

# CONNECTIONS

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

## Fathers Network Conference is Coming

The 2017 Fathers Network Conference will be held on Saturday, November 4th from 8:30 am to 5:00 pm. This year we'll be located at the Bellevue School District Wilburton Instructional Service Center ([WISC](#)). Early registration is now open and the registration site can be found [here](#). The theme this year is *Dads as an Anchor in a Sea of Change* and our keynote helping to convey that message will be Lance Morehouse, Executive Director of Sherwood Community Services and long time Fathers Network member. Of course, we'll have our dad panel and give out the Big Time Daddy Award. Breakout sessions this year are:

- Meaningful Relationships: Dreams and Concerns for the Future
- Getting the Most From Your Active Play Time
- Guardianships and Special Needs Trusts
- Washington's ABLE and DDETF Programs
- Bio Medical Treatment and Beyond: What is Possible for Your Child?
- Finding Your Voice: You Can Make a Difference
- Systems Navigation
- Understanding Your Medical Insurance: From the Basics to the Specifics



Photos from last year's conference

## Annual Kickoff Breakfast and the Carnation Farms Family Campout

Two exciting events are coming up in September:

- Our Annual Kickoff the school year breakfast will take place at the Kindering office in Bellevue. It's a wonderful tradition and a great way to meet new families and reconnect with old friends. Please RSVP with the number who will attend by September 5th to Louis Mendoza at [louis.mendoza@kindering.org](mailto:louis.mendoza@kindering.org). More information can be found [here](#).
- On the weekend of September 22-24 come at join us at Carnation Farm for a family weekend. It'll be a fun event at the very reasonable price of \$20 per person. More information and the link to register can be found [here](#).

## Not So Hidden Treasures

*Note: Since this story was written, Don and his wife have adopted another girl. By the way, Don will be at our conference this year and will part of the dad panel.*

My name is Don Joss and I own DJ's Sportscards, a small sportscards and collectibles store in Renton. I started the store as a very young man and it has been my full time job for the last 29 years. I am now 46 years old. My wife and I have been married for 23 years. We have 19 children, 12 adopted and 7 by birth. We also adopted a 4 year old girl with Down's Syndrome that died a few days after we brought her home from China.

One of our children by birth, Mercy, has special needs. We didn't know this until about 15 minutes after she was born and things were not going well. My immediate reaction was telling God that if he did not let her die that I would do everything I could to take care of her and not complain. She had many long hospital stays and almost died at a year old. Today she is 9 years old with severe special needs (she looks like and is the size of a 2 year old) and will

probably die at a young age. We know she will live with us her entire life. She is very happy, crawls all over the house, keeps herself busy, and is full of smiles. We are thankful for every day with her. Taking care of her and seeing what a blessing she was got us over the fears of adopting more children with special needs. She has probably saved 8 or 9 other children just because of her life and the blessing she is to us.

In our family we now have a girl with a missing chromosome, 3 girls with Apert's Syndrome, 1 girl with Down's, 1 boy with Down's, 1 boy missing a nose who is also blind, 1 boy with autism, 1 girl with Cerebral Palsy and brain damage and 1 girl with facial issues and damage from neglect in her orphanage.

We love our children greatly and they love us. I feel like every special needs child I have adopted was a precious jewel that we got to grasp and keep for our own when so many others walked by and left them there, not seeing the value. Every one of them is a blessing in my life and a joy to be with. There are so many more like them out there for people to be blessed with if only they could see what I see. They are living examples that every life is precious, made in God's image, and that they have a soul just like everyone else. They are not tragic beings to pity. They are gifts for us to enjoy and bless.

I know that for some dads it can be devastating to learn that their child has a diagnosis of a special health care need. I have not gone through that. I have never dealt with devastation or disappointment over my kids with special needs. I have been weary at times taking care of their needs and I have cried out to God for help in caring for them, relieving their occasional pain, for financial provision for the doctor bills and other costs, and even for their healing if possible. I have just never understood people struggling so much with disappointment over their special child. For me it was my job as a parent to take care of these special ones and along the way I discovered what a blessing it was as well. These are our sons and daughters. Their soul is just as precious as anyone else's. They are not defective people or burdens to society. I would love to see more people realize this. I would love to see a "new normal" where parents who are expecting the birth of a child with special needs or discover that they have one after birth are just as excited about the birth of their baby as they would be if the baby was "normal." I would love to see doctors and nurses encouraging these parents

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## Can a Wet Dish Rag Win a Gold Medal?

*Note: the following story comes from Eliya Stromberg, a dad in Israel who has started his own group for dads,*

### [Fathers Connect.](#)



My second son, Ariel, has Down syndrome. He is now 27. He was a scrawny, funny looking newborn who arrived two weeks earlier than expected. I could hold him in one palm and all four limbs dangled limply over my hand; he wasn't tight

like most newborns.

My son's first PT referred to him as a "shmatta", a not so complimentary term that means "dish rag" in Yiddish. The PT actually called him a "wet" shmatta. She said that Ariel's low muscle tone (hypo tonicity) was off the charts.

Hearing a professional call my son a "wet shmatta" did not bolster my hopes for his development. And then when Ariel was eleven months old a pediatric cardiologist told me that he would need open heart surgery to survive. Between being a "wet shmatta" and a cardiac patient I envisioned my son as a feeble child who wouldn't run and play like other kids. Who would likely need physical assistance all his life. I didn't frame a positive future for my son.

Thank G-d, the surgery was successful. The surgeon assured me that my son could now have a "normal" life. While I cautiously accepted that Ariel would not be limited by a heart condition, his "wet shmatta" status didn't change. Nor did my frame of his future. I continued to feel disappointed by what I thought I was losing: that my son would not become the robust, energetic boy or the man I dreamed he'd be.

Ariel never learned to crawl. Instead he sat on his behind and scooted across the floor. It worked for him, but again I took it as a sign of weakness. He didn't take his first step without support until he was three years old.

Nothing in Ariel's physical development gave me encouragement to change my negative frame. I developed an attitude of resignation: this is what is and what likely will be and there isn't much I can do to change it. This kind of resigned acceptance did not strengthen my bond to my son. Nor did it bring me very much joy in being his father.

When Ariel was about three my wife read a book detailing the physical development of children with Down syndrome. The author advised parents to acquire clothing with zippers or Velcro because children with Down syndrome typically do not learn to button. My wife threw the book away. She said: "Adult clothing is not made with Velcro and zippers; it's made with buttons. Ariel will learn to button so that I don't have to dress him his whole life."

My wife's insistence that our son could learn to dress himself resulted in us spending six months training Ariel to button. (He will never need Velcro on his shirts, or anywhere else.) And her insistence shook up my resigned acceptance that there was nothing much to be done to build my son. Not wanting to be disappointed again that Ariel would not meet my expectations I tentatively accepted that he might have more physical (and mental) capability than I imagined. Ariel would soon prove to me that I had no need to fear for his future.

There are essentially two ways fathers bond with their children: intellectually and physically. With my first born son, besides hugging him, playing catch and climbing trees together, I read him stories, crawled on the grass with him looking at bugs, scanned the night sky searching for the moon and outlining the Big Dipper, and asked him questions and looked up answers. Our bond began through physical contact, but deepened through intellectual exchange. Ariel loved my hugs but we didn't connect intellectually.

Without the stimulating intellectual exchange that I experienced with #1 son, my bond with Ariel maintained but didn't deepen. While Ariel now walked and played I didn't acknowledge the magnitude of his physical development: in my estimation he was still a "shmatta"; he just wasn't so "wet" any more.

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*(Continued from page 2) Not So Hidden Treasures*

and explaining all the resources available to them instead of leading them down the abortion track. I would love to see men get over being discouraged or sorry about the situation and instead just love their kid and tackle the job at hand with all their heart, mind and soul, just like they would do with any other challenging situation in their life or work.

I would not want anyone reading this to feel like I am saying that I am better than them or that the challenges we have as special needs parents are not real. However, I do want to encourage fathers to lift up their eyes and see that the life they have been given is a blessing, not an accident, and to see that there can be much joy in taking care of these children.

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*(Continued from page 3) Can a Dish Rag Win a Gold Medal?*

Since he could walk on his own now, I took him to a nearby playground to play ball. He loved it. It didn't matter to Ariel if he caught the ball or not. We laughed together when the ball bounced off his chest or I wasn't looking when he threw it to me. He never tired of chasing after the ball when either one of us didn't catch it. My "shmatta" had boundless energy playing with me on the playground.

During rest breaks that I needed he'd lean against me even if I was sweaty in the heat. As we rested, all we ever talked about was playing ball. Even without a deep intellectual exchange I felt close to Ariel. In these moments on the playground he was using his full potential and I was free of the disappointment that had so clouded my relationship with my son.

Ariel's physical development continued to strengthen. As it did I stopped having expectations of him becoming what I wanted him to be. I began to just want him to be what he could be. I finally buried his "shmatta" label when he was about eleven years old and wanted to ride a bicycle like his big brother. I was all for it. Riding a bike would make him more independent, let him blaze trails with boys in the neighborhood, and continue to build him physically. So I set out to teach him how to ride.

I thought about how my teaching Ariel to ride would tap into his physical and social potential. Little did I know how it would lead me to realize my potential as a father and a man.

My only experience as a bicycle riding instructor was to put #1 son on his two-wheeler, give him a firm push and tell him to "keep pedaling." He fell two or three times, and then discovered on his own to just keep pedaling. By the end of the second day he was scaring his mother by riding without hands. (From day one, our boys never rode a bicycle without wearing a secure helmet.) Given my "success" with #1 son, I confidently started with Ariel.

Nearly four weeks of daily effort and Ariel still couldn't "just keep pedaling". I was not a success. But because I had let go of expecting Ariel to accomplish things in time frames or manners of my design, I was not disappointed in myself. Instead, I looked for another teacher. I enlisted my future "Tour de France champion" first born son to teach his brother. I figured someone closer in age to Ariel would know how get the message across. I was wrong. But I didn't give up. I hired a sports teacher, took Ariel and his bike to him, and two months later, Ariel "got it".

Even though it didn't happen as I expected, Ariel's accomplishment was also my accomplishment. Without self-criticism as a "failed" teacher, I became the "captain" of the team. I found the right teacher and offered encouragement. It wasn't an issue of meeting my expectations. It was all about doing what I could to have my son realize his potential.

This learning has become fundamental in my thinking. I repeat it: It is not about having my children meet my expectations. It is only about doing what I can to have my children reach their full potential.

By the way, once Ariel learned to ride he has been riding ever since. In fact, he has won four gold medals for cycling in national competition in the Special Olympics.

So the answer is "yes": a wet dish rag can win a gold medal.

And a father can have pride and joy in his child if he lets go of the frame that his child may not be what he expects, and does everything he can to help his child to become what he can be.

## Quick Bits

### New Pullman Chapter:

*The Network now has a chapter in Pullman and the dad heading up that chapter is Anthony Gayle. In his own words, here is why he has joined us and started this chapter:*



I'm a widower Father of one toddler. My awesome son is Hezekiah, he was born early at 29 weeks and spent two months in the NICU unit. He is "Developmentally Delayed."

The Father's Network reminded me that just as I felt when I served my country as a Combat Veteran, there is a team of wise men behind and next me, who are willing to hold me up with words of encouragement, and walk with me with proven advise, and their validated experiences. Their wisdom is what has gotten me through those moments of; who, what, when, where, why and how am I going to do this.

It would be my honor to represent the Father's Network in Whitman County, in the Pullman area to also assist Father's in my town and nearby, who may need support in the form of information , and an ear to listen, and since I am Military Retired , if they need another child for a play date they can call.

In between all of my son's sessions for Speech, Occupational Therapy, Feeding Team, and Developmentally Delayed Preschool, my son and I visit all of the local parks and swimming pools daily since my schedule is available and very flexible.

Dads can reach me at:

Cell phone/ Text Message 509-330-0608

Email: [Anthonylgayle@yahoo.com](mailto:Anthonylgayle@yahoo.com)

### The Fathers Network and Social Media

As I mentioned in the last newsletter the Fathers Network [website](#) underwent a major revision last year and it has continued to be tweaked. If you haven't taken a look at it lately I would encourage you to do so. We also have a much stronger presence on Facebook (at Washington State Fathers Network) and we're working on getting better at our Twitter. Check us out on Facebook , like us and share our posts.



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.

