Spring 2016

CONNECTIONS

A newsletter for fathers and families of children with special needs.

Join Us for the 33rd Annual Fathers Network Campout

It's that time of the year again. Our annual campout at Washington Park in Anacortes happens over Father's day weekend, the evening of Friday, June 17, all day Saturday, June 18th and the morning of Sunday, June 19th. You can come for all of it or just part of it. If you need more information contact me at louis.mendoza@kindering.org or 425-653-4286. I'll send you information that covers what to wear, food, weather, location and a checklist of what to bring. This year the campout includes a special event, a presentation and discussion on adaptive recreation which will take place Saturday afternoon.

As always a special shout out goes to Ed and Jeannie Gegen, Anacortes residents, who head up organizing this great event. It'll be my first time attending and based on all the wonderful things I've heard I'm really looking forward to the experience. See you there!

Inside this issue:

What's the News About the Conference?

The Steering Committee has begun conversations about the conference and is looking at holding the event in Bellevue on one of the first two Saturdays of October of this year. If you have ideas on presenters, breakout session topics or would like to be involved in some way, the committee would appreciate hearing from you. Those suggestions and offers to help can be sent to Louis Mendoza at louis.mendoza@kindering.org or 425-653-4286.

Helping Parent Training Tailored for Dads

The Helping Parent training offered by The Arc of King County prepares parents who have children with special needs to mentor other parents on a similar journey with their children. Historically the program participants have been almost exclusively women. In an attempt to get more men involved in this effort, The Arc and the Fathers network brought together a focus group of dads to discuss how tailor the training to the needs and interests of dads. The first of the workshops incorporating this feedback will take place on June 4th and 11th at the Arc of King County from 9:00-Noon. If you're interested in attending, contact Rachel Nemhauser at RNemhauser@arcofkingcounty.org or 206-829-7046.

Have You Seen It? New Fathers Network Video

For those who haven't seen it, the Network does have a new video which we're using to promote our organization. We have a long and a short version, feel free to share them. Special thanks go to Greg Schell, the previous Director of the Network, for laying the ground work and creating a pilot video and to Laura Garcia, the videographer who created the pilot as well as the final versions.

Memories Vivid 10 Years After Ski Trip of a Lifetime

by Spencer Hatton

The following story was written by one of the dads who submitted a photo for our new video. It was written in 2012 and published in the Yakima Herald-Republic. The author, Spencer had this to add: "I wanted to share with you how my late son Jed and I pushed the envelope with respect to what kids with special needs can do. For Jed and me, there were no limits. Too often Dads who have kids with special needs are told by others what their sons or daughters cannot do. It was always "no" whenever Jed tried to do anything when he was very young. One day he said "no" about 100 times in a row before we got the message. Let's dwell on what he can do. And guess what, a whole new world opened up to us and to our son. I hope the story helps to explain the utter joy that I felt literally conquering mountains with my wonderful son Jed leading the way."

Fifty skiers were to our left and another 50 to our right. Together we formed a half circle, each skier poised to take the sudden drop down the hill into a bowl-shaped slope near the summit of 7,160-foot Whistler Mountain.

I stood directly behind my 17-year-old son, Jed. The front of his skis hung over the lip of the hill. I felt a sense of dread and could taste the bitter swill of adrenaline slicking my mouth. We are going to crash again, I thought.

I raised my hands and placed them on my son's back. We were ready to take the plunge. That's what dads do, right? Push their kids off a mountaintop. If I hesitated, all would be lost.

I shoved my son forward, and down we went.

The packed snow vanished beneath us. Wind blasted my face. Tears streaked my goggles. But Jed held firm, the snowplow wedge of his skis a mirror image of mine. I pulled back on the nylon strap, which cinched us together, and gained control of our free-fall.

For the next hour, we weaved our way down the slopes, attracting scores of onlookers who marveled at our tandem skiing. We eventually made our way back to a gondola station midway down the mountain.

Somehow we had conquered Whistler, future home of the Winter Olympics, and in so doing, made history.

This month marks the 10th anniversary of our trek to British Columbia. My heart still races when I think back to that day in March. We accomplished something no one had done before — skiing down Whistler Mountain using an adaptive ski device perfected by Outdoor for All Foundation, a nationally recognized, Seattle-based organization that provides year-round outdoor activities for children and adults with physical and developmental disabilities.

I confirmed our record-setting feat a few months after our trip when I met up with the foundation's executive director at a conference in Seattle. I asked him if anyone had skied down Whistler Mountain using the adaptive ski reins. He stared at me in amazement and replied, "Not that I know of. Who would be crazy enough to do that?"

I smiled back. "My son and I."

The device, which Jed and I used, consists of a pair of metal clamps, a long nylon strap that loops around the skier and a short bungee cord, which prevents the skis from crossing. By pulling to the right on the nylon strap, I was able to get my son to make a right-hand turn, and by tugging the strap to the left, Jed would turn left. Deceptively

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Dads Help Promote the Network

On May 11th, Network members Hameed Quraishi (pictured) and Cliff Gillett helped get the word out about the Fathers Network at the Auburn School District Family Health Fair at Auburn High School. Thanks guys!!

What a Great Day! Dads and Children Photo Event

On May 15th, the photographers of the Woodinville Media Group donated their time and talent to take photos of dads and their children with both the studio time and the photos free to those who attended. The photographers and I had a great time meeting everyone. Some people came dressed casually; others came in dresses or suits. One dad and his son came dressed to support their favorite college, Washington State and another dad and son wore Hawaiian shirts and some absolutely beautiful Hawaiian necklaces. Two sets of twins took part and the age range of the children went from 10 months into adulthood. It was a lot of fun. As one of the photographers put it, “It's not every day I get to be a total goofball just to create smiles! I had a blast. Thank you for such a great opportunity to get to know these wonderful children even if just for a few moments.”

Dads Groups Collaborate

The Fathers Network, WA Dads, Dads Move and D.A.D.S. have begun working together to find ways to better serve dads across the state. We met on Sunday, May 22nd and plan to continue meeting quarterly. At this first meeting we spent time getting to know each other and the work of the respective organizations. We also came to agreement that working together held great potential. This collaboration will have many benefits including referral options for dads that are closer to where they live or work, sharing of activities or events to our respective members and possible financial and logistical support for activities and events.

The Tao of T-Rex by Lindsey Miller

This story was written by another dad in our new video who I recently had the pleasure of meeting.

It’s a sunny Saturday afternoon and I’m at the park with my kids. I’m pushing my twin girls Bhumi and Moxie on the swings, and across the park I can see my son Kaze trying to play with other kids. He’s stomping around, pretending to be a T-Rex. He walks up to a boy around his age and roars loudly. The boy looks at him strangely and walks off. The other kids at the park react the same way, and the parents do as well. Some of them even look around nervously, as if to say, “where is this weird kid’s parents and why don’t they step in here? Clearly my kid doesn’t want to be harassed by this T-Rex child.”

If it’s not obvious by now, my son Kaze is on the autism spectrum and doesn’t always know how to relate to people. He loves dinosaurs and everything about dinosaurs. Pretending to be a T-Rex is to him how Andrea Bocelli must feel when singing opera. Stomping and roaring is Kaze’s magnum opus, and nothing in the world makes him happier.

Honestly, I can’t say I haven’t struggled with it. Scenes like the one at the park used to really bother me. Not because I wanted Kaze to act differently, but because I wanted people to understand who he was and be ok with it. I wanted the other kids to “get it” and not shun him because he’s “weird.” I wanted Kaze to be able to have friends and play with the other kids.

But then one day I realized that I was really the one with the problem. Kaze was always happy being a T-Rex whether other kids would play with him or not. Why was I so upset about it if he wasn't? I was forcing my own preconceived notions about who my son should be just as much as all these other judgmental parents were. As much as I believed I was different, the truth is I really wasn’t. I had just packaged it differently, but I was the same as anyone else. I wanted something “normal” for Kaze when ultimately that didn’t matter to him. That’s exactly what makes him so extraordinary, and I was almost too myopic to notice it. Once again, he was teaching me something crucial about life and the universe, and once again I was completely missing it.

At 18 months, when we first noticed our son Kaze wasn’t developing the way we were expecting, we were really concerned. The pregnancy and birth was fine, and he was a healthy happy boy. Having a special needs child was the last thing I expected. He’d been a very late walker,

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Memories Vivid 10 Years After Ski Trip of a Lifetime (continued)

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simple.

Though Jed was diagnosed with autism when he was nearly 3 years old, he never lacked for physical strength or agility. He loved to bounce on a trampoline and won numerous gold medals at Special Olympics track events. When the foundation held a clinic at White Pass Ski Area in 2001, I signed Jed up. He did great, so I decided to buy one of the devices.

A year later we got our chance to use it when a college friend living in Iowa called and asked if we wanted to join his wife and daughter for two days of skiing at Whistler.

Our first day was a blast. Jed and I found an easy beginner's slope, where we performed a ballet of sorts — both of us cutting a path across the slopes with me tugging at the ski reins and Jed making graceful turns by forming a wedge-like V with his skis.

The next day, though, was a different story. My legs were stiff. I could barely bend my knees. But that didn't stop me from accepting a challenge posed by my friend: How about taking the gondola to the top of the mountain? Sure, let's do it, I replied, with a bravado that comes from growing up in the 1960s when no idea seemed too crazy.

To get to the gondola, Jed and I first had to ski down a short slope. I nudged Jed forward and we started our descent. I pressed down on my skis to make a wedge. Suddenly my legs tightened. Two turns later and my legs cramped up completely.

In a split second, I whizzed by Jed. He looked at me and I stared back at him. Up ahead, a bridge over a ravine was fast approaching. I had only one choice. I collapsed to the snow and locked my skis into the slope.

An eerie calmness set it. The ski reins lay on the snow, slack at my side as Jed zoomed past. I braced myself for the inevitable. Like a horsewhip, the nylon strap snapped loudly. I felt my shoulders strain as I absorbed the impact of Jed's 195-pound body slamming into the snow. His skis flipped wildly into the air.

After a few minutes of sheer panic, we calmed down and checked our body parts. No broken bones, no limbs hanging by a torn tendon. I decided discretion, not valor, was called for, so I picked up our skis. We slowly made our way to the gondola, beaten but not defeated.

No wonder I feared the worst a half-hour later when I pushed my son down that steep slope at the top of the mountain. What a frightening yet fabulous memory.

I'm still amazed it ever happened since two weeks before our trip, Jed suffered his first seizure and was taken by ambulance to the emergency room. I called my college friend, who's a doctor, and told him I thought we shouldn't go. He said Jed would be fine. "When are you going to get a chance like this again?" he added.

So I said "yes" to the trip and to that wild ride up the gondola.

My son would die seven months later following complications from another seizure. I don't have any photographs from that trip. It doesn't matter. How could I ever forget the sight of my son leading me down the face of Whistler Mountain, with his skis creating a perfect arc in the snow, and me holding on for dear life.

The Tao of T-Rex (continued)

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but we didn't think much of it. However, he still didn't have any words, and we began to notice some of the telltale signs of autism—obsessions with trains and cars and playing alone for long periods of time.

At first, I shrugged it off. Kids develop at different paces right? No need to be too concerned at this point. His pediatrician said the same thing. There were enough indications that Kaze was going to be fine. My wife, on the other hand, wasn't buying it, and started the process of having him assessed.

I'm so glad she did.

There was a long waiting list for a diagnosis. We were told it would take at least a year before there would be an opening, and as time passed, it seemed more and more likely that he was on the autism spectrum. We were starting to get nervous. If we didn't get the diagnosis soon, and get him help, we might miss some of the really important windows in cognitive development. Six months passed and we got the call. Someone canceled and there was an opening.

The tests confirmed what we'd been thinking. Kaze was on the spectrum, but high functioning. There was a bit of disappointment knowing that we were going to be raising a special needs child, but having the diagnosis was a huge relief. Knowing who your child is and the kinds of things he's going to struggle with is very empowering. Now it was time to roll up our sleeves and get him the help he needed.

However, this road wasn't without its bumps. Even with the diagnosis, our health insurance provider was refusing to cover payment for his therapies. This is illegal according to Washington State legislation, so I reached out to a lawyer and formed a class-action lawsuit. The process was long and arduous, with many late nights writing lengthy appeals in order to build the case. Two years later, we won.

This was the biggest hurdle, but there have been other things we've encountered, and often we have to work a lot harder to see the same pace of cognitive growth. Unfortunately, I think the standard perspective from parents who have children with special needs is that because their lives are harder, because there are more long nights and bumps in the road, they're really missing out on the great experiences other parents with "normal" children get to have. Originally I felt the same way.

But now I don't.

Now, I have exactly the opposite perspective. I'm actually elated that I have a special needs child. He's wonderful and quirky and has opened up my world in ways I never knew would be possible. He's got an amazing imagination, and although people stare when he pretends to be a T-Rex for hours, I think his complete dedication to it is incredible. He really embodies the T-Rex and won't break character for anything.

I'm grateful to my son that he's given me the opportunity to have experiences other parents with typically developing children won't have. In fact, I think they should be jealous of me. I got to take part in a class-action lawsuit that resulted in justice for everyone across the state of Washington. The things I learned in my parenting classes were applicable for many other aspects of my life, and helped me learn how people think and the best ways to motivate them. Because I have to be more involved in his education and progress, I'm required to spend more time with him. Coming home from a high stress job, often the last thing I want to do is work extra hard to be a good parent. The joy and love I experience, though, in giving my all to my family is incomparable. My hard work is immediately rewarded.

When I look back on my life once I'm old and my kids are grown up and have kids of their own, I will have no regrets. I will have thrown my life into raising my son and my twin girls, and will have reaped all the rewards of a life well spent in the love of my family. I'm just glad the T-Rex taught me these lessons before it was too late to learn them.

Update -Technical Assistance Family Leadership Project

In the last newsletter I mentioned that the State Department of Health, Healthy Starts and Transitions Unit received an award of $10,000 from the Association of Maternal and Child Health Programs (AMCHP) to enhance family engagement and leadership efforts across the state. And, I mentioned that a group would be traveling to New Jersey to study their model and that I'd update you on the work.

The visit to New Jersey was very informative. Lots of good information and best practices were learned in regards to outreach, training, incorporation of diverse populations, modifying training based on the audience, establishment of a mission and value statement, and creation of a plan for implementation and sustainability. Since then a larger group of organizations interested in this work meet with a consultant provided by AMCHP to discuss next steps. From that meeting an organizing committee has been established that will create a mission statement and develop an overall work plan of long and short term action items. Once this is done specific work groups will be established.

It is still my hope that this work will result in more opportunities for dads to take leadership roles that will allow them to share their knowledge and experience.

WASHINGTON STATE FATHERS NETWORK

The mission of the Washington State Fathers Network (WSFN) is to promote fathers as crucially important people in their children and families' lives. We firmly believe men are superb resources for each other and fathers have special needs of their own when it comes to raising a child with chronic illness or developmental disability.

WSFN, a program of Kindering, is funded by the Office of Children with Special Health Care Needs Program - Washington State Department of Health, grants, and private donations.

KINDERING Washington State Department of Health