WINTER 2013

CenterLines

Center for Disabilities and Development *Useful News for Families*

Our Journey

A parent's perspective by Tara Ellison

Three and a half years ago we started our journey with Leah, our daughter with Down syndrome. And three and a half years later, I have to admit the journey is a lot more "normal" than I ever expected. That's why it takes me by surprise when I hear from a friend who knows someone who's expecting a child or just had a baby with Down syndrome. The announcement of a new baby with Down Syndrome isn't surprising. Beautiful babies with extra chromosomes are born every day around the world, one in every 691 babies, in fact.

My reaction to the news is what throws me for a loop. Three and a half years later, and I'm really quite comfortable in our journey. Why then is the news of a new baby with Down syndrome met with so much emotion on my end? I almost always catch my breath and wipe away the tears.

Is it because this new life is any less precious and perfect than any other new baby? Or is it because these new parents will face insurmountable challenges? Or they're somehow doomed to an awful new existence?

No, no, and no.

So, why the tears? It certainly isn't because I pity this family. On the contrary, I know the blessings that are in store. They are great big blessings and hearts that burst with pride and joy with every hard-earned milestone.

I know what's in store for them, but they don't. And that's why I struggle. Because they have to find out for themselves, in their own time, the joy that comes from loving a child with Down syndrome. In the meantime, I know the immediate worry and disappointment that accompanies a Down syndrome

University of Iowa Children's Hospital
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diagnosis, and the fear that your life will never ever be the same. It takes me back in time to December '08. Back to the hospital and the very instant I learned about Leah. The pain was gut wrenching. Surreal. It took time to figure it out. It took time to believe that everything would be okay.

There are great big colorful banners hanging outside the Chicago Public Library that read "I WANT TO BE ORDINARY". They stopped me in my tracks. Profound. In our quest to fit in, are we striving to be ordinary? I WILL say, being ordinary is indeed a whole lot easier than being different. But ordinary is so... ordinary. Our family, like most families who've been blessed by Down syndrome, has found peace and wonderfulness (if it's not a word it should be) in being anything but ordinary. Our new normal feels quite normal. But I wouldn't call it ordinary. Not at all.

So to the new family blessed by Down syndrome, sugar coating aside, if you aspire to be ordinary, hold on tight. You're bound to exceed your expectations. Three and a half years ago, when we were "the new family," we were blessed with a great big wonderful community of people who already knew what was in store for us. They were families who'd been blessed by Down syndrome, who knew what we didn't know yet. These families were there to tell us it would be okay. They were our best resource back then and they still are - the families.

The Hawkeye Area Down Syndrome Association (HADSA) provides education, support, and advocacy to individuals with Down Syndrome, their friends, families, and professionals in the Iowa City and Cedar Rapids area. Their website is **www.hadsa.org/** and it has great information and resources. You can call them at 319-775-5146 or email them at **contact@hadsa.org**.

The National Down Syndrome Society at **www.ndss.org/** has a lot of information and resources and can provide you information on a local program near you. The Center for Disabilities and Development welcomes infants, children, and adults who have Down syndrome. We work closely with you and with your local care providers. We can clarify the diagnosis and coordinate healthcare. We work with you to ease the transition into new services at each stage of life. For more information or to make an appointment, please feel free to call us at 877-686-0031 or email us at **cdd-scheduling@uiowa.edu**.

Your Kids Health Connection – MyChart

MyChart is a web-based service used by the University of Iowa Hospitals and Clinics that lets you see your own or your child's personal health information. It also helps you keep in touch with your CDD health care team. With MyChart, you can:

- See test results online
- Get shot records
- Make an appointment
- See a list of your child's medication
- Look up medical records
- Send a message to your health team
- Get health information

You can do it all from your computer. Just go to **www.uihealthcare.org/mychart** to get more information and to sign up.

Aging and Disability

Joni Bosch, AARNP, PhD
Center for Disabilities and Development

Many more people with disabilities are living into their senior years. Many more people who did not have disabilities when they were young are living long enough to have a disability as they get older.

Everybody needs to think about how they want to live their life if they get too sick to take care of themselves. If they have a serious problem, like a stroke, and can't talk, there needs to be a record on file of their end-of-life wishes. This is called a living will or durable power of attorney for health care. The organization Aging with Dignity has a site called "5 Wishes Online**."** They have an example of a simple form at **https://fivewishesonline.agingwithdignity.org/**. If you are the parent of a grown child with disabilities, you need to be sure to have a plan about where your child will go and who will look after them if you cannot be the caretaker. It is a good idea to talk to a lawyer about inheritances or special trusts to protect services that your child depends on.

As people get older, it can be harder to get around. Someone who never had a wheelchair before might need one now. You see a lot of people using scooters, but for most people a power wheelchair is a better option and it is more adaptable. Medicare has very specific rules about the purchase of power wheelchairs. Generally, there have to be problems with falling or the ability to safely and independently complete your daily living within your home to get a power wheelchair. It would be a good idea to identify a qualified therapist and vendor in your area to assist you with getting the right wheelchair. You need to be sure it can get through your doors and halls. You will also need a car or van to carry the wheelchair. Iowa Compass, **www.iowacompass.org/**, can help you find people who sell medical supplies and adapted vans. They also have want-ads for used equipment. Your vendor can assist you with identifying the adaptations you need.

It can also be a good idea to have a qualified physical therapist or occupational therapist come out to an individual's house to do a home safety assessment. They can help figure out ways to make it easier to keep their independence.

The Iowa Elderly Waiver program can help people stay in their

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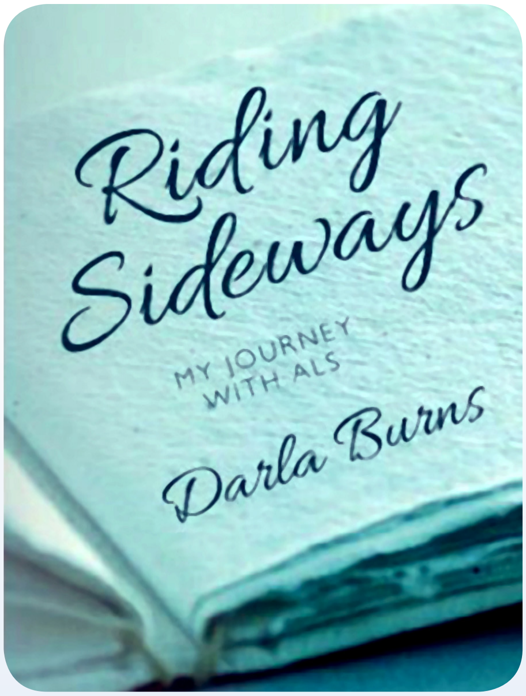
home and not move to a nursing home. This waiver can provide a monthly amount that meets the level of care they might need at a nursing home. This can go toward services to help them stay home and still live as independent a life as possible. For more information on the waiver and eligibility information, go to **http://www.aging.iowa.gov/living/cmpfe.html** or contact Iowa Compass at 800-779-2001.

Some conditions, such as Down syndrome, can increase the risk of having Alzheimer's type dementia. However, not everybody with a disability who starts having problems has Alzheimer's. Keep track of what skills your loved one already has, like going to the bathroom, eating, and getting ready in the morning. If you have it all written down, it is easier to see if anything changes. Things like depression, hearing loss, sleep apnea, or infections can change the way they may act. Don't let anybody assume that changes are just because of a disability or diagnosis. A complete medical workup may be needed.

Someone said that getting older is not for the faint of heart. It can be hard on everyone. Be sure you are planning to get the support you need.

Riding Sideways:
My journey with ALS

Darla Burns



I have been living with ALS (Amyotrophic Lateral Sclerosis / AKA Lou Gehrig's Disease) for six years. The neurologist who diagnosed me said that the average time between diagnosis and death is one to three years. I had never seen a book written by a 'regular person' living with ALS. I get that. Many people would, quite literally, run out of time or they would have more urgent priorities. Although I had spent my entire adult life working in the field of disability, I found myself continuously being surprised by the actions of people in general. The more important reason for me: I miss words! Not just being able to speak but the fluidity of speech, the reciprocity of conversation, being able to use the nuance of language, to turn a phrase. I also miss the feeling of my hands on a keyboard and the speed at which my thoughts could spill out through my fingertips. Now my thoughts are haltingly expressed through a keyboard that I operate with my eyes. It is a different experience but thank God for technology that allows me to communicate and write what you now have in your hands.

This book is a look back through the tears, and the laughter, of the last six years. My hope is that you will be reminded to treasure what is right in front of you.

Darla is a CDD patient with ALS. You can find Darla's book at local book sellers or online at Amazon.com. We have a copy here at CDD in the Disability Resource Library (DRL). Check out the DRL online at **www.uichildrens.org/cdd/drl,** call us at 800-272-7713, or email us at **disability-library@uiowa.edu.**

10 Tips for Keeping Kids Active during the Winter

When the weather turns cold and it gets dark early, keeping kids active can take more creativity and determination. Here are some ideas for keeping your family moving all winter long:

1. Bundle them up and send them out! Get the whole family out and do some sledding, build snow forts/snowmen: anything that keeps the kids moving and having fun.

2. Discover your local indoor facilities. Visit an indoor pool, ice skating rink, basketball court etc.

3. Walk the mall, but steer clear of the food court!

4. Visit the library. Check out a variety of fitness videos and books.

5. Sign 'em up! Enroll your child in an instructional group class like dancing, gymnastics, martial arts - anything that will get him/her staying active.

6. Crank up the music and dance!

7. Clean it up! Recruit kids to help with the house cleaning. Pick up toys/do laundry/scrub the tub, etc.

8. Pick up a shovel or broom. Encourage kids to not only shovel their walks, but the neighbor's as well.

9. Play a game. Play an interactive/active game system if you have one or play a game that involves some movement like charades or Twister.

10. Find the middle ground! If it is impossible to pry kids away from the screen, encourage them to do jumping jacks, sit-ups, and push-ups during breaks.

Prevent Winter Slips and Falls

Winter is here again! Everyone needs to think about preventing slips and falls, but especially anyone, old or young, who has walking or balance issues. It is important to be careful and remember the following:

- SLOW DOWN – don't rush or run to and from your car.
- When it is icy, take small steps or shuffle your feet.
- Wear proper foot gear with rubber or neoprene soles that provide good traction on snow and ice.
- Considering carrying your "good" shoes with you to wear inside, changing into your winter boots when you go to your car or ride.
- Keep hands free for balance. Let someone else assist you by carrying your things or try using a backpack.
- Be careful when first entering a building; your shoes may be wet and slippery. Or the entryway may have a slippery combination of ice, snow and water.

Are you Looking for Extra Winter Traction?

Consider keeping a container of sand within easy reach by your door and in your car to provide traction wherever you are: store, visiting friends or doctor's appointment. A container with a handle will allow you to shake out the contents while you walk and also hold onto a handrail, walker or cane. They can be refilled from less expensive large bags of sand. For this DIY ("Do It Yourself") shake container, drill holes in the lid of a small laundry soap or softener bottle. A bottle of sand can be very heavy, so you will want to be sure to have a smaller container you can easily lift and hold. *[A great gift idea or youth project!!]*

Try out a pair of Yak Trax. Yak Trax slip on over your shoe or boots and act like a pair of snow chains on your feet. They usually cost around $15-25 and are available at many stores locally or on-line. **Caution Note:** Take off your Yak Trax immediately when indoors. Yak Trax can be very slippery on indoor cement floors. They also can catch on carpet loops and cause you to stumble or fall.

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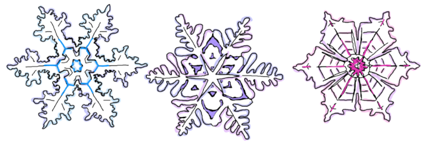

In this issue

Centerlines for Families is published quarterly. CDD encourages subscribers to read partner newsletters ***Iowa COMPASS News*** and ***Possibilities in Education and Training***. You can find them all by going to our website at **www.uichildrens.org/cdd** and then clicking on the link for newsletters on the right.

CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uichildrens.org/cdd. Click on Centerlines for Families.

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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.