

SibNews

News for and about siblings of people with disabilities
Volume 19, Issue 3 **May-July 2021**

Calendar

Looking forward to Summer 2021.

The Gift I Got

An interview with sisters growing up with Tourette Syndrome

Sibling Success

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The Gift I Got

An Interview with the Jarvie Sisters by Harriet Redman

Recently the Tourette Association-Wisconsin asked me to speak at their conference. To prepare, I spoke with several adults who grew up with siblings with Tourette Syndrome (TS), including Ellie Jarvie, an advocacy specialist with Disability Rights Wisconsin in Madison, WI who has TS and her younger sister Michelle Jarvie Eggart, Sr Lecturer in engineering at MI Tech University.

What was it like growing up?

Michelle: Ellie is my older sister, so I've never known a time without her. Growing up, I always idolized Ellie because she read to me every night.

I picked on her and she picked on me. One time we were walking on the road and other kids started picking on Ellie and I remember being so mad. As teens, I became aware at the Mall that the world was not kind to Ellie. When we'd go to restaurants Mom passed out pamphlets to educate people who were staring at us.

Ellie: As a kid, I remember wanting time by myself without a little sister hanging around. All I ever tried to do was blend in and all my sister wanted to do was stand out. We would physically fight. I teased her about being short.



Do you recall when you learned of the Tourette diagnosis? What was that like?

Ellie: I was diagnosed when I was 14. Getting the diagnosis was amazing. I am a reader so I read all about TS. I found a phone number and I called for more information at age 14. Mom got very involved in the state TS chapter and attended national conferences. The Tourette story is complex so having a diagnosis, a label, opened doors. Since my diagnosis, I've made lots of connections and lots of friends thanks to the Tourette Association.

“All I ever tried to do was blend in and all my sister wanted to do was stand out.”

Michelle: Before the diagnosis I remember being confused. Can't she stop? Is someone lying? Why are mom and dad yelling at her? I wanted to protect her. But I also wanted her to stop. After the diagnosis, it was amazing to see Ellie's self-confidence grow because she suddenly had friends who understood TS. The diagnosis explained why ... and it wasn't her fault.

What's been the hardest thing about living with Tourette Syndrome?

Ellie: When I was a young child, there was no information and I was often misdiagnosed. I had to take heavy doses of medications; feeling drugged, the weight gain, it was a struggle.

Michelle: There was lots of fighting at home before Ellie's diagnosis. We



thought she was doing every behavior on purpose. Mom was also fighting with the school for Ellie to stay in class.

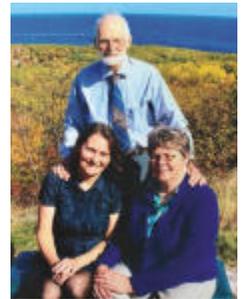
Has your experience with Tourette Syndrome influenced your career choices?

Ellie: Definitely, TS has influenced my career choice to pursue social work. My advocacy spirit fits me in my position with Disability Rights Wisconsin.

Michelle: I know our mom would be proud of you, Ellie. TS did not influence my choice of career. My dad was an engineer, so I'm an engineer. But Mom's advocacy and having watched Ellie struggle completely influences the way I do my job and my perspective as an educator. I don't make it harder for students or make students struggle to be heard.

What's been the best part of living with Tourette Syndrome?

Ellie: For me, it is the connections I've had with various people that I never would have without TS. The TS experience has helped me understand others with different abilities and better able to help them function in a world not made for us and may not want us.



Creamy Lemon Asparagus Pasta

(Dairy Free, Garlic/Onion Free, Optional Gluten and Top 8 Free)

This springy dish combines a dairy-free lemon cream sauce with fresh green vegetables for an exciting spin on pasta night!

Ingredients:

- 1 bunch fresh asparagus, chopped
- 1 1/2 c. frozen peas
- 1 1/2 c. frozen green beans
- 16 oz of your favorite pasta
- 2 tsp. kosher salt
- 1 Tbsp. olive or vegetable oil
- 1 1/2 c. diced ham or chicken
- 1 1/2 Tbsp. all-purpose or gluten-free flour blend
- 1 (15 oz.) can reduced-fat coconut milk (or 1 3/4 c. milk of your choice)
- 1 1/2 Tbsp. grainy mustard
- 1/2 tsp. dried thyme leaves
- 1/2 tsp. kosher salt
- 1/4 tsp. ground pepper
- Zest and juice of one lemon

Directions:

1. Prepare pasta according to package directions using the kosher salt.
2. Three minutes before pasta is done, add the asparagus, peas, and green beans. Continue cooking until pasta and vegetables are done to your liking. Drain, then return pasta and vegetables to the pot. Reserve.
3. Meanwhile, heat oil in a large skillet over medium high heat. When oil is hot, add ham or chicken and saute for 2-3 minutes or until heated through.
4. Make the roux: sprinkle flour over meat until thoroughly coated and no clumps of flour left. The mixture will be thick. Slowly stir in coconut milk, 1/2 cup at a time, stirring thoroughly after each addition. Once you have incorporated all of the coconut milk, stir in the mustard, thyme, 1/2 tsp salt, pepper, and lemon zest. Simmer for 3-5 minutes to thicken sauce, stirring occasionally. Do not let the sauce mixture boil because it will separate.
5. Pour creamy sauce mixture into the pasta and vegetables. Add the lemon juice, and stir to combine. Enjoy!



Enjoy this delicious, allergy-friendly recipe submitted by WisconSib Kristin Lanari. Find more recipes on Kristin's Instagram @coffeetableeats

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Success! Thank You

By: Stephenie Mlodzik

Every October, WisconSibs holds its signature fundraising event Celebrate Sisterhood. The months leading up to this celebration are full of excitement, enthusiasm, and non-stop preparation. There's a familiar comfort in watching how it all comes together—a comfort that was noticeably absent this year. Due to the COVID-19 Pandemic, the 15th Annual Celebrate Sisterhood had to be cancelled. But out of adversity came opportunity. In lieu of gathering in-person, we were given the chance to host a virtual event and feature siblings in their own words.

Sibling Voices: Stories of Hope premiered on November 17, 2020. Viewers could tune in via Facebook Live and YouTube. The focus of this event is what makes this one-of-a-kind non-profit so valuable: the siblings we serve. With introductions by WisconSibs Executive Director, Harriet Redman and everyone's favorite emcee, Bill Jartz, siblings of people with disabilities took center stage and shared their stories in their own words.

The goal? Raise \$40,000 in donations and sponsors from at least 100 donors.

The result? We not only made that fundraising goal we exceeded it with over \$23,000 in donations and \$31,000 in sponsorships. Success!

A Special Thank You

Thank you to everyone who volunteered their time and talents, participated in the event, and donated to support our exceptional siblings. Your generosity has kept WisconSibs going through the



uncertainties of this pandemic. Thanks to you, siblings of people with disabilities and their families have access to the vital supports and services they need.

A very special thank you to our sponsors and event emcee, Bill Jartz. You helped make this magical night possible.

If you missed the premier, check out our YouTube channel and the 8-minute version of the **Sibling Voices: Stories of Hope**. Go to YouTube.com and search "WisconSibs". You can subscribe or simply browse the videos that pop up.



Mark your calendar when you can once again join us for **Celebrate Sisterhood!**



To make a one-time donation set up an automatic monthly gift visit our website and look for **DONATE**.

*Your gift could be matched. Check with your employer.



Stephenie is the WisconSibs Fund Development Coordinator. She is currently also serving as a member of the WI Board for People with Disabilities.

Contact her at Stephenie@wisconsibs.org.

WisconSibs Board of Directors Welcomes New Members

The WisconSibs Board of Directors is expanding as part of our strategic initiative to build greater awareness of WisconSibs and develop collaborations throughout Wisconsin. Meet just a couple of our newest members.

Sean Drury, Attorney

Sean lives in Waupaca and is ready to 'roll-up-his-sleeves' and help WisconSibs expand our mission. He brings experience working with nonprofits and will be helping us with legal questions.

Jean Haznar, retired Project Search Instructor

Anyone who knows Jean knows she has a big heart for people with disabilities and jumps into any opportunity to support them in the community with both feet. Now retired, she serves on boards to promote Human Rights and will help WisconSibs explore new ideas to better serve siblings into the future.



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Calendar of Events

MORE INFO OR TO REGISTER, VISIT WISCONSIBS.ORG

All events are subject to change.

Summer 2021 Teen Sib Leadership Awards

May 15

For the past 10 years, WisconSibs has recognized teen siblings who have demonstrated eagerness for a challenge and a heart for serving others. The 2021 winners will be announced May 15. Watch our Facebook page and website.

WisconSibs Summer Intern Program

We are excited to announce our two sibling summer interns starting May 17.



Thalia Mann and Sophia Schinke. They will be working on our summer programs and special projects.

More in-person and online events and activities will be scheduled as we have more certainty about reopening. Safety will always be our top priority in determining when, where, and how programs are presented.

TotalTek/WisconSibs Golf Outing Fundraiser

June 1

Oconomoc Golf Club

TotalTek, a technology company focused on managed services specializing in engineering and IT solutions. Their core value is Improving lives. They have chosen to help WisconSibs expand our mission to more siblings throughout Wisconsin by hosting their first golf outing. Thank you TotalTek!

Teen Sib Leadership Day

Wednesday, June 16 10 am-3pm

River Tyme Bistro/Fox River Tours

Teen Sib Leadership award recipients and alum attend this event and the volunteer opportunities they choose in the future to develop leadership



skills important in their role as a siblings and in service to their community.

The theme “Siblings Cruise” will prepare us for our summer camps.

Neil Ihde, motivational speaker and leadership trainer, will inspire and challenge teens with his presentation, ‘Putting the SHIP in LEADERSHIP’. The teens end their day with a cruise down the Fox River.

SibDays of Summer

Mon-Fri, July 19-23 10 am—3 pm

Plamann Park

1375 E Broadway Dr., Appleton

SibDays is a great opportunity for kids growing up with siblings with disabilities to enjoy some outdoor relaxation, games, crafts, swimming and much more. Sibs make friends and discover new ideas and information every day. Deadline to enroll-June 1



Sib Camp - Door County

July 31-August 19

For siblings ages 9-17, Sib Camp is an opportunity for some respite, kick back, and experience the freedom and thrill of adventure. Sibs have a great time with peers who truly understand the ups and downs of life with siblings who have special needs.

Sib Camp activities include biking, hiking, swimming, paddling, zip lining, stargazing, camp cooking, campfires,



ecology, photography, and much more!

Ages 9-14

July 31 NOON—Aug 3 NOON

Ages 9-11

Aug 12 NOON -15 NOON

Ages 12-16 **SOLD OUT**

Aug 16 NOON -19 NOON

Interview cont'd

Michelle: I can't image having another sister. The gift I got is this; I got the confidence to be done with what society thinks. I care more about what I think about me. I don't care if the whole world is staring. I'm less likely to dismiss people for their difference. I never noticed this about me until I'm with my peers and they don't have that gift.

I remember I was at an airport in Oregon. A man there was tic-ing. The stewardesses were going to call the police. I was able to explain what was going on.

What advice do you have for others living with Tourettes?

Ellie: Connect with other families and the Tourette Association. Don't let TS hold you back. Don't forget the siblings. One of our new members that

attended your presentation, Harriet, told me "my son was diagnosed with TS a week ago and now I feel support for both my kids". Siblings are so important. No other organization is doing what WisconSibs is doing.



Michelle: If you become a Tourette family, or any other disability, remember you are still a family. Traditions and togetherness are so important. TS is just one part of your family. Find to do fun things. Our parents were persistent, and it paid off. Find resources and keep advocating for access to medical care.

Facts about Tourette Syndrome (more info at www.tourette.org)

- ⇒ Tourette Syndrome (TS) is a neuro-developmental disorder characterized by motor and vocal tics.
- ⇒ 1 out of every 160 children between the ages of 5-17 in the USA has TS and that 1 out of every 100 children has TS or another Tic Disorder.
- ⇒ It is common for people with TS to be affected by another co-occurring condition such as ADHD and OCD.
- ⇒ There is no cure for TS, but thanks to years of dedicated research, there are various treatment options.

For more about TAA-WI, visit tourette.org/chapter/wi/

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- 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. Even the very youngest of us help care for our siblings with special needs.
- As we grow, we play a vital role in the quality of life of our siblings.

New!! WisconSibs Program for ages 3-5

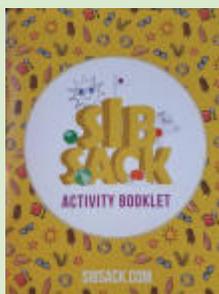


Do you have a sibling child age 3 to 5 years old? Or perhaps a very young grandchild who has a sibling with disabilities?

Sibsack was developed to help parents talk with their 3-5-year-old(s) about their sibling's disability diagnosis. How to discuss such a big topic with young children can seem overwhelming. This kit provides simple, fun tools and tips. A \$30 Value

Activity Book

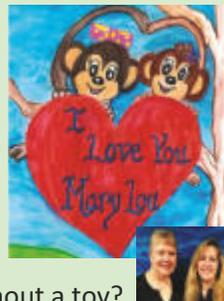
is a collection of



activities and stickers for young sibs. Each page also provides conversation starters between child and parent.

Story book The *I Love You Mary Lou* story provides parents an opportunity to help children feel that they are not alone, and they are loved. Additional books listed also help children value the unique traits and special gifts each child brings to the family and the world.

Toy What would a kit for children be without a toy? The toy included in the Sibsack is intended to encourage relationships through play, whether it be play between siblings, or play and conversation with a parent or friend.



Parent Guide A short, informative guide is included to help parents use the kit with their child along with parenting tips.

Order Your FREE Sibsack

During May, June, and July we are making Sibsacks available to individual families **free of charge**. 1/family. Visit www.sibsack.com or email info@wisconsibs.org to get order information.

Developed by WisconSibs, Inc in collaboration with

- Fox Valley Technical College Occupational Therapy Assistant students
- Ruth Schmeckpeper, teacher, author of *I Love You Mary Lou*
- Michelle Raatz, special education teacher, Illustrator of *I Love You Mary Lou*
- Ruth McDonald, adult sibling, artist

With funding support from

- SAC Developmental Disabilities Fund
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