

UI Joins National Online Autism Study



Jacob Michaelson, PhD

The University of Iowa is partnering with SPARK (Simons Foundation Powering Autism Research for Knowledge), a national autism research initiative that will connect individuals with a professional diagnosis of autism and their biological family members to research opportunities to advance our understanding of autism.

Jacob Michaelson, PhD, assistant professor of psychiatry in the UI Carver College of Medicine, is the principal investigator of the SPARK trial site at the University of Iowa. Michaelson's lab is the only Iowa site in the SPARK network and has already built a strong genetic registry of neurodevelopmental conditions, with roughly 900 individuals involved.

What is SPARK?

Autism has a strong genetic component. To date, approximately 50 genes have been identified that almost certainly play a role in autism, and researchers estimate that at least an additional 300 are involved. But to identify all the genes at play, many more genetic samples are needed from those with autism and their immediate families.

That's where SPARK comes in. SPARK is an online scientific study and community of individuals with autism and their families. The trial was launched just a year ago, and the University of Iowa in Iowa City has now partnered with SPARK in enrolling more than 60,000 people, so far, 23,000 of whom have autism.



SPARK's goals are twofold: first, to identify the hundreds of autism genes at play and to link them to the biological mechanisms that they govern as well as to any environmental factors to which participants with autism may have been exposed. Researchers can better understand the condition's causes by linking specific identified genes to the diverse array of symptoms, skills, and challenges of those affected. Second, it seeks to connect these individuals and families to research opportunities that advance the understanding of autism.

Why genes? And why 50,000?

It is estimated that it will take 50,000 genetic profiles of people with autism to identify a large percentage of the genetic factors contributing to autism. SPARK principal investigator Wendy Chung, MD, PhD, says, "Statistically, if we succeed in working with 50,000 participants on the

(Continued on page 2)

UI Joins National Online Autism Study

(Continued from page 1)



New genetic study aims to enroll 50,000 individuals with autism and their families, making it the most ambitious study of autism genetics to date.

autism spectrum, we will be able to identify at least 250 genes that contribute to autism that can be used to better understand how the brain is different in individuals with autism and potentially identify targets to develop medications that can be used to support individuals with autism.”

In a genetic study of this scope, it is important to collect not only DNA from the person with autism but also that of both of his/her biological parents (a “trio”). The study currently has 23,000 people with autism enrolled but only 9,500 of them are members of trios. Trios enable scientists to identify whether an autism gene was passed down from a parent or ‘sprung up’ in a different way.

“Since every kid is like a genetic snowflake, you need really big numbers to capture the genetic diversity that’s out there in autism,” says Michaelson, who also is a member of the Iowa Neuroscience Institute.

Michaelson’s lab uses computing and genomics to improve the understanding, diagnosis, monitoring, and treatment of conditions like autism and developmental language disorder.

“SPARK empowers researchers to make new discoveries that will ultimately lead to the development of new supports and treatments to improve lives,” he says.

A family’s story

Through the project’s website and on social media, participating individuals and families have begun to express enthusiasm for all that SPARK makes possible:

Gemma is a curly headed four-year-old from Cedar Rapids who enjoys going on weekend adventures, which includes throwing rocks to watch water ripple. “She’s super smart. She can do her ABCs. She can count to 100. But you don’t know because she can’t communicate the best,” says her mother, Shayna Franks. “She’s strong and difficult.” Titus, her three-year-old brother, is a charmer who is entertained by anything with wheels.

Both children were diagnosed with autism at a young age and Franks has worked tirelessly since then to learn as much as possible about their diagnosis while also ferrying them to several therapy appointments every day.

The family has already participated in research conducted in Michaelson’s lab, including SPARK. Franks says it’s amazing to know that her kids are a part of research that may bring groundbreaking treatments for kids that face similar daily struggles, such as difficulty communicating and emotional instability.

“I just believe in research,” Franks said. “Why not? Even if it takes a half hour. Everybody benefits from this.”

She also says that participating in research has provided her with new resources and information that’s made it easier for her children to navigate the world.

Learn more

Anyone interested in learning more about SPARK or in participating may:

- Visit SPARKforautism.org/uiowa
- Find the Michaelson Lab at UIowa on Facebook, facebook.com/MichaelsonLab
- Find the SPARK study on Facebook, facebook.com/SPARKforAutism
- Contact the researchers at SPARK-study@uiowa.edu and 319-335-8882

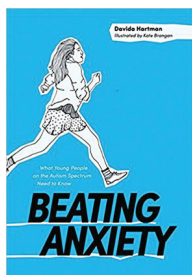
Authentically You: Tween Books for Life's Challenges



Social Fortune Or Social Fate: ***A social thinking graphic novel map for social quest seekers***

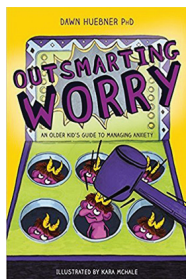
Pamela Crooke & Michelle Garcia Winner

This book lures in readers with the catchphrase, “Watch their destinies unfold based on the choices they make.” There are obvious social rules here; even better, there are hidden social rules! The book has engaging anime characters who work through classroom situations and social engagement.



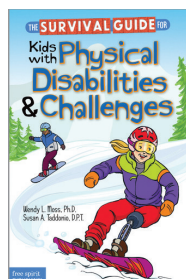
Beating Anxiety: What young people on the autism spectrum need to know Davida Hartman

Anxiety has a look and a feel. The author takes youth on a safe journey through their bodies in order to identify mental and physical stressors. Solutions are suggested from which youth can pick and choose, or maybe even discuss with their parents.



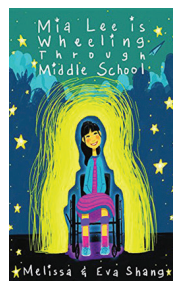
Outsmarting Worry: ***An older kid's guide to managing anxiety*** Dawn Huebner

Written by one of the best-loved authors of psychological analyses masked as entertaining self-help books for young people. Outsmarting Worry is currently #1 on the Amazon hot list for Books: Teens: Social Issues: Special Needs.



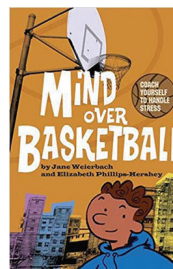
The Survival Guide For Kids With Physical Disabilities And Challenges Wendy L. Moss, & Susan A. Taddonio

Above all, remember: “You are not your disability.” A very positive and insightful book with a host of tips how to become strong, independent young adults.



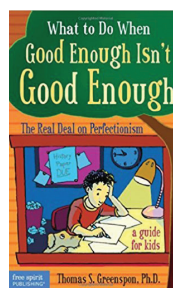
Mia Lee Is Wheeling Through Middle School Melissa & Eva Shang

This work of fiction from the Shang sisters, tells the story of Mia Lee's first year of middle school. Mia uses a wheelchair due to Charcot-Marie-Tooth disease in her hands and feet, a fact of life that is not at all a hindrance to her desire to be cool in sixth grade. Unfortunately, the placement of her wheelchair in a school hallway causes a brief run-in with blonde and gorgeous Angela, and hackles fly. Will Angela eventually become Mia's friend or frenemy? Only a school election will tell.



Mind Over Basketball: ***Coach yourself to handle stress*** Jane Weierbach & Elizabeth Phillips-Hershey

Too many responsibilities crowd young lives today and emotional and physical problems can result. This is a story about Tuck, who lives for basketball and dreams of joining the team, but there are so many obstacles in his path. Worry leads to stress, and Tuck must work himself out of this dilemma. What works for Tuck might work for your teen. Follow the pointer clues and the questions at the end of the story to find out.



What To Do When Good Enough Isn't Good Enough: The real deal on perfectionism: A guide for kids Thomas S. Greenspon

All over the world, we observe young people making marvelous strides in every sort of endeavor. For some it is a gift, for others mastery, and for many it is a struggle. Any one of these adolescents can struggle with perfectionism. This book is intended to give your child some perspective on the pitfalls of perfectionism at their level of understanding, and give tips on how to escape from its stranglehold.

For additional information please contact the Disability Resource Library
by phone 800-272-7713 or via email: disability-library@uiowa.edu
uichildrens.org/cdd/drl



Provider Highlight

Shruti Tewar, MD

Division of Developmental and Behavioral Pediatrics

Medical School (India): B. J. Medical College, Ahmedabad

Pediatric residency: The Children's Hospital at Albany Medical Center, Albany, NY

Developmental and Behavioral Pediatrics Fellowship:

Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Master of Public Health: West Chester University of Pennsylvania

How long have you been practicing? 2 years

Why did you choose your field?

Working with children and families with developmental disabilities and behavior challenges is my passion. "It takes a village to raise a child" –it takes a team approach working with parents to raise a child with developmental difficulties.

What areas interest you in your field?

ADHD, autism spectrum disorders, and learning difficulties.

What is a Developmental and Behavioral Pediatrician?

We are medical doctors who have completed four years of medical school, three years of residency training in pediatrics and are board certified in pediatrics. On top of that we have specialty training in developmental-behavioral pediatrics. If your child has a developmental, learning, or behavior problem, a developmental-behavioral pediatrician has the training and expertise to care for your child.

Who benefits from seeing a Developmental and Behavioral Pediatrician?

Developmental-behavioral pediatricians evaluate, counsel, and provide treatment for children, adolescents, and their families with a wide range of developmental and behavioral difficulties, learning difficulties, attention and behavioral disorders including:

- Attention-deficit/hyperactivity disorder
- Sleep disorders
- Feeding problems
- Discipline difficulties
- Complicated toilet training issues
- Cerebral palsy
- Spina bifida
- Intellectual disability
- Autism spectrum disorder
- Developmental/behavioral problems in children with chronic illnesses or disabling conditions (for example, genetic disorders, epilepsy, prematurity, diabetes, asthma, cancer)

How do these services help people live independent lives?

The care we give helps reduce the impairment for a child or individual so they can be as independent as possible in their daily life. We help

"level the playing field" so that the child can achieve their potential. We may not be able to change their medical condition, but we can provide ways to reduce stress for the child and family while improving their quality of life.

What does your department offer to patients that other programs don't?

We have a process where providers from different disciplines work together to coordinate services. Therapists and behavioral specialists are talking to the medical providers and vice versa. Most of our work is done in the same building and families don't have to travel elsewhere.

Why did you choose CDD?

People at CDD are motivated and passionate about what they do. They are champions for families, are experts in what they do, and are always willing to listen and lend a helping hand!

What would you say to a patient and family coming to the CDD for the first time to see you?

You know your child the best. My job is to inform, educate, and empower you with resources as best as I can so you can help your child be the best they can be.

Jiggling Juice

This is like the just-add-water gelatin dessert that comes in a box—only it's yummier and healthier because you're making it yourself with real fruit juice! We promise your body won't miss all that extra sugar and those artificial flavors and colors. For an extra-pretty dessert, use white grape juice so that the colorful fruit can shine through.



MAKES: 4 Servings
HANDS-ON TIME:
10 minutes
TOTAL TIME: 4 hours, 10 minutes

KITCHEN GEAR

Measuring cup, Small pot, Spoon, Heatproof bowl or large heatproof measuring cup, and 4 short glasses or small bowls

INGREDIENTS

- 2 cups real (100%) fruit juice
(NOT mango, papaya, kiwi, or fresh pineapple)*
- 1 envelope (1/4-oz) unflavored gelatin
(such as Knox, which you can find at the supermarket, near the other gelatin desserts)
- 1 cup berries or cut-up fruit
(NOT mango, papaya, kiwi, or fresh pineapple)*

INSTRUCTIONS

1. Put 1/2 cup fruit juice in the bowl and sprinkle the gelatin over it. (This is called "blooming" the gelatin, and it makes it easier to dissolve later.)
2. Put the rest of the juice in the pot and put the pot on the stove. Turn the heat to medium and bring the juice just to a boil. (You'll know the juice is boiling when you see bubbles breaking at the surface.)
3. Carefully pour the boiling juice (this is a job for an adult) over the gelatin mixture and stir until the gelatin dissolves, about 2 minutes.
4. Put 1/4 cup fruit in each glass or bowl, then add 1/2 cup of the gelatin mixture.
5. Refrigerate until firm, about 4 hours.

***Did you know?** Gelatin is made of a protein called collagen, and it works by creating tangles of protein strands that turn a liquid, like juice, into a wiggly solid. But some fruits, such as mango, papaya, kiwi, and fresh pineapple, contain a substance called protease that works like scissors to cut up the protein strands so they can't form a solid. If you use those fruits, your gelatin won't set properly!



Carrot Cupcakes

Carrots add a natural sweetness to cake so you need less sugar. Try them with delicious maple cream cheese icing!

MAKES: 12 Servings
HANDS-ON TIME: 20 minutes
TOTAL TIME: 45 minutes

KITCHEN GEAR

Measuring spoon, Mixer or large bowl, 2 ounce scoop or tablespoon, Small bowl, Table knife, Measuring cups, Box grater, Cupcake liners, 12-cup muffin tin

INGREDIENTS

- 1/2 cup canola oil
- 3/4 cups sugar, honey, agave or maple syrup
- 2 large eggs
- 1/2 pound carrots, scrubbed and grated
- 1/2 cup chopped lightly toasted pecans, walnuts or hazelnuts
- 1/2 cup all-purpose flour
- 1/2 cup whole-wheat flour
- 1 tsp baking soda
- 1/2 tsp salt

INSTRUCTIONS

1. With the help of your adult, turn the oven on and set it to 350 degrees.
2. Put cupcake liners in 12 cupcake or muffin tins.
3. Put the oil, sugar and eggs in a large bowl or in a stand mixer with paddles attached.
4. Beat the mixture until everything is evenly blended.
5. Add the rest of the ingredients and mix until just combined.
6. Using the scoop, fill each of the prepared muffin tins 2/3 of the way to the top.
7. With the help of your adult, put the muffin tins in the oven and bake 22–25 minutes or until the tops are slightly browned and rounded. (When they're done, a toothpick should come out clean.)
8. Let sit until cool (10–15 minutes). Then remove the cupcakes from the tins.

Did you know? Carrots have been used to sweeten cakes since medieval times when pure sugar was too expensive.

Maple Cream Cheese Icing Combine 3/4 cups low-fat cream cheese (at room temperature), 1/4 cup low-fat plain greek or low fat yogurt, 2 tablespoons maple syrup and mix until smooth. Frost cupcakes when they are completely cool.



We have many ways you can stay connected

Would you like to get CenterLines-News you can use from the Center for Disabilities and Development by email? If so, email us at:

CenterLines@uiowa.edu

Please give your name and all email addresses where you wish to have the newsletter sent. We will still mail copies to those who want them.



Have you been looking for us on Facebook? Look no further! The Center for Disabilities and Development will be sharing stories, photos and information on child and adult development. Make sure to "Like" University of Iowa Stead Family Children's Hospital Facebook page.

Would you like to share your story? Please email: **heather-roman@uiowa.edu**.

New Caregiver Guide Helps Families Navigate Iowa's System of Care following an Autism Spectrum Disorder Diagnosis

by Kelly Pelzel, PhD, CDD Psychologist,
Peggy Swails, Program Manager, and Erika Hertel, Program Coordinator



Has your child recently been diagnosed with autism?

If yes, you may be wondering what will happen next. Each family is unique, with emotions ranging from relief to sadness. Although there will likely be challenges ahead, you are not alone in this journey. The Iowa Regional Autism Assistance Program (RAP) has developed a caregiver guide outlining many resources, services, and supports for your family.

The caregiver guide is available to view and download online at:

https://chsciowa.org/sites/chsciowa.org/files/resource/files/navigating_iowas_system_of_care_a_caregivers_guide_to_autism_spectrum_disorder_2017.pdf.

If your child was diagnosed at The University of Iowa Stead Family Children's Hospital Center for Disabilities and Development (CDD), a copy of the caregiver guide was provided in the folder given to you. Inside the caregiver guide you will find information on many topics, such as:

- Understanding Your Child's Diagnosis
- Iowa Resources for Your Family
- Your Family's Rights in an Education Setting
- Common forms of Assistance and Medical Referral Interventions
- Iowa's Autism Support Program (ASP)

Should you have any questions or concerns, please feel free to contact a Family Navigator with RAP. Family Navigators are parents or primary caregivers of a child or youth with special health care needs. To reach a Family Navigator, please call RAP toll-free at: (866) 219-9119, ext. 2, or send an email to: Iowa-RAP@uiowa.edu.

Getting Ready for Winter Winter weather can be challenging if you live in Iowa with a disability. But assistive technology (AT) items can help you stay safe and independent in snow or on ice. You can borrow some of these items through the Lending Library at the Easter Seals Iowa AT Center.



Finishing up fall yard work?

Sit down on a rolling garden cart to rake. Use a shorter rake with a fixed handle. This garden cart has four 10-inch wheels on solid steel axles. It rolls and steers easily. It also has a basket to hold tools.

Clearing the sidewalk after the first snow?

Holding a shovel handle can be tricky, even if you're not wearing winter gloves. What can you do for a better grip? First, wrap foam pipe insulation around the handle. Then use GearTies to attach the tool to your hand. You can find GearTies at the Lending Library.



Walking on ice with a cane?

This ice tip for your cane can stop you from slipping or falling on snow or ice. When you don't need it, just flip it up and out of the way.

Looking for more information?

These are just a few types of AT that can help you this winter. Borrow an item from the Easter Seals Lending Library to make sure a product works for you. There is no cost for Iowans to borrow items from the library. You can check out up to five items at a time for up to 30 days. If an item works for you, buy one for yourself!

If you would like to borrow any of these items, or if you have questions about how to be more independent during the winter months, get in touch with Easter Seals Iowa Assistive Technology Program. Reach them by phone at 1-866-866-8782; or by TTY at 515-289-4069. Email them at: atinfo@eastersealsia.org

View all items you can borrow from the Lending Library online: <https://eastersealsia.at4all.com/>

There are many lawn care/snow removal providers for people with disabilities around the state. While most are Chore Service providers under the Medicaid Elderly Waiver, they also help people with disabilities over the age of 18. Call Iowa Compass at 800-779-2001 with questions about eligibility or other resources.

Agency Name	City	Phone
Maple Manor Village Care Center	Aplington	(319) 347-2309
Westview Care Center	Britt	(641) 843-3835
To The Rescue	Cedar Rapids	(319) 826-6068
Aging Services, Inc.	Cedar Rapids	(319) 398-3644
C & J Quality Jobs LLC	Corydon	(641) 872-3801
Concord Care Center	Garner	(641) 923-2677
Eagle Ridge Independent & Assisted Living	Guttenberg	(563) 252-2288
Westview of Indianola	Indianola	(515) 961-3189
Caring Hands & More LLC	Iowa City	(866) 537-8922
Maple Heights Nursing Home	Mapleton	(712) 881-1680
Senior Resources Inc.	Muscatine	(888) 667-2026
Chickasaw County Public Health and Homecare Services	New Hampton	(641) 394-4053
Oelwein Health Care Center	Oelwein	(319) 283-2794
American Gothic Home Care	Ottumwa	(641) 682-0006
Howard Center, Inc.	Sac City	(712) 662-7844
Urbandale Community Action Network	Urbandale	(515) 278-3936
Northgate Care Center	Waukon	(563) 568-3493
West Des Moines Human Services	West Des Moines	(515) 222-3660

CenterLines

University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
100 Hawkins Drive
Iowa City IA 52242-1011

FREE Subscription

A subscription to **CenterLines** is free. If you would like to subscribe, please send your name and address to:

CenterLines@uiowa.edu

or by regular mail:

Heather Roman
University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
100 Hawkins Drive, Iowa City, IA 52242-1011



IN THIS ISSUE

UI Joins National Online Autism Study	1
Authentically You: Tween Books for Life's Challenges	3
Provider Highlight: Shruti Tewar, MD	4
Recipes	5
New Caregiver Guide Helps Families following an Autism Spectrum Disorder Diagnosis	6
Iowa Compass News	7

CenterLines is published quarterly. We encourage subscribers to also read our partner newsletter *Possibilities in Education and Training*. You can find that newsletter and others at disabilitytraining.org.

CenterLines, the newsletter of the Center for Disabilities and Development at University of Iowa Stead Family Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting

Newsletter staff Editors

Heather Roman
Darci Roehler
Elayne Sexsmith

Graphics editor Leigh Bradford

people with disabilities, and resources available to them and their families. The newsletter is available in print, in Spanish, and also by email.

For correspondence relating to the newsletter, or to request permission to reproduce information from it, please contact:

Heather Roman
University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
100 Hawkins Drive
Iowa City, IA 52242-1011

CenterLines@uiowa.edu

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.