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CIDSO NEWS

PO Box 595, Normal, IL 61761 309/452-3264 WWW.CIDSO.org



32nd Annual CIDSO Open & Gala

Gala: Friday, May 31, 2013 - Bone Student Center Ballroom

Doors open at the Illinois State University Bone Student Center Ballroom at 6:00 PM for a social hour (cash bar), with dinner served at 7:00. A silent auction will run from 6:00 to 9:00 PM. There is no charge for CIDSO members.

Golf: Saturday, June 1, 2013 - Weibring Golf Club @ ISU

Entry fees are \$170.00 (one golfer, one Gala ticket, awards luncheon and gift pack); \$180.00 (one golfer two Gala tickets, awards luncheon and gift pack); and \$850.00 (golf five-some, ten Gala tickets, awards luncheon and gift packs). Pick up a registration form at the Weibring Golf Club at Illinois State University, contact Darin Schrader at Ipal4u@aol.com, or register on-line at Cidsogolf.com. Check-in at the golf course opens Saturday, June 1, at 6:30 AM, with a continental breakfast served until 8:15 AM. Shotgun start is at 8:30 AM and an awards luncheon following play at 2:00 PM.



Take Me Out to the Ball Park!

Watch our local CornBelters take on the Windy City Thunderbolt on opening day, May 21, at 7:00 PM. CIDSO has block seat tickets available for \$5 each. If you would like tickets, please contact Roby Wenzel by May 15th so she can mail you the tickets. Robyn can be reached at <u>robynwenzel@hotmail.com</u> or 309-242-1839.



Playgroup at the Zoo

Join the CIDSO Playgroup at the Miller Park Zoo on Saturday, June 1^{st.} Admissions fees will be covered by CIDSO if you meet Shelley Marquis at the main entrance at 10:00AM. Please bring a picnic lunch to enjoy after visiting the animals. If the weather is nice we will plan to end our adventure by playing at the sprinkler park. If the weather isn't so nice...call Shelley directly to determine if the activity is still happening or will be rescheduled. She can be reached at 309-212-1917.

President: Steve Newbold 309-826-1658

Vice President: Dawn Mattia 309-750-9164

Secretary: Brenda Harms 309-378-2388

Treasurer: Randy Mattia 309-750-9164

Newsletter Editor: Open Position

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Social Chair: Judy Bates 309-726-1145

Event Coordinator: Open Position

Advocacy & Resources: Sandy Ginther 309-829-0968

Self Advocates: Abbey Heins Kathy Peden



The Penguin Project of McLean County provides theatrical opportunities for artists with special needs. The Project matches artist with special needs with same aged peer mentors to create a production that will impress.

This summer they will be presenting "Peter Pan". Performances are June 7th & 8th at 6:00 PM and June 9th at 2:00 PM. All performances will be in Stroud Auditorium, at University High School in Normal.

Message from Mindie

Mindie Crutcher has been using the services of a personal trainer for the past several weeks to help with weight loss and just get in better shape. Brittany Gardner is a Eureka College graduate with a degree in Fitness Leadership (Exercise Science) and uses that education to guide her numerous clients in their quest for improved fitness and health. Brittany has gone the extra mile with Mindie—she has studied about Down syndrome so that she has a better sense of the challenges Mindie faces to assure that the program she takes Mindie through is absolutely the best one for her. Brittany is personable, friendly and engaging with Mindie—completely comfortable with her and proud to have her as a client at Gold's Gym Express. Brittany is also a personal trainer at the larger Gold's Gym on the South side of Bloomington. If any of you are considering a focused fitness program for your child/adult with Down syndrome, Brittany would welcome the opportunity to be of service. She may be contacted at<u>Bgardner1221@yahoo.com</u>. Bill or Diane are glad to provide more specific information should any of you wish that—Bill (287-0041) or Diane (287-0042).

NDSC National Convention: It's Closer Than You Think

This year's convention is just around the corner, July 19-21, 2013. This is the 41st NDSC Convention and will be held in Denver, Colorado.

Each year, thousands of people from across the globe attend the National Down Syndrome Congress Annual Convention. For most, it's to hear the latest information from world-renowned experts. For others, it's a great vacation. But, for nearly all, there's the one-of-a-kind NDSC family reunion feeling that permeates the convention weekend.

Conference information and registration materials are available at http://convention.ndsccenter.org/

A Big Thank You!

We would like to recognize the following for their generous donations to CIDSO:

- Dominick Bullinger and matching gift from Grand Trunk-Illinois Central Rail Pac
- Gail Johnson and matching gift from GlaxoSmithKline Foundation
- Brad Wiggins and matching gift from Hewlett-Packard
- PepsiCo Employee Giving Campaign
- Chuck & Joyce Walker in honor of Kelsey Dunlap

Now Showing: Sensory Friendly Movie

Join us for "**Wreck-It-Ralph**" on Saturday, May 11th at 10:00 AM. This "sounds down/lights up" movie is hosted by the Starplex Theater in Normal. They offer one child's admission free with every paying adult. Paying adults and children's ticket prices are \$6.00 each.

In Honor of the Moms

"Moms Lie", by Julie Borkowski

My friend is expecting her first child. People keep asking what she wants. She smiles demurely, shakes her head and gives the answer mothers have given throughout the ages of time. She says it doesn't matter whether it's a boy or a girl. She just wants it to have ten fingers and ten toes. Of course, that's what she says. That's what mothers have always said.

Mothers lie.

Truth be told, every mother wants a whole lot more. Every mother wants a perfectly healthy baby with a round head, rosebud lips, button nose, beautiful eyes and satin skin. Every mother wants a baby so gorgeous that people will pity the Gerber baby for being flat-out ugly. Every mother wants a baby that will roll over, sit up and take those first steps right on schedule. Every mother wants a baby that can see, hear, run, jump and fire neurons by the billions. She wants a kid that can smack the ball out of the park and do toe points that are the envy of the entire ballet class. Call it greed if you want, but we mothers want what we want.

Some mothers get babies with something more. Some mothers get babies with conditions they can't pronounce, a spine that didn't fuse, a missing chromosome or a palette that didn't close. Most of those mothers can remember the time, the place, the shoes they were wearing and the color of the walls in the small, suffocating room where the doctor uttered the words that took their breath away. It felt like recess in the fourth grade when you didn't see the kick ball coming and it knocked the wind clean out of you. Some mothers leave the hospital with a healthy bundle, then, months, even years later, take him in for a routine visit, or schedule her for a well check, and crash head first into a brick wall as they bear the brunt of devastating news. It can't be possible! That doesn't run in our family. Can this really be happening in our lifetime?

I am a woman who watches the Olympics for the sheer thrill of seeing finely sculpted bodies. It's not a lust thing; it's a wondrous thing. The athletes appear as specimens without flaw - rippling muscles with nary an ounce of flab or fat, virtual powerhouses of strength with lungs and limbs working in perfect harmony. Then the athlete walks over to a tote bag, rustles through the contents and pulls out an inhaler. As I've told my own kids, be it on the way to physical therapy after a third knee surgery, or on a trip home from an echo cardiogram, there's no such thing as a perfect body. Everybody will bear something at some time or another.

Maybe the affliction will be apparent to curious eyes, or maybe it will be unseen, quietly treated with trips to the doctor, medication or surgery. The health problems our children have experienced have been minimal and manageable, so I watch with keen interest and great admiration the mothers of children with serious disabilities, and wonder how they do it. Frankly, sometimes you mothers scare me. How you lift that child in and out of a wheelchair 20 times a day. How you monitor tests, track medications, regulate diet and serve as the gatekeeper to a hundred specialists yammering in your ear. I wonder how you endure the praise and the platitudes, well-intentioned souls explaining how God is at work when you've occasionally questioned if God is on strike. I even wonder how you endure schmaltzy pieces like this one saluting you, painting you as hero and saint, when you know you're ordinary. You snap, you bark, you bite. You didn't volunteer for this. You didn't jump up and down in the motherhood line yelling, Choose me, God! Choose me! I've got what it takes."

You're a woman who doesn't have time to step back and put things in perspective, so, please, let me do it for you. From where I sit, you're way ahead of the pack. You've developed the strength of a draft horse while holding onto the delicacy of a daffodil. You have a heart that melts like chocolate in a glove box in July, carefully counterbalanced against the stubbornness of an Ozark mule. You can be warm and tender one minute, and when circumstances require intense and aggressive the next. You are the mother, advocate and protector of a child with a disability. You're a neighbor, a friend, a stranger I pass at the mall. You're the woman I sit next to at church, my cousin and my sister-in-law. You're a woman who wanted ten fingers and ten toes, and got something more.

CIDSO News

Coming Soon!

Sensory Friendly Movie May 11th

CornBelters Game May 21st

> CIDSO Gala May 31st

CIDSO Open June 1ST

Playgroup at the Zoo June 1st

Penguin Project's *Peter Pan* June 7th, 8th & 9th

> CIDSO Board Meeting July 1ST @ 6:30 pm

> > CIDSO Picnic August 25th

CIDSO Buddy Walk September 28th

CIDSO Board Meeting October 7th @ 6:30pm

We're on the Web! See us at: www.cidso.org

About Our Organization

The Central Illinois Down Syndrome Organization (CIDSO) is a not-for-profit organization of families and interested persons working to increase public awareness, support families, and improve opportunities for those touched by Down syndrome. Established in 1974 to act as a support service, we serve Bloomington, Normal, and the McLean County area. Our organization is the oldest Down syndrome parent group in Illinois and the second oldest in the nation.

New Parent Outreach

The process of acceptance begins as soon as Down syndrome is suspected. To support parents and extended family during this time, a parent outreach member will gladly make hospital or home visits. Informational packets are also available to new parents. Parent Outreach Members, *Brenda & Kevin Harms, (309) 378-2388* and *Rick & Jennifer Bauersfeld, (309) 874-2038*, can be contacted any time.

Enrichment/Participation Fund

This fund is designed to enrich the lives of those born with Down syndrome and promote community involvement/participation. It is available to any person with Down syndrome regardless of involvement/participation in CIDSO. Applications are reviewed at the quarterly board meetings and must be received by CIDSO at least 10 days prior to the board meeting. Additional details and applications can be found in the "Resource" section of the CIDOS website. http://cidso.org/resources.asp

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