptance, a simple gesture she craved for her son. "If I am asking the world to be accepting of my son as a double arm amputee," recalls Hilda, "then I'd better be willing to accept my friend's choices in life too."

Hilda appreciates how fortunate she was that her son was never bullied or ridiculed upon his return to school as an amputee. "There wasn't a time, not one, that Jeff wasn't accepted by his peers," she commends. "They always did whatever they could to help and encourage him." The only instance that Hilda can remember that called for her to be an advocate for Jeff at school is when he got off the bus dejected, only to report that the soccer coach had dismissed him from a weekend tournament because parents at a rival school feared their children could be injured playing alongside Jeff. Hilda would not stand for it, and headed directly for the school to confront the teacher. "I don't remember my exact words," Hilda laughs, "but I let him know that my son would be playing that weekend come hell or high water. He played."





Far from her nature to stand up and speak her mind, Hilda had to become an advocate for her family and her disabled son. “Strangers bothered me the most,” she confesses. “The apartment where we stayed in Toronto had a pool and Jeff loved to go swimming. It was quite obvious at times that other tenants didn’t approve of Jeff swimming in the pool but I didn’t once back away.” There were times on the streets that people would literally stop and stare at her son with mouths wide open. “At first I got angry,” confides Hilda, “and I would stop and stare back at them or stick out my tongue. Jeff took it better than I did. On the surface, it didn’t seem to bother him as much as it did me. It must have been a mother’s protectiveness that got me so riled up, but I learned over time

to forgive those people.” Every day away, she longed for the comforts of their community back home. “It was the love and support of his family and friends, and his teachers, that built self esteem in Jeff. It was the foundation for how self-confident he is today.” Jeff’s confidence taught his mother a thing or two. She ponders for a moment and says: “He taught us how to survive a tragedy. He’s taught me patience, compromise, perseverance – he certainly persevered at everything he did. Most of all he’s taught me about bravery.”

Hilda has difficulty recalling many of the daily challenges and strategies of those early post-accident years. Maybe the human spirit erases what we cannot cope with. But she does know she did the best she could with what she knew at the time. “We muddled our way through our everyday lives,” she admits. “We searched and searched for the best resources we could find for Jeff. We even tried horse cream and equine acupuncture from a veterinarian,” she divulges. “The vet promised it would eliminate Jeff’s phantom pain [pain sensation in missing limbs, commonly experienced by amputees].”

The War Amps of Canada was a huge help and a wonderful resource for her family, but for the most part this family had to find their own road. They lived in the moment, dealing with adversity as it came, constantly faced with making life changing decisions for their son. “Do we take this help? Do we send him here?” she offers as examples. “What if this doesn’t work out? What if this actually does? It was a record that played over and over in our heads. By the grace of God, this brave kid turned out to be a champion – a Paralympic medalist – a successful author, publisher, horseback rider, father, husband and friend to so many people.”

Muddling, as Hilda puts it, leaves ample room for mistakes too. Going through life in a fog guarantees something will get lost in the heavy mist. Hilda does not shy away from voicing what she considers the biggest mistake of her life. “If I had one do-over in my life,” Hilda reveals, “I’m sure people would think it would relate to Jeff.” But it would not. Hilda wishes she could have been there more for her other two children and acknowledges that they too were suffering and needed help. “Knowing now what I didn’t know then, I would better understand that while my two younger kids may not have lost their arms that day, they were just as affected by this accident as Jeff was.” She regrets that therapy was not as readily available back then as it is today. “If Jeff’s accident happened now, each member of my family would be in post-traumatic stress therapy by sundown. No doubt about it. Each one of us suffered,” she insists. “I don’t think my two younger kids would have had as

many problems growing up as they did if they had the necessary counseling after witnessing such a tragedy and living through its aftermath.”

Unbeknownst to her, Hilda’s life re-started that day, she herself jolted into the woman she is today. The meek, timid, small-town mother was unceremoniously reborn, forced to become a steadfast advocate for her children. But when reading the stories of the other mothers being shared in this book, she offers that she feels very inadequate. Maybe it’s understandable that Hilda wears her insecurities like a sweater. Maybe it’s her badge of honour for time served. Her journey began 35 years ago and she does liken herself to a soldier, one that blazed the trail for the next generation of mothers. What’s more, she has clearly led by example, teaching all three of her children how to stand up for what they believe in and to strive to be the best they can be, and to never underestimate the power of their own will, and never, ever say that you can’t.

It’s hard to face failure. It’s even harder to take something positive away from tragedy. But if you can look past perceived failures and learn life lessons from them, then you are living with purpose. Hilda’s children have not always seen eye to eye over the years. All three are successful. All three are outgoing and all three are advocates for their own causes. But still, Hilda isn’t happy with the disconnected relationships among them. “My children are my biggest success and my biggest failure.” She sees a very detached family and blames herself. She feels that her two younger children developed resentment for each other growing up that was misdirected. She feels that she failed to keep her family together. Outsiders might disagree, but only a mother knows which of her dreams were realized and which ones fell away. But her disappointment begs the question: how does a family that is torn apart at such a tender age be held accountable to keep itself together?

But you cannot deny the intense bond Hilda shares with Jeff. It’s a lifetime of gratitude they owe each other. A mother and her son – travelling to hell and back together. They have been to some of the darkest places two human beings can go, together. They weathered the storm *hand in hand*. They marched through darkness and found the light on the other side. Always as one.

In actuality this mother had two Guardian Angels – her friend Cam and her first-born son, Jeff. All three restored hope in one another’s souls. Life moved on and Cam and Hilda lost touch over the years, but each found comfort in the notion that they had the kind of friendship that could withstand distance and silence. They reunited years later when Hilda wrote Cam a letter of thanks. “I wanted to tell him how much he changed my life,” she shares. “I wanted to thank him for everything he had done for us and tell him that he was my Guardian Angel.” Cam religiously carried that letter with him everywhere he went until the day he died. How a simple kind word or gesture can change a life forever... a powerful act in someone else’s life story.





Loving Memories

A single mom since her twins were four years old, Brenda Keleher approached life as a special needs parent with optimism and celebration. Her twins – Paige and Hayden – have cerebral palsy. As young teenagers, both gregarious and clever, her kids learned at an early age how to confidently self-advocate for themselves – a tremendous life skill. It’s a skill that Brenda very much valued, in her last years especially, with much of her attention turning to her own challenge... her battle with cancer. She lost that battle on September 18, 2011, at the age of 49.

In our interview with Brenda slightly more than a year before her death she described her kids as a gift. Paige is older than her years in terms of her maturity. But she has a youthful side to her too. “She’s playful and optimistic... always positive. She’s the cheerleader of our family, Brenda elaborated. “Hayden is more serious in some ways. He puts a lot of thought into what he says. He’s a happy kid, a fun kid, with a very interesting sense of humour for a boy his age. And he’s a very appreciative kid. Doing something for him leaves you feeling really good about yourself.”

As for being kids with a disability, Brenda often wondered if being twins might make it easier for them. They always have each other which they appreciate. They live in the same environment, or world, so to speak, so they can empathetically support one another. They have separate friends, and are in different classes at school, but they are each other’s best pal. They look for each other first to ask for help and share experiences. “I think it’d be harder for them, in terms of their disabilities, if they were singletons or different ages,” she assured herself.

Brenda saw in herself many of the traits that define her two children. “I’m pretty optimistic. Determined. I know that I have a lot of drive and perseverance. Where there’s a will there’s a way.” She never looked at parenting a twosome with special needs as a litany of challenges. “I don’t really look at parenthood that way,” she emphasized. “Parenting kids with special needs is different, and

BRENDA KELEHER'S LEGACY OF SELF-ADVOCACY

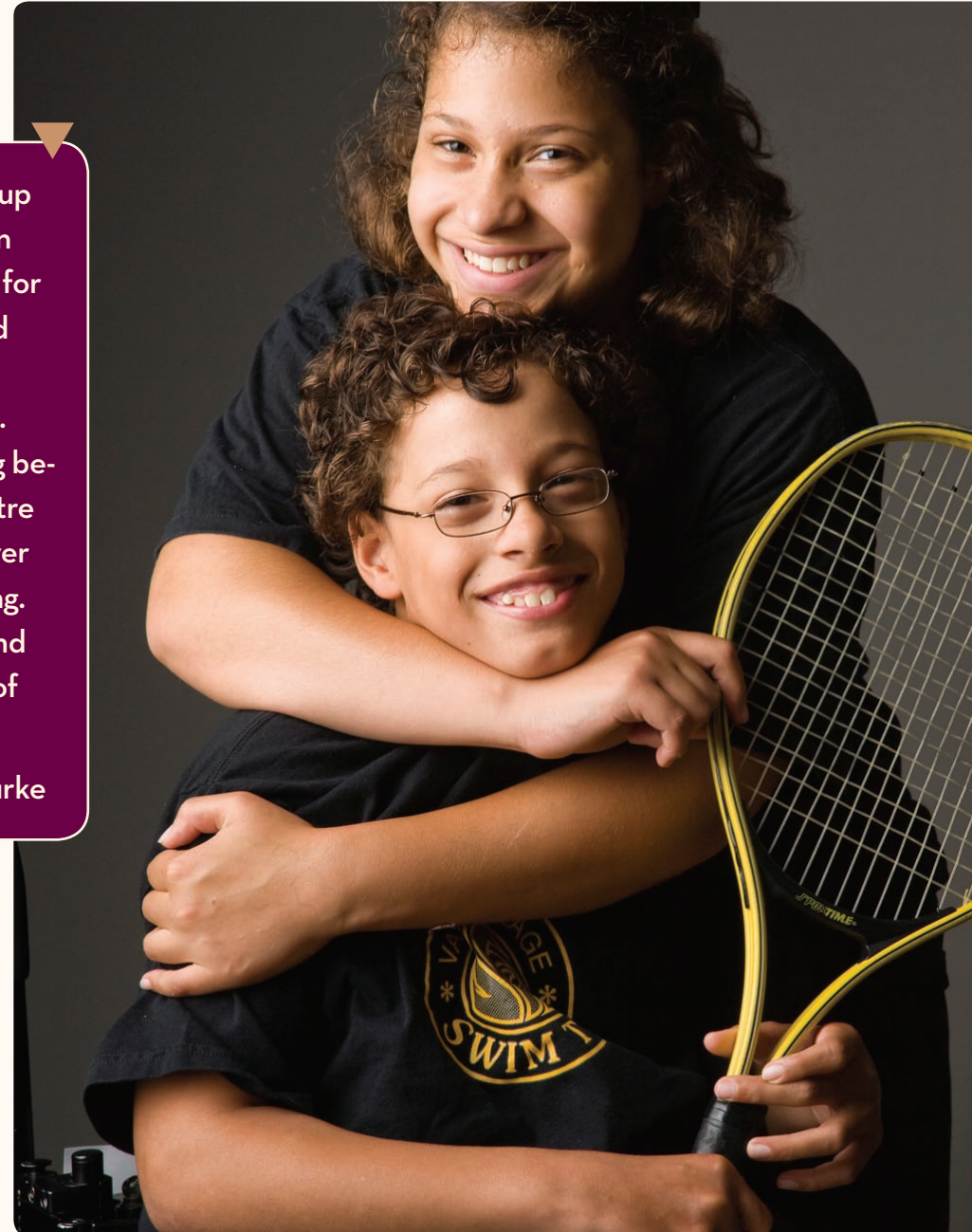
again different for every parent. But a big challenge for us as a family is getting past others' views of Paige and Hayden's limitations."

It annoyed Brenda when people would do too much for them, especially for Hayden, likely because his disability is more visible. When people jumped to the conclusion that he couldn't do something, it got her back up. "I tell the kids that nothing is impossible; not everything is possible, but nothing is impossible." She explained her mantra through a story about Hayden coming to her after school one day and telling her that he wanted to play soccer because there was a big soccer tournament coming to his school. She didn't know what to say. "I took some time to think about it and came back the next day and simply said: 'You know Hayden, we'll try. I don't know what's possible right now, but you never know what's possible in a year or five years.'"

Acceptance challenges at school can be a hurdle for some kids with differences. Not for the Keleher kids. The twins have had great experiences in school. Brenda knew that they were fortunate in that regard and points to a couple of reasons for their success. For one, from their experiences at a children's rehab centre as their first school experience, the kids were taught how to advocate for themselves. And two, their mom made it a habit of listening for objections, negativity, or stereotyping from school administrators which raised red flags for her. "Each child with a disability is different and special needs kids can't be painted with the same brush," she promoted.

"Paige and Hayden, you have grown up with the best role model any children could have. Your mother made a life for you, because she believed you would accept all the love this life will offer. Your mom was proud of your talents. You were at the centre of everything because you have always been the centre of her world. Never stop singing, never stop learning, and never stop laughing. Your mom believed in you, always, and knew you can embrace a future full of promise. You are her legacy."

- Natalie O'Rourke





Brenda knew how important her approach to advocacy was to her success for Hayden and Paige.

“I don’t bang my fist or go into these situations as a demanding parent,” she shared. “I want to work with the school and help them try different things. Educating in a gentle way brings people around. I listen and try to understand their barriers. Helping schools overcome obstacles, instead of leaning on my child’s rights, is more productive and often appreciated.”

Parents across the board, with or without a child with a disability, worry about scenarios in the future perceived to present problems. But Brenda learned early on that when we get there, it’s usually really not an issue for our kids, or an issue at all. “I can’t say that I never think about the road ahead for them, but I don’t dwell on what we’ll do when this or that happens in the future,” she admitted. “I

trust that their personalities will get them where they need to go. People ask me what I’m going to do when they’re older, when I can’t lift Hayden for example, or when Paige won’t listen. Experience has proven to me that when we get there, there’s a way. Maybe it’s a different way than we envision now, but there’s a way. Jumping into the future doesn’t help.”

She worked on their strengths, what she considered to be their best ally. She isolated their interests and helped them develop skills and strengths around those interests. Hayden for example wants to be a cartoonist. He doesn’t have the fine motor skills that most would presume to be necessary for such a profession. But his mother intuitively noted that not she, nor anyone else, knows what will be available to him in years to come. “We can’t limit kids; we can’t predict the future and the technology that’ll be at their fingertips,” she advanced. “There’s no way of telling what’s around the corner for our kids. We must keep an open mind.”

An introspective woman, Brenda was not the type of mother quick to portion advice to other special needs parents.

Acceptance was important to her. She looked for the beauty in what her kids have and who they are. “For me,” she said, “everything has been a gift with them. They were born so early – 27 weeks – and I’ve celebrated every developmental milestone along the way... first with the news that they were alive, and made it through the premature birth, to them breathing on their own, to talking, and so on. One day at a time.”

She lived her life admiring what her children accomplished. She refused to worry about what they hadn’t achieved for fear of putting them in a position of doubt. She simply kept encouraging them. She kept giving them opportunities. “Kids who are willing to try and even fail, are the kids who succeed,” she understood. “Many parents fight labels but I disagree with that,” Brenda qualified. “Often times without the label, you’re not going to get the accommodation. Call it whatever you want to ensure the best environment and opportunities for your child.”

How about regrets? When asked if there was anything she’d do differently in hindsight, Brenda paused and replied: “That’s hard to answer. I live in the moment and look at what we have now. It’s hard as a parent to let your child struggle. Sometimes I think I should’ve let my kids struggle a little more on

things. Like working harder on homework without me jumping in, or working on new skills like dressing which might have come sooner without my intervention. Sometimes it's easier for everyone, parent included, to jump in and help but that doesn't always benefit the child. You catch yourself after the fact."

The temptation to rush to help for parents with a child with a disability is greater today, Brenda believed, in part because the world around us is watching, and witnessing our parenting. "I remember teaching Hayden how to open doors at the mall so he'd be prepared mentally to manage his path when people aren't there to help," she began. "The people who were watching were no doubt wondering what kind of mother I was - letting my child struggle and not helping." That's when the judgment of others comes into play. "Am I bothered by it? No. Other parents with kids with disabilities get it. But the outside world sometimes underestimates what we do in a big way."

Brenda will always be remembered for her strength of conviction and spirit, and the skills she imparted within her children, particularly those that fortified their ability to advocate on their own behalf. The only thing that could weaken her was her own personal struggle with a very rare cancer, a fight she fought for five years. But even in her darker days, her indomitable spirit would still shine through. "I'm grateful for the days I wake up feeling good," she would say. "I try to stay optimistic and live each day. My kids are my inspiration. They wake up with pains too but they carry on with their days with a smile. They've had challenges with their health since the beginning. But we've always focused on their strengths and I never hear them complain about having to get up and face a new day."

Being a very independent single mom, battling cancer taught Brenda one last life lesson... how to accept help from others. She had to rely on others to care for her kids when she traveled to England for her treatments, or simply when she just wasn't feeling well. "I've had to learn how to ask for that help," she confessed. "And it's been overwhelming. I never imagined how much help was out there just waiting for me to ask for it."

With no family nearby, friends delivered meals to the Keleher house for a year. Thirty people were on a roster to help. "It's so great for my kids to see what kind of giving community we live in," she commented with an eye to her inevitability and their eventuality. "Whatever happens, I know this is how it is supposed to be."



A Cherished Friend Excerpts from Brenda Keleher's Eulogy • Saturday, September 24, 2011.

Paige and Hayden, as sad as we are, today is a day of thanksgiving.

A day of appreciation for what Brenda gave each of us, in all the moments and memories which brought joy to this world.

We give thanks for Brenda: the exceptional mother, the remarkable friend, the superb shopping partner, the tender voice of counsel, the generous hostess, the driven swimmer and Mayfair workout partner, the sophisticated and talented artist, the brilliant and elegant woman, the gifted leader, the outstanding colleague, the thoughtful neighbour, the committed team member, the invincible advocate, the capable organizer, the meticulous planner, the careful teacher, the faithful church member, the beautiful soul, our Brenda.

Brenda made an impression on everyone she met. Some to whom she grew close, and others with whom she may have had a brief acquaintance. But wherever Brenda went, she struck people by her gracious confidence, and her demure ability to convey sincerity.

Your mom, Paige and Hayden, was a woman who could achieve anything. She was able to find solutions without losing sight of what was important: You.

You, Hayden and Paige were at the centre of everything, because you have always been the centre of her world. Your mom loved you before she knew you were there. She made all of her decisions and all of her plans around what was best for you. Everyone here knows that nothing Brenda contemplated was ever done without both of you at the heart of all of the choices she faced.

Together as a loving family, her kids were Brenda's existence, her greatest strength, and her most powerful softness.



She was a pioneer in groundbreaking advancement for treatment not available to Canadian families. She fundraised, she travelled overseas and upon her return, she lobbied and advocated for other families who could benefit from the calculated chance she orchestrated for Paige and Hayden's care.

Brenda routinely lent her wisdom to families of twins, and multiples. She gave sound counsel when asked, and she was compassionate beyond words when friends and strangers alike needed her insight.

When Paige and Hayden were ready for their own start at school, Brenda carefully assessed what would be best. At Bloorview, Brenda made sure everything was as optimal as it should be. She again earned a reputation for being knowledgeable and invested. Parents, teachers, health care providers, therapists, doctors, social workers, executive board members, everyone knew that Brenda was the mom who gave 100% for her Paige and Haydie.

Brenda ensured that Paige and Hayden embraced life in her mother tongue, and worked diligently to have them excel in their French schools. She believed they needed to be well-rounded to prepare for independent life, so she made all the necessary arrangements for them to go to camps, and to take equestrian programs, to learn how to enjoy cold Canadian Sundays on a ski hill, to swim and represent their sport at the highest levels.

Brenda knew that Paige and Hayden had it in them to face the challenges that a rewarding life will offer.

She had the vision and the patience to systematically introduce activities and life lessons that would develop the necessary tools for you to realize: you can do it.

With all that Brenda had to expertly manage in her adult years, I have never heard her say the words: "why me". I heard her say "why them". She was concerned, always, for her precious children. Her reasoning was devotedly this: Paige and Hayden had never asked for any of these incomprehensible stresses.

When she learned of her diagnosis in late November 2007, we knew Brenda would face the course ahead with determined focus and a battle plan. She was practical to an extreme, and knew to draw on expertise in every respect, and

from every discipline. She took on every appointment, and every treatment, as though it was a business. The objective was profit. The gain was everything to be done for the kids. It was all about meeting the next objective, to make sure the kids would be OK. She never complained for herself, but she was always clear and frank about reporting the facts.

You could consistently count on Brenda telling you what she really thought: it would be honest, and it was always her truth.

Paige and Hayden, you have grown up with the best role model any children could have. Your mother made a life for you, because she believed you would accept all the love this life will offer. Brenda was proud of your talents, and so are all of us present here today. Never stop singing, never stop learning, and never stop laughing. Your mom believed in you, always, and knew you can embrace a future full of promise. You are her legacy.

Brenda surrounded herself with people who put their kids first, just like she did. Being with Brenda was like being drawn to a magnet, because she let you know with her bright eyes and her gentle smile that she was interested in hearing what was being said. She didn't always agree, but it was always OK.

After her third and what would be her final trip for treatment abroad, Brenda began to take note of new symptoms and again, planned to face them with all her courage, and solution-oriented thinking.

There were more trips to see her team in southern Ontario, and eventually her admission to hospital. She remained determined to keep Paige and Hayden secure in knowing that mom was taking all the necessary steps to garner resilience against her changing health status.

Still, she used all of her energy to make plans for her kids. Brenda was on the phone, or e-mail, checking on delegated tasks to make very sure nothing was left to chance.

Brenda gave of her time, generously. She gave of her knowledge, effortlessly. She gave her love, genuinely.

Even after Brenda let go of her last earthly breath, she made two new friends: strangers, who celebrate with their loved ones today, with grateful hearts. Brenda's generous belief in humanity, allowed for two friends she had not yet become acquainted with, to see a gracious world with her eyes. Two strangers were blessed by Brenda's zest for life, and her constant selfless desire to create good. Brenda's gift through organ donation reminds us that she is still among us.

Brenda took Paige and Hayden to Sauble Beach again this August, as it was their end of summer ritual for many years. This is where memories to last a lifetime were created. And, as Brenda had wished, she will rest there when her ashes are scattered as her final farewell.

So when you see the sunlight twinkle on open water, remember Brenda's sparkling eyes.

When you hear waves rolling along a shoreline, know that she is telling you: "I'm OK".

When you feel sand between your toes, and wind brushing your cheek, remember Brenda's calm spirit, and be grateful for the moments you shared.

Our Brenda is free, she is free.

Adieu, ma belle amie.

Thank God for the life, that was Brenda, now she is free.

I have dearly loved you, my friend.

Natalie O'Rourke



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The Canadian Foundation for Physically Disabled Persons (CFPDP)

is all about "Changing the Way We Think About Disability." Since 1985, Rotarian Vim Kochhar and his fellow Rotary Club of Toronto - Don Valley members helped raise funds for the Rotary Cheshire Homes and Ontario Sport for the Disabled. Intended to be a one-time event, the Great Valentine Gala became so successful that a charitable organization was created to stage subsequent events and allocate funds.

The Hon. Kochhar, now a retired Senator, serves as CFPDP's Founding Chair. Its goal from its inception has been to assist individuals with physical challenges to live fuller lives and raise awareness of their achievements and contributions to society. CFPDP has carried the torch for the Paralympic Movement and initiated dozens of important projects, including the Canadian Disability Hall of Fame and the Rolling Rampage on the Hill, raising over \$25 million. The Gala celebrated its 28th year in 2012.



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Henderson Structured Settlements, as a company and as individuals, is dedicated to the principle of giving back to those most in need. Among other charities and public institutions, the company is presently a major sponsor of and fundraiser for the Canadian Paraplegic Association, both in Ontario and British Columbia, the Ontario Brain Injury Association, Hamilton Health Sciences and various other brain injury associations and hospitals across Canada. To learn more, visit www.henderson.ca.



The Canadian Association for Prosthetics and Orthotics (CAPO)



capo

Canadian Association for Prosthetics and Orthotics

is a non-profit, volunteer organization representing more than 500 professionals across Canada in the fields of prosthetics and orthotics. Our professional members are practicing prosthetists and orthotists certified through the Canadian Board for Certification of Prosthetists and Orthotists (CBCPO). CAPO evolved from a national association established in 1955 to provide a national, professional organization with a strong voice to represent the interests of the growing number of practitioners in the fields of prosthetics and orthotics across Canada. Certified professional care to move, to live, to thrive. To learn more, visit www.pando.ca.

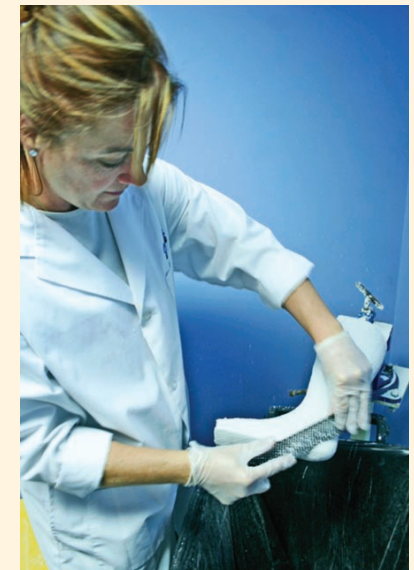


The Canadian Board for Certification of Prosthetists and Orthotists (CBCPO) is the regulatory body for the prosthetic and orthotic profession within Canada. CBCPO is recognized nationally and internationally for its adherence to the highest standards for the orthotic and prosthetic profession. These standards are critical to the CBCPO certification, registration, facility accreditation and professional discipline programs.

The mission of CBCPO is to regulate the Prosthetic and Orthotic profession by maintaining and enhancing professional, educational and technological standards so that the general public, paying agencies, patients, and the medical community can be confident that the quality of prosthetic and orthotic care in Canada remains world class. When selecting your orthotist/prosthetist, make sure he or she meets the profession's highest standards: CBCPO certification. To learn more, visit www.cbcpo.ca.



CANADIAN BOARD FOR CERTIFICATION OF PROSTHETISTS AND ORTHOTISTS
CONSEIL CANADIEN DE LA CERTIFICATION DES PROTHÉSISTES ET ORTHÉSISTES



*“Always concentrate on **how far**
you’ve come rather than
how far you have left to go.”*

- Unknown



ABOUT THE BOOK

Inspired by the overwhelming response from parents to the first two books in the *Glowing Hearts* series (*Play to Podium* and *Skates and Skis for All Abilities*), the *Mother & Child* edition departs from a “for kids” format to serve as an enlightening resource for moms (and dads) with a child with a disability.

Mother & Child delivers an anthology of honest, heartfelt personal accounts about embracing differences, and surviving and thriving as a special needs family. Ten magnificent mothers are reverently celebrated through their triumphs, trials and tribulations, joys, fears, hopes and dreams.

“Our” moms, like all moms, rejoice in their child’s accomplishments and relish in their smiles, but they are most inclined to cherish even the smallest of victories. *Mother & Child* honours their journeys as a signpost for other families traveling a similar path. Remarkable women. Incredible stories.

“Much has changed in the field of advocacy and disability in the past 60 years, but what hasn’t changed is the fact that families raising children with disabilities also need great role models to inspire and guide them. There are many ways of fostering self-esteem and autonomy in children with disabilities. The Glowing Hearts series is a treasure trove of terrific role models.”

– Arlette Lefebvre, MD, FRCP, OOn, CM

“Who are these moms, the ones who wield such love that they forge paths where none exist? The ones who see far beyond their child’s impairment or limitations, and into the land of limitless potential that exists within every child. The ones who foster happiness with a vision of what is possible, not what is not. Can their stories be told? You be the judge, but I promise that what you will discover in Mother & Child will inspire and encourage a generation of mothers and fathers, teachers and coaches.”

– Joe Millage, Coach and Mentor

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