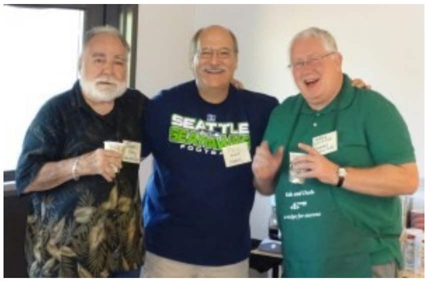


CONNECTIONS

Winter 2015-2016

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

Inside this issue:

How My Dad Being in the Fathers Network Has Affected Me

by Sabra Quraishi

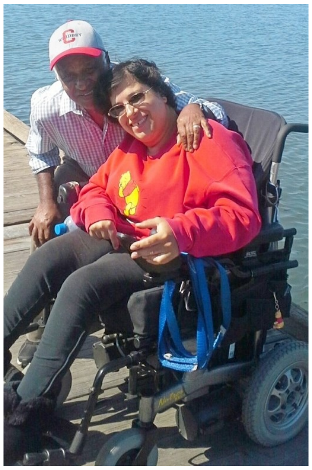
This first piece is written by Sabra Quraishi. She's someone I had the pleasure of meeting at last September's pancake breakfast. She's the daughter of one of our long time Network members and offers an interesting perspective on the Network and how it's affected her, her dad and her family.

It's my honor to be asked by Louis Mendoza to write something about my experience growing up with Fathers Network, ever since I was ten years old.

I remember my brother and sister going with my dad to the meeting. I fondly remember, upon entering the then "Merrywood" building in Bellevue and getting a "warm and friendly" greeting from James May: The Director of Fathers Network. He'd give each of us: fathers and their children, "personal" attention just like a dad would give to his children.

Back then we had childcare. I'd help out while dads would attend the meeting. It was all due to James' love for children of Network Dads. Dads would bring their children to give moms a break so dads would bond with their special need children.

James bestowed an honor, "Chef Hameed" to my dad and he has been fulfilling this duty ever since at the "Kick-off-Breakfast". It's held on the second Saturday in September. My Dad and I go shopping for supplies on Friday, the night before the breakfast. He, with many helpers, would prepare breakfast: scrambled eggs with mushroom, sauté onion and cheese, sausage, potato patties, orange Juice, pancakes and salsa. I, along with others, my mom too, play the role of "Food Runner": keep food coming from the kitchen to the dining tables. It is fun and I love being a



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The State of the Network and Some Goals

by Louis Mendoza

In these first 5 months of work I've been getting some sense of the state of the Network. This has resulted in some thinking on my part about goals. These are thoughts I have knowing that with only 5 months under my belt these goals may change.

Currently the Network has active chapters in Chelan, South King County, East King County, Seattle, Everett, Spokane and Yakima. I don't know if that number is surprising to you or not, I've been told the number of chapters ebbs and flows a bit. But, because we know the need is there, it would be nice to have some additional chapters as well as make sure our existing chapters are sustained. So, chapter maintenance and development is one goal.

I think recruitment will always be a goal but there is a new aspect to it that needs to be considered - social media. Bringing in new members can certainly be enhanced by making the Network better known on the internet but I'm very interested in using social media to communicate

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Getting Involved, Staying Involved

by Otto Goettel

Otto is a dad I met through Seattle Children's Hospital. He's very passionate about a lot of things but especially about dads being involved with their families. I think you'll sense his passion as you read his article. FYI, the photo is of their guide dog, Ulti.

I'm writing this to encourage you to continue being involved in the lives of your children and family members and to consider doing even a bit more.

Isn't it our fatherly duty to protect and teach our children and family? I decided long ago that my daughters schools needed to see more men around the facilities (school grounds) and I'm not talking about sporting events, I'm referring to things that in the past were run mostly by our wives, so I became part of the system, and it turned out you can get many things done that benefit not just your children, but all those who do not have a voice!

I became the PSO president (and since then many fathers have been an active participant in the schools program), participated as a math tutor for an hour a day as class sizes are overwhelming (actually went back to night classes for a basic math refresher), and chaperoned field trips. Yes, there was resistance from my girls, but I wanted them to know I'm there if you need me. It is a difficult balance between work, family, marriage and having a child that requires extra attention! But who's better to guide them?

Yes, it would have been easy to just have my wife take our daughter to the doctor's office, yes, it would have been easy to have the hospital do Hemo dialysis 3 times a week at the hospital instead of taking on the challenge of doing peritoneal dialysis 7 days a week 10 hours a day at home. Same goes for when we were told she had cancer over and over and over, but what message does that send if I, the person she looks to for strength, hasn't been involved? I had to be our family advocate, just like at school, fighting for the rights of all visually impaired kids not just mine. Getting involved in her medical care was a natural step, but out of that came an opportunity; the hospital asked me to become involved with their family advisory council as an advocate for all of us dads who have no experience, and are afraid to fail or even make a choice that takes your child's life!

To this day, from talking with other Dads, I know that even with all the hardship going on in our lives, there were other families in a more difficult place then ours, and if I could help them in any way I needed to. I started a guild at the hospital to raise money for uncompensated care, I hadn't ever done this but a couple phone calls to the hospital and two years later we had raised 1.4 million. DADS we can do anything!!!

Gentleman, I know you're busy and I ap-

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How My Dad Being in the Fathers Network Has Affected Me

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part of it.

Fathers Network Campout at Washington Park in Anacortes on Father's Day weekend always has been a highlight for me. We: my parents Hameed and Sue, my sister Areesa and brother Rizwan have been going almost every year. We go on Saturday and have fun revisiting veteran dads and their children as well as meeting new dads. Some fathers are grandparents now and they keep coming to this fun event.

This last summer my brother brought Molly, his fiancée. I am sure she'll come to many more.

I recall, in 2009, when my aunt and uncle came from Texas for a visit we brought them along. They happened to witness a wedding ceremony at the beach in progress. To this day they still talk about it.

Once in a while I still go with my dad to the meeting. After the meeting we go to lunch. Other fathers, with their children and Moms join us.

In the summer The Network has a BBQ plus an occasional a potluck dinner. I am looking forward to being a part of this organization for a long time. And I encourage new fathers and their family to take an active role.

The Sword of Damocles

by Roland E. Bainbridge

I recently had the pleasure of meeting Dr. Nicolette Christians. As we talked about the Fathers Network she told me about one of her brothers who was born three months premature and the effect it had on her family, especially her father. She thought it would have been helpful for her father to have had a resource like the Network. As we talked further we discussed the idea of having her father write a story, from his perspective, on how his son's needs affected him. The result is below; I think you'll find it to be a powerful statement, and perhaps a familiar one, on how fathers approach these situations.

In October 1977 our family was changed dramatically for the foreseeable future. Our youngest son was born three months premature. After the euphoria, reality ensued that when he was released from the intensive care unit, he would require twenty-four-hour care.

In the coming months the problems kept accumulating. All the attributes one associates with typical development were now hurdles to overcome. The ability to move and communicate seemed like insurmountable goals. How does a family cope with the constant pressure, without respite, to give all the love and attention our son deserved? My wife shouldered the physical and emotional responsibility. His brother and sister only 7 and 12, by necessity became the extension of their mother's caregiving. In normal circumstances extended family might be called upon to provide support, but we had emigrated from England and had no family here to rely on. Therefore, my wife, two oldest children and I looked to each other.

At this time one may ask, what was the father's role? It was quite apparent that not only would the emotional toll be extensive, but the financial burden would be the proverbial Sword of Damocles hanging over our family. With limited family resources, using the predominant amount to support the care and wellbeing of one might result in my other children not receiving what they needed. It was quite obvious to my wife and I that for the family to continue to survive, a seismic change had to be made.

After significant and troublesome discussions, it was agreed that I would accept a transfer to another area of the country. This meant that my wife and two oldest children essentially took care of the ongoing needs of our youngest child. However it also meant that our family would not have to worry about financial stability.

Quarterly visits were emotionally draining. No matter what one hoped in terms of improvement, our hopes didn't materialize. The status quo, of a family separated by 1,200 miles, was unacceptable. So another difficult decision was made to relocate the family to my new area of work.

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The State of the Network and Some Goals

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with members. Especially since I expect that more and more dads (especially younger ones) are accustomed to receiving information and communicating using tools like Facebook, blogs, Twitter, etc. Personally this will be a challenge for me since I'm not a social media user myself. But, I think it's an area the Network needs to play in effectively so it's time for me to learn.

In case you didn't know the Network does have some social media presence, we can be found at:

Blog / Website: http://www.FathersNetwork.org

Twitter: @WSFN (http://www.twitter.com/WSFN)

Facebook: Washington State Fathers Network (https://www.facebook.com/Washington-State-Fathers-Network-181197305235376/timeline/?ref=br_tf)

I encourage you to check these sites out and to use them to share information and to let others know what's going on in your area. If you have any questions about the sites or need access let me know, since I'm still learning I may not have an immediate answer but I'll get it for you.

Other goals that I'd like to accomplish are having more of a Network presence and impact in communities of color, immigrant communities and possibly the military. And, I'd also like to develop a comprehensive data base of all our members.

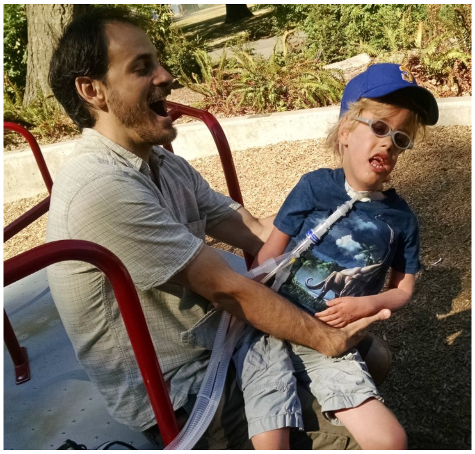
If you have ideas or thoughts on any of this I'd appreciate hearing from you.

Sharing Our Special Needs Parenting Experience Through Blogging by Burke Stansbury

Burke Stansbury and his partner Krista write a wonderful example of a blog, about their son Lucas. I think you'll enjoy the story of why they blog and what it means to them.

In August of 2009, my son Lucas was born two months premature. He was immediately put on a respirator and barely survived his first few days of life. We knew that the health issues he was facing were a lot more severe than the typical effects of prematurity but the doctors couldn't figure out what was going on. On the fifth day of his life, my partner Krista and I decided to create a blog. We had started to understand that Lucas's life was going to be full of challenges – things like genetic disease, brain damage, and neuromuscular condition were being thrown around by doctors -- and we needed a way to communicate about what we were going through to our family and friends.

As we began our journey into the world of special needs parenting I had no idea how important that blog would become. Indeed, its rather remarkable to read the first thing we ever wrote on August 21, 2009, or begin to scroll through the 405 blog posts and 2200 comments that have since made up a very public segment of our family's story. Through the blog people were immediately able to read about the specifics of Lucas's health issues as well as our reflections on what it all meant; they could also send us needed love and support throughout the ordeal of his early life in the hospital.



It wasn't until he was five months old that Lucas was finally diagnosed with a neuromuscular disease called myotubular myopathy, or MTM. By that time we had spent three months with Lucas in the Neonatal Intensive Care Unit at Children's Hospital in Washington DC, then two months with him in our home, which became a veritable ICU, complete with a pulse oximeter, suction machine, ventilator, and home nurses to go along with it. Lucas has a tracheotomy and needs a ventilator to help him breathe, gets all of his nutrition through a g-tube, and has used a wheelchair to get around ever since he grew out of the stroller (which was never big enough to fit all of his equipment anyway!) The diagnosis at five months was both devastating and a relief. We finally had a name for what Lucas would deal with for the rest of his life, and though it was a debilitating muscle disease, it was not degenerative, and it affected his muscles but not his brain.

We continued blogging throughout, shifting between straightforward health updates and deeper reflections on disability, special needs parenting, and social justice. Krista and I have always shared the blogging responsibilities and taken turns writing, often using the collective "we", and though it wasn't always easy to sit down to the computer and write, it became a sort of therapy for both of us. Writing on the blog gave us a way to process the complex emotions we were muddling through – elation at bringing a beautiful little boy into the world, fear about what his life would be like, anger at the people who didn't do everything to help Lucas, pride when we overcame a series barrier, and so on. There were times when we argued over the tone of a particular post, or about how intimate to be, about how much to really share. Other times it felt like a burden to update the blog. But mostly it has succeeded in opening doors and giving us a positive outlet for discussing Lucas's life.

Lucas's blog also allowed us to share our writing in other places, such as when I had a story about Lucas published in the anthology Rad Dad: Dispatches from the Frontiers of Fatherhood. I feel especially proud of some of this very personal writing since most writing about parenting – and special needs children – comes from women. I strongly believe that Dads need to step up and prove that we can play an equal role in tackling the challenging emotions and routines of parenting a child with disabilities. Being public about my own determination to be involved in every aspect of Lucas's life and care was one way to model that belief, even if it

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Getting Involved, Staying Involved

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plaud you for the time you spend with your children and families. But, I encourage you to reach out to the places that your children are at, and ask if there is anything you can help with. If you have an extra hour a week to volunteer, fantastic! The schools would love to have you there, same with a hospital, don't be a shy. For example, Children's Hospital has 500 guilds that raise funds for many parts of the hospital, find one; they are listed on the hospital's website and see if you can help. The Fathers network: stay involved and reach out to other dads, invite them to a chapter meeting. It's amazing if we listen, what we can learn.

Sharing Our Special Needs Parenting Experience Through Blogging

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made me vulnerable at times.

Three and half years ago we moved from Washington DC back to Seattle, where I grew up. We feel fortunate to have settled back in the Northwest – my family lives in Seattle and Krista's in Oregon, so love for Lucas is always nearby. Our life as it relates to raising a child with disability has become surprisingly stable, even after a new addition to the family: Lucas's sister, Ida, who was born in February, 2015. Which isn't to deny all the deep challenges and struggles we deal with every day – from frequent doctors appointments, to dealing with broken equipment, to sore backs from lifting a floppy child going on 50 pounds. Mostly, we live with the disappointment and frustration of facing a society that doesn't try very hard to include and love people with disabilities.

Yet despite it all, we're a pretty happy bunch. And that's in large part because of Lucas, the joy and humor he brings to just about everything. He's in first grade now – in a mainstream class – and is a remarkable reader and writer (the latter he is able to do using augmentative technology.) He is passionate about dinosaurs, music, and learning about outer space… but mostly about dinosaurs!

One thing we often lament is that the rest of the world rarely gets to witness how amazing Lucas is. He can talk despite the fact that he has a tracheotomy, but his voice is quiet and his words somewhat slurred, so it takes some real patience to have a conversation. In groups of his peers his is quickly overshadowed by typically developing kids running about with loud voices, and he doesn't do well with commotion himself. Meanwhile, his weak torso muscles lead to fatigue when he sits up for long periods of time, causing him to totally tune out, or making it necessary to lie down. On top of that, his suctioning, feeding, and bathroom needs often create a barrier between our world and that of others. It can be as exhausting for us to navigate as it is for Lucas to sit in his wheelchair for hours at a time.

So the blog gives us a way to illuminate and celebrate the complexity of Lucas and his life as a child with special needs. It has also allowed us to connect with many other families of kids with similar (or very different) disabilities.

Though we write less frequently now, Lucas's blog still proves to be an important outlet for us during life's highlights, or moments of reflection, or the tough times. When Lucas broke his leg last year we wrote about it and posted pictures, mentioning that Lucas enjoys getting mail. Soon a flood of "get-well" cards was coming in, providing some smiles while he spent day after day on the couch waiting to heal.

A few months ago we published Lucas's first blog post written entirely by himself! He had been composing dinosaur poems over the final weeks of summer, and we suggested that he write an intro to turn it into an actual blog post. The result was a hit, with more blog comments from his fans than we've gotten in years.

Lately we've struggled with how much to share. Lucas is getting older and understanding things a lot better – he says he doesn't mind that we share stories about our life on the blog, but maybe someday it will bother him. We have decided to dial back some of the more intimate details, though a recent blog post about challenges at school solicited a lot of helpful comments from friends, especially adults with disabilities. Can we continue sharing in a way that draws people in and elicits helpful advice and support without violating Lucas's privacy?

Ultimately, blogging is not for everyone, and I certainly wouldn't recommend it to every special needs parent. But I do think there can be profound benefits to being open and public about dealing with disability, especially in a society that often pushes us to deal with things like grief and frustration by turning inward. For my family at least, the decision to share our life has been cathartic.

The Sword of Damocles

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The major question of any father in the predicament is how does one remain emotionally focused? I did this by immersing myself completely in my work, in the pursuit of achieving security for my family. I felt I had to reassure my family that the caregiving our son so desperately needed was not going to be impacted by a lack of resources, nor that our circumstances would prevent his siblings from achieving whatever goals they set.

Over the next sixteen years, until my young son succumbed to pneumonia, our family forged a bond born out of love, necessity, grief and shared responsibility.

Roland's story is a strong example of the burden dad's can place upon themselves and how it can sometimes separate them, emotionally and physically, from their family. And, it gives credence to the social safety net that the Fathers Network provides for our members.

Technical Assistance Family Leadership Project by Louis Mendoza

I want to let you know about an exciting project that has lots of potential. 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. This will result in technical assistance from AMCHP to enhance parent leadership programs in Washington. For dads, I'm hopeful that it will be a springboard to organizing opportunities to get more of them to share their knowledge and experience. The basis of this assistance will come from studying and implementing elements of the New Jersey Statewide Parent Advocacy Network (SPAN) model which is recognized as a best practice program.

To study the SPAN model and implement changes in Washington representatives from the WA Department of Health, State Parent to Parent Program, Seattle Children's Hospital, PAVE and the Fathers Network will be traveling to New Jersey in February and hosting a consultant here in Washington. I'll keep you informed of developments, on the website and in the Spring CONNECTIONS newsletter.

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.

Hello from the New Guy by Louis Mendoza

In case I haven't met you or you haven't heard, I'm the new guy leading the Fathers Network. Since this is my first Connections newsletter I thought I'd take the opportunity to introduce myself.

So, who am I?

On the personal level, I live in Woodinville with my wife Paula who is an IT Director. And, we have two daughters who are now adults and living locally. One works for Costco and the other is a theatre stage manager, working at the various theatres in the Seattle area.

Professionally I spent the early part of my career as a trainer in the retail, defense and insurance industries. Most of that was done in the Southern California area. In 1988 I was recruited up to Seattle by Safeco Insurance and worked for them for 7 years. Early on my wife and I decided that we wanted to have one of us at home to raise our girls and my wife did that initially. When I left Safeco we swapped places and I became a stay at home dad. Being a stay at home dad was a great experience and one benefit is that my girls now have high expectations of the men in their lives regarding household duties and involvement with raising children.

Once the girls were old enough to be in school full time I decided to go back to work. And, so that we didn't have to worry about daycare during the summer and other school holidays I went to work for our local school district, giving me the same days off that the girls had. My job at school was as a paraeducator working with students with special needs in 4th, 5th and 6th grade. To be honest, I had no training or experience with children who had special needs and I was intimidated. But, I worked at a wonderful school with great staff and learned on the job. I had the job for 10 years, loved the work and can honestly say that it was the best job I had in terms of feeling like I made a difference when I left every day. It was while in this job that I had my first exposure to Kindering Center and where I got involved in helping to coach Special Olympics athletes in basketball, soccer, track and bowling.

From this job I went to work at United Way of King County. My primary function there was running a program called Project LEAD which trains people of color to serve on the boards of non-profit organizations. I also spent a lot of time helping corporations find opportunities for their employees to get involved in the community as volunteers. Then after almost 8 years in that job I was fortunate enough to find my way to Kindering Center to manage the Fathers Network.

I'm now in the 5th month of this job and in that time I've met some amazing and very interesting people. I've asked some of them to write articles for this edition, I hope you enjoyed their perspectives. If you have a story or perspective you'd like to share, let me know, I'd love to get it out to our network. I wish everyone a wonderful 2016 and I look forward to meeting more of you.

KINDERING
Embracing children of diverse abilities and their families

Washington State Department of Health

Washington State Fathers Network

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