

The CIDSO News

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"A Brighter Tomorrow"

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Eight Pounds of Forgiveness

By Cindy Nehrbass, Hopkins, MN

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Some time over the past month, one of my daughter's ear tubes that assist her genetically horizontal ear canals to drain got twisted and somehow lodged in the canal behind some wax blockage, creating a massive infection. Ear and heart issues are Sarah's chronic Achilles heels. After a traumatic and painful ear-cleaning visit, we spent a week treating her with liquid antibiotics and steroid drops. They hadn't worked; and, once again, I found myself in the same small office with my extremely sick child.

The room smells of alcohol and iodine. Micro-cleaned by stale and clammy; the air is humid with anticipation of the inevitable. The nurses and I, after years of doctor visits, look at each other knowing full well what the others think. An unspoken rule with Sarah, my 12-year-old daughter with Down syndrome, is that no words can be spoken. Non-verbal nods and pointed hand signals become our vocabulary; sign language and simple verbal cues are Sarah's modes of communication. Although Sarah says few words, she is quick to pick up the gist of ours. She will bolt, dreading the unavoidable antibiotics shot.

The head nurse turns her back to Sarah and quickly fidgets with a vial and plunger with a long needle. My daughter has been seriously sick for days with this resistant-strain of infection, burning up and listless all night. Still, she rallies off of my lap, avoiding what is to come. Her clue: no good can come of having more than three adults in the tiny doctor's office.

My daughter can't do many things as proficiently as those more typical; but, she excels at recognizing danger. Sarah's eyes dart from the nurse to her assistant, to the door covered in note pad paper drawings. Seeing no escape path, she looks to me. I am her protector, caregiver and mom. Her face tenses with eyes wide, telling me she already knows what situation she faces; and that I am in on it.

I am no longer on her side. Any hope slides off her cheeks as she looks at me with her almond-shaped hazel eyes. Those expressive eyes fill in the constant gap of her inability to verbalize. Sarah and I have full conversations with just a glance. Most of her glances are mischievous gleams or occasional crocodile tears. When she is having one of her stubborn, "preteen" moments, she can tease me with a sideways\$ stare closing one eye as if I will disappear. But this look now is the one that makes my heart feel heavy. It is the one that repeatedly convicts me.

Sarah paddles backward, her barely four-foot height bangs against the metal table, making a loud thud. She reaches back for the crisp, white paper that covers the table

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Fundraising Efforts

The Gala and CIDSO Open are June 6 and 7 and the Fourth Annual Buddy Walk is scheduled for September 27. With both of our major fundraising events just around corner, I thought this would be a good time to let you know about some of the programs the funds raised at these events go towards supporting:

CIDSO Grant Program
ISU Speech & Hearing Grant
Literacy Program
Conference Scholarship Funds
New Parent Packets
Library Updates
Educational Meeting & Social Events
School Awareness Programs
Enrichment/Participation Fund

This is not a complete list, just a sample of what CIDSO supports. While not everyone enjoys fundraising activities, please keep in mind without these efforts, none of these program would exist. We appreciate your support and dedication to keep our organization moving forward and enable us to provide these valuable services to people with Down syndrome and their families in the Bloomington/Normal community.

Maytag Moms

By Samtra K. Devard, Delaware New Scripts, parent

Everybody knows the commercials featuring the Maytag repairman. This is the guy who has nothing to fix.

Of the millions of washers, dryers and dishwashers that are sold - the guy who was hired to fix any problems that Maytag appliances may have, has nothing to fix. Surely there is something that he can fix. Yes, only if something is broken!

Just like the Maytag repairman has nothing to fix, Mom's of children with disabilities have nothing to fix. We are in essence Maytag Moms.

Many of us are given a diagnosis for our kids and a laundry list of all the things that are wrong. We are presented with scenario after scenario of circumstances too bleak to contemplate. The problems that face children with disabilities and their families sometimes seem endless. And for many who are faced with a problem - the natural tendency is to fix it.

A wise woman whom I love and respect once told me it took her a long time to figure out that her role in her daughter's life was to NOT to "fix" her daughter, because she wasn't broken. Once she learned that, she was able to come into acceptance of what is and find peace with that. To function in a mindset that is about maximizing potential and life chances, rather than fixing the problems of a "broken" child or family situation is so much more meaningful. The Maytag Mom is expending valuable energy trying to fix something that isn't really broken.

Broken means out of order, not working, damaged, ruined, destroyed, defeated, dejected, crushed, dispirited...without hope. Our children are anything but broken. The sooner we stop trying to fix the situation or our children, the sooner we can begin the healing process and begin to function in a positive, less energy draining way.

I have learned I am a Maytag Mom. I have been doing all I can to fix things. Acknowledging this has been so profound for me. It has taken a lot of soul searching in a short period of time to realize that no matter what, we have some circumstances that just are what they are. Nothing's broken.

The good news is Maytag Moms are good at what they do and can redirect their energies to things that are about building and growing and uplifting. We can do with our lives what was intended - to live and love to the fullest. Love our children and the joy they bring. Resist any temptation to fear the unknown about what lies ahead. Certainly, what the Moms of children with disabilities face can be different than if our children didn't have a disability -but guess what there would still be something to deal with; just a different something.

But I believe wholeheartedly that the heart, energy and passion of the Maytag Mom is why God blessed our lives in such a great way. Reminding ourselves of the blessings during times of turmoil all around us becomes the challenge.

Maytag Moms - there is a great future ahead!

Mark the Date:

June 6 & 7:
Gala and Golf Tournament

July 11-13:
NDSC Conference

July 28:
CIDSO Board Meeting

September 7:
CIDSO Picnic

September 27:
Buddy Walk

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with your health care professional.

Eight Pounds of Forgiveness

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and makes that crinkling sound she loves as she squishes it in her fingers. During routine visits she usually likes to pull a few lengths off the roll of paper, just to hear that sound. But now, she digs her feet in the floor and keeps her eyes firmly on my face. Pleading her case in a single word, she takes her hand to her mouth and ear and signs “home.” Shaking my head, I put my fist to my chest and make a circular gesture signing “sorry.” I feel a twinge up the back of my neck, knowing what is about to come next.

Anticipating that we have less than a few moments before a complete meltdown, the nurses come from both sides, synchronized. My daughter lunges to me, arms open. But betraying her trust, I scoop her up. Her weight drops in its unwillingness; and her mere 80 pounds becomes 800 as I drag her a few feet and hoist her onto the table’s edge. I am amazed at her strength and mine.

“It’s okay.. .two minutes.. .fast.” I reassure her in broken sentences that are more for my benefit than hers relying on the hope that she might believe that when something is quick it won’t be SO bad. But who am I kidding. I cannot do this again. I place my arms around her in a gentle hug. Noticing my caving resolve, the head nurse takes charge saying, “Mom, hold her arms.. .her legs.” Now, hearing the nurse’s voice and understanding the body parts to be under siege, Sarah begins her metamorphosis to an animal-like child, with the agility of a gibbon.

Letting out a combination of a growl and a whine, she attempts to slide through my arms. Just as quickly, we take hold as Sarah’s limbs flail in different directions at once. Swiveling her to the side, racing time, our hands grab moving wrists and knees. Sarah arches her back, kicking the nurse’s hand that holds the needle. In an act of brutal genius, I throw off my flip-flops and climb the table behind her and wrap my legs around her, securing her in the lock of a violent hug.

Chanting numbers in order “One... Two.. .Three...” the nurse jabs her thigh. And then, “Nooooooooooooo!” Sarah screams, her face turning shades of red. Blood vessels behind her ears burst, leaving tiny red dots similar to the ones on my forehead after giving birth. Her face then turns purple and mottled. I worry that the stress will affect her fragile heart and I need to get this over fast. My fingers strangle back her upper arm as she reaches for the syringe. I struggle to keep her still. I count in my head to stay calm. The plunger slowly lowers. It takes way too long. “This is a lot of medicine,” the nurse justifies as if this fact will make the sabotage okay. As she pulls the needle out, I can see the pocket of blood and a bruise that remain. Sarah, realizing this too, starts sobbing. I have just helped torture my child.

The band-aid is placed and a sticker promised, in an attempt to fix the multi-layers of scars; both emotional and physical. I need one too. As the nurses leave, I lean Sarah back and gently hold her. Brushing her matted hair off of her forehead, I whisper “all done, all done, all done” like a mantra. Her body relaxes, melting down as one hand still holds her stiffened leg. I have betrayed her but she still accepts my care. She lets me lift her to the chair, which now seems yards away from the table. Her face registers defeat. She signs and speaks a clear “home.” And this time I agree “yes.” Noticing her upper right arm still marked with my fingers, I drop my head and slip on her shoes.

Sarah runs a warm finger from my eye to my chin, signing “sad” on my face. She can tell that the past moments have been tough on her worn-out mom, Sarah places her gentle hands on my face and says. “It’s okay”. She then reaches up and curls her arms and legs around me, securely locking me in a gentle hug. As I stand, her forgiveness makes her seem only eight pounds.

In this extraordinary moment I am reminded that my child, who isn’t proficient in many typical things, is much more capable than most of us at something far more difficult and important — unsolicited, unconditional forgiveness.