

# SibNews

News for and about siblings of people with disabilities

**APRIL / MAY / JUNE 2017**

## Every Day's a Sib Day

Children and teens  
benefit from sibling  
summer camps.

## Finding Balance

A mother shares her  
discovery about balance  
and nurturing healthy  
sibling relationships.

## MAPPING It Out

Good news for WI  
wage earners with  
disabilities.

# Finding Balance

## A REAL SIBLING STORY

by Lyssa Schmidt

Life as a parent is always a balancing act, whether it's finding individual time for multiple kids, yourself, work or otherwise. While it's not easy for anyone, parents of a child with a disability face extra difficulties in finding this equilibrium.

For 14-year-old Sylvia Walentowski, her childhood included a lot of attention placed on her sister, Anna: doctor's appointments and in-home therapy and nursing care. Anna has Alexander Disease, a disorder of the nervous system that causes her to experience difficulties swallowing and eating, bronchial spasms and deteriorating motor skills.

Anna was diagnosed shortly before turning 2, around the same time that Sylvia was born. Later, Anna was granted a Make-A-Wish experience to meet Brett Favre and the Packers, and local news covered the event.

"Then we had reporters coming to the house ... that was kind of my first clue as to how the attention was affecting Anna's sibling," her mother, Jennifer, said. "Even at that young age, Sylvia was becoming more boisterous and more naughty."

Sylvia loves her sister, but at a young age was showing unhealthy amounts of jealousy because of the attention her sister received for her care. Now, as a teenager, Jennifer says she still struggles emotionally.

The family is thankful to have found support in WisconSibs, opening more opportunities for Sylvia to have the extra attention and emotional care she needs.

"The biggest factor is the support for Sylvia — specifically planned questions, activities to get the siblings talking. WisconSibs is able to get them to be able to open up and say, 'Yea, sometimes my sibling with a disability really bugs me,'" Jennifer said. This type of open conversation and acceptance, Jennifer said, has helped Sylvia cope with her feelings.

While WisconSibs participants have siblings with a variety of conditions, Jennifer said the specific diagnosis is not really important — what matters for Sylvia is having others her age whom she can relate to, and be honest about her feelings with.

## "We needed to set aside time for her alone..."

When Sylvia turned 13, she and Jennifer attended the Mom-Daughter Sibshop (known as S.P.A.—Sisters are Pretty Awesome Sibshop), and Jennifer said the experience created big, positive change for their relationship.

Jennifer feels overall her family has done well with their own balancing act, being able to maintain an active lifestyle and enjoying typical family outings — and keeping individual needs in mind.

"In general, most days, there's a bit of juggling, between whose needs are being met," she said.

"Sylvia's acting out showed us that we needed to set aside time for her alone - where we were just focused on her and doing something that she enjoyed."



Sylvia and her sister Anna have lots of good times together.

## On In-home Visits

Anna's care requires in-home therapy and medical care. Sylvia was often at home during these visits, and at first, Jennifer didn't think much of it.

When Sylvia was about 4-years-old, however, Jennifer noticed what she calls "amplified" sibling rivalry. Sylvia was feeling overwhelming jealousy of the attention Anna received. To get attention, she interrupted therapy.

Over the years, Jennifer noticed that some nurses would acknowledge Sylvia, while others would simply ignore her — and this made a difference. So, Jennifer started taking charge with any new caregivers.

She would navigate the introduction to include both Anna and Sylvia, keeping both engaged with the individuals who visited the home — even if the bottom line was they were there for Anna.

"The best have been those that remember Sylvia's birthday," Jennifer said, "and talk with her."

### You can help.

The Walentowskis were introduced to WisconSibs by Steve Rieth, a colleague of Sylvia's father Jeff, at Thrivent Financial. If you know a parent raising children with disabilities and their siblings, pass along this SibNews, send them a link to [wisconsibs.org](http://wisconsibs.org), or offer to make the call or send an email.





# Easy Daisy Cake

*Make something special for Mom this Mother's Day. Christiana Redman recommends making her this super easy pretty cake with your sibling. Tastes like cake from a gourmet bakery.*

- 1 box cake mix, any flavor
- Eggs according to package directions PLUS one more
- Instead of oil, use 2 times that amount of melted butter (ex. If it calls for 1/2 cup oil, use 1 cup butter)
- Substitute milk for the water

1. Follow package instructions mixing together the mix, milk, eggs, and butter in a bowl.
2. Pour into 2 9" cake pans and bake according to directions.

For a pretty, spring daisy cake, frost the cake and sprinkle chocolate chips on top in the center. Then place PEEPs chicks around the top edge.

Your Mom will love it!

*If you or your sibling have a recipe to share, send it to [info@wisconsibs.org](mailto:info@wisconsibs.org) along with a photo of you or the prepared recipe.*



Christiana's brother Phillip carefully adds the PEEPs to decorate their cake.



# Every Day's a Sib Day

By Harriet Redman, Executive Director



Siblings are everywhere. You see them in parks, schools, businesses, even as characters portraying siblings in movies and on TV. Whether you watch the make-believe siblings in ABC's "Speechless", or know every detail of the squabbles between Anna and Elsa in Disney's "Frozen", you can't deny that siblings are everywhere, every day.

Sometimes dealing with your own real sibling every day is a pain. They can be aggravating. They can get you in trouble with your parents. They can mess up your stuff. Right?


But all that is pretty routine and tolerable as long as you don't get the sense that your sibling is the "favorite" in the family. That is just too much.

It is understandable that when a child in the family has disabilities or medical concerns, parents need to spend time and resources to support them. But to a young child, it can appear that their sibling is their parents' favorite. It can feel like every day is their sibling's day. This real imbalance can be very difficult for both the child with special needs and their sibling. Both can feel bad.

Most parents find that when they talk with their child about "why" the

differential treatment, siblings relax. Add to that an agreement that the sibling will get their own time with at least one parent, and jealousy melts.

One more tip. Find ways, especially during summer, that siblings can get a break from one another and meet other siblings. This year at camp siblings will discover that when you are a WisconSib. *Everyday's a Sib Day* means every day is a FUN day.

***"My son has gotten increasingly kinder to his sister over the years and I think a large part of that is having an outlet like SibDays."*** Parent 

## **Sibling Summer 2017** For Children and Teens

**Teen Sib Leadership Day**—June 20

**SibDays of Summer**—July 17-21

**Teen Sib Leaders Camp**—July 25-27

**Sib Camp**—Aug 5-8 & Aug 10-13

## For Adult Sibs

**Sibling Leadership Network Conference** — June 24-25 (see calendar)

## For Parents and others

**Golf Fore Children**—Aug 15

Royal St Patrick's - More info on website

## MAPPING It Out

By Stephenie Noggle,  
Fund Development Coordinator  
[Stephenie@wisconsibs.org](mailto:Stephenie@wisconsibs.org)



Employment is a priority for people with disabilities and their siblings. But overcoming the barriers to employment can be daunting, especially when unrealistically low limits on assets and earnings force wage earners to lose vital benefits.

But there is some good news.

Governor Walker included in his state budget some important changes in a work incentive program called the Medical Assistance Purchase Plan (MAPP). That makes me happy.

### How it works

MAPP helps wage earners with disabilities keep their Medicaid while they work.

Medicare covers up to 80% of healthcare costs. MAPP picks up where Medicare left off, covering the remaining 20% of the cost for a monthly premium.

Participants pay at least a \$25 premium and others who may have been paying more will see their premiums lower as they work and earn more.

In addition, independence and retirement accounts can help MAPP recipients save and plan for the future without affecting their coverage.

Reforms will incentivize and sustain MAPP; making it a worthwhile insurance option for me and others with disabilities interested in working.

The goal is to keep healthcare affordable so people with disabilities can keep working.

I'll keep working for YOU here at WisconSibs. That makes me happy.

To find out more about MAPP eligibility, work incentives, and premiums contact a Disability Benefits Specialist through your local ADRC office.



Thank you to all the sponsors, volunteers, and attendees who helped make Vegas Madness a success. You made it possible for people of all abilities have fun and raise funds for sibling camp scholarships. The MBM team proudly took the cheesy trophy as our **Family Feud** winners. Congrats and thank you! Sponsors included:

**Arthur. J. Gallagher & Co.**

**Dr. Jeff Cherney & Women's Health Specialists  
MBM**

**Ridgeview Highlands Apartments**

**Thrivent Action Teams (2)**

**Esser Consulting, LLC**

**Northland Electrical Services**

**Valley Drafting, Inc**

## Need Volunteers

If you can help drop off copies of SibNews at various agencies in the Fox Valley and beyond, email us to [let us know](#).

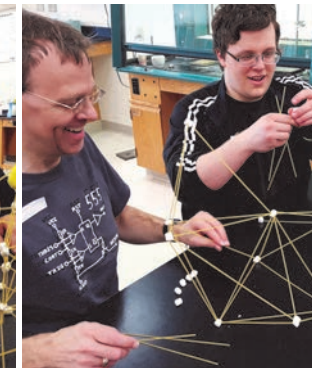
# WisconSibs Fun

Vegas Madness



Family Feud Team

H.U.L.K. SIBSHOP for boys  
and their dads





# Calendar of Events

MORE INFO AT  
WISCONSIBS.ORG

## APRIL 2017

### Mar 31 & Apr 1 — Sibshop Training with Don Meyer

Milwaukee

This two-day training makes it possible for more Wisconsin communities to offer Sibshops.



### April 8 — KIDZ EXPO

9:00 am—3:00 pm

Fox Valley Technical College  
1825 N. Bluemound, Appleton



A FREE family event that is fun, educational and adventurous. Visit our booth sponsored by WE Energies and celebrate National Siblings Day with us.

### April 10 — National Siblings Day Have a great day with your sib!



### April 29 — Autism Sibshop\* — WI Autism Conference

8:00 am—11:00 am

Kalahari— WI Dells

\*Sibshop offered in collaboration with the Autism Society of WI. For more information, contact Melissa Vande Velden at 920-973-6636 or [mvandevelden@asw4autism.org](mailto:mvandevelden@asw4autism.org)

## MAY 2017

### May 1 — Sib Camp & Teen Sib Leader applications due

Online registration on website or contact us.

### May 4-5 — WisconSibs Sibshop at Circles of Life

Conference Center—Stevens Point

Annual conference for parents and family members who have children with disabilities and professionals who support them. For info call John Shaw at 608-294-8716.



### May 6 — HUMAN RACE

9:00 am—Registration

10:00 am—Race begins

Thrivent Grounds

4321 N Ballard Rd.,  
Appleton



Online donations and race

registration at [https://](https://www.crowdrise.com/WisconSibsInc)

[www.crowdrise.com/WisconSibsInc](https://www.crowdrise.com/WisconSibsInc)

### May 6 — Diversity Day featuring WisconSibs

and dozens of other organizations,

performances, and cultural activities

9:00 am—3:00 pm

Building for Kids Children's Museum,  
Downtown Appleton



FREE Museum admission. Local diversity groups with hands-on activities to learn, discover and celebrate diversity.

### May 13— Wings for All Appleton Internat'l Airport

11:30 am —1:45 pm



This airport "rehearsal" is specially designed for individuals with autism or other developmental disabilities and their families to help alleviate

some of the stress of travelling by air. FREE but registration is required. To register, visit: <http://bit.ly/WingsForAutismATW>

## JUNE 2017

### June 1— SibDays of Summer registration due

Online registration on website or contact us.

### TBD — Listening Session with Congressman Mike Gallagher

### June 20 — Teen Sib Leadership Day

10 AM—3 PM

City Park, Appleton

If you're a teen who wants to be more confident, learn how to have greater influence with people, and practice personal leadership in a very fun group setting, this day is for YOU! By invitation only. Contact us for application.

### June 24-25 — National Sibling Leadership Network Conference

Hartford,  
Connecticut



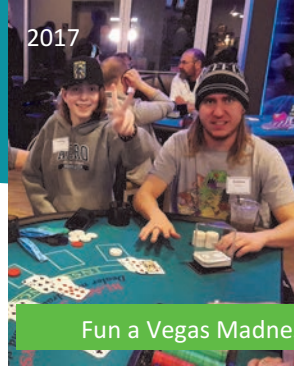
"Celebrating the Sibling Voice" is the theme for this opportunity to connect with other adult siblings of people with disabilities. Hear national experts on the latest in sibling services, and research. More information at <http://siblingleadership.org>

## THEN & NOW!

Got a "then and now" story?  
Email us.



Fun at Santa Celebration



Fun a Vegas Madness

Ten years ago, Zach Watry and his little sister Ashley were hanging out together at our Santa Celebration. They are still finding ways to get out and have fun together, but now with grown ups at Vegas Madness.

WisconSibs' casino night (now called Vegas Madness) originated in 2007 as a response to adult siblings looking for social opportunities in the community that welcomed all abilities to have fun together and stay close to one another as siblings.

## LITTLE SIBS SAY

## HAPPY MOTHER'S DAY

Got a joke,  
puzzle or color-  
ing page to  
share?  
Email us.



# wisconsibs

Sisters & Brothers of People with Disabilities

211 E Franklin St. Ste #C  
Appleton, WI 54911

Phone: 920-968-1742  
E-mail: [info@wisconsibs.org](mailto:info@wisconsibs.org)  
[www.wisconsibs.org](http://www.wisconsibs.org)

- We are Wisconsin siblings of people with disabilities.
- We are role models to our siblings, our peers, our friends, and our community.
- We are caregivers and companions.
- We advocate with and for our siblings for a bright future.

Get Involved. To register FREE as a WisconSib or a WisconSib Fan, to donate, or volunteer, visit [wisconsibs.org/get-involved/](http://wisconsibs.org/get-involved/)



# HUMAN RACE



FEATURING



PRESENTED BY  
**COMMUNITY FIRST**  
CREDIT UNION  
*We'll Find A Way!*



Join our online team and  
donate today!

<https://www.crowdrise.com/WisconSibsInc>

Come walk or run with us. Enjoy food, music, and fun while raising funds for sibling programs.

## Saturday, May 6, 2017

9:00 am—Thrivent Grounds

4321 N Ballard Rd, Appleton

All ages, all abilities welcome!

Wheelchairs, strollers, and pets welcome!

Goal: \$4000 for camperships and teen sib leader program.