



SPARCS Newsletter

SPARCS Update!

Happy Holidays from the SPARCS lab! The study continues to be in full swing. We're thankful for all the time and energy our participating families have volunteered! We have completed enrollment with almost 250 participants in our study from all over Western Washington.

As we enter our fifth and final year of funding, we are pleased to have completed enrollment visits with all children, and we continue to contact families for their 6 and 12 month follow up. SPARCS is also excited to start analyzing our data and prepare it for publishing.

As our study moves forward, we would like to reacquaint you with our staff. Dr. Sara Webb is the principal investigator; Dr. Karen Toth is the Clinical Director; Sarah Corrigan is the Project Manager; and Sheila Ghods is our Clinical Research Associate. We also have a team of 13 volunteers and undergraduate students assisting with sessions and other projects. Christina Healy and Shannon Chen are both UW Honor students who are utilizing the SPARCS study for their honors thesis.

In addition, we are pleased to have Dr. Noa Navot, Child Psychiatrist

from Israel and Krystle Jalian, graduate student from Birkbeck University in the UK assisting our lab on various projects.

Please feel free to contact us with any questions at 206-884-1547 or sparcs@seattlechildrens.org.

From left to right: Dr. Karen Toth, Sarah Corrigan, Dr. Sara Webb, and Sheila Ghods.



Study of Physiology, Attention, and Regulation in Children: Study Description

The SPARCS study is looking at how paying attention and controlling your feelings is related to learning language and social skills. We think that understanding this could help us identify children who are at risk for social and language difficulties

earlier, such as children with autism. This might also help us design better interventions for children. As a first step, we are studying whether attention and controlling feelings is related to language and social ability in early childhood. By coming

back 6 and 12 months later, we are able to assess if attention is related to growth in your child's language and social skills.

SPARCS

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Seattle Children's Autism Center Support Groups

The First Steps support group is for parents of children age 6 and under who have been diagnosed with autism in the last year and who are patients at Seattle Children's Autism Center. The group meets the first Thursday of the month from 6 to 7:30 p.m. at the Autism Center. Monthly meetings alternate between parent support and parent education. Please contact the Autism Center for more information at 206-987-8080.

The Next Steps support group is a three-part class series designed to provide information and support for parents and caregivers who have a child with ASD age 15-21 who is transitioning to adulthood. Please contact the Autism Center for

more information at 206-987-8080.

ALLY (Autism, Living Life and You) support group for parents of children age 7 and older who have severe autism. The group meets the first Thursday of the month from 6 to 7:30 p.m. at Seattle Children's Autism Center. Please email Lynn Vigo at lynn.vigo@seattlechildrens.org for an intake application. This support group is open to the general public. Registration is required.



Seattle Children's Lecture Series & Resources

Seattle Children's offers resources for parents, families, friends, and professionals. Please call **206-987-8080** for additional information.

Lectures

Autism 101 is a free 90-minute lecture that is offered quarterly to provide information and support to parents and families of children recently diagnosed with an autism spectrum disorder (ASD). Next Class is **Thursday, Jan. 22, 2015** 7 to 8:30 p.m. Presenters: Katie Harrison, ARNP and Amy Bohlander, PhD

Autism 200 is a series of 90-minute lectures for parents and caregivers of children with autism that cover a wide range of topics. Next Class: **Autism 201: The State of Autism in 2015**

Thursday, Jan. 15 Instructors: Raphael Bernier, Ph.D. & Jim Mancini MS, CCC-SLP

Websites

Try the website **KidsHealth.org** for information about general child health and development. On the website, you can find resources about communication skills, suggestions on games to play, and smart toys for kids of all ages to name a few.

Blogs

Mama Doc is published by Dr. Wendy Sue Swanson MD MBE. Dr. Swanson is a mom, pediatrician and clinical instructor. In the past month, she has tackled issues such as flu shots, helmets, antibiotic use and difficult school drop offs. Find it @ Seattlemamadoc.seattlechildrens.org

Additionally, more information and resources can be found on **The Autism Blog** provided by Seattle Children's Autism Center at:

Theautismblog.seattlechildrens.org.

Families for Effective Autism Treatment (FEAT)

FEAT is a non-profit organization that offers many programs and services to help support families of children with autism. They created the Rising Star Academy, a precision learning preschool environment that specializes in both one on one and group learning for children with autism between the ages of 3 and 7. They are an ABA based program, and they have just opened a new location in Tacoma! FEAT also offers Super Saturdays on a

monthly basis in Sumner, University Place, and Bellevue. These Saturday programs from 10 a.m. to 1 p.m. provide an interactive environment for children with autism ages 3-8 and their typical peers, as well as much needed respite for families. Families for Effective Autism Treatment also offers mentoring services, as well as open houses and workshops. For more information, visit: www.featwa.org



Seattle Children's Sibshops

Seattle Children's Sibshops are lively, pedal-to-the-metal, award-winning celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many, somewhere in between. They reflect a belief that brothers and sisters have much to offer one another - if they are given a chance. The Sibshop model mixes information and discussion activities with new games (designed to be unique, offbeat and appealing to a wide ability range) and special guests. There are currently more than 200 Sibshops across the United States, Canada and elsewhere. All are

modeled after Children's Seattle-area Sibshops! To learn where else in the world you can find a Sibshop, visit <http://www.siblingsupport.org/> a national program dedicated to the concerns of brothers and sisters of people with special needs. Sibshops for Siblings of Kids with Special Developmental and Learning Needs includes, but is not limited to, autism, Down Syndrome, ADHD and developmental delays. Sibshops for Siblings of Kids with Developmental Needs and/or Special Health Concerns includes, but is not limited to, diabetes, cancer, cystic fibrosis, muscular dystrophy and heart, kidney, liver, gastrointestinal or lung disease, autism, cerebral palsy, Down Syndrome, ADHD and spina bifida. Classes in

September, November, January, March and May are for siblings age 6 to 9. Classes in October, December, February, April and June are for siblings age 10 to 13. Please call Sibshops registration at 206-987-4133 or email sibshops@seattlechildrens.org with questions.



Washington Autism Alliance and Advocacy (WAAA)

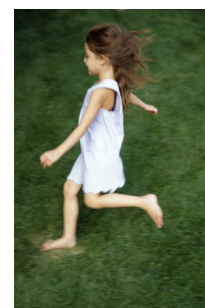
WAAA is a network dedicated to improving access to healthcare, education, and social services for children with autism. Their mission is to improve access to autism insurance benefits and effective services in schools and communities for everyone, no matter financial standing. WAAA has been very active in passing and funding legislation that ensures families have access to treatment. Some specific services they offer include:

- Tutorials on maximizing your autism

insurance benefits

- Parent Advocacy Network run by volunteers who help member families navigate through social services, education and healthcare services
- Statewide training workshops
- Statewide resource directory
- Volunteer mentors who help children learn social skills.

For more information, please visit www.washingtonautismadvocacy.org



Personal Safety and Wandering

Individuals with ASD are much more likely than their typically developing peers to wander or bolt from safe environments, which places them at increased risk for drowning, getting hit by a car, victimization or abduction, or weather-related issues such as dehydration or sunstroke. A high level of close and constant supervision is strongly recommended. While there is no substitute for close supervision, certain additional preventive strategies to

consider might include: securing your home, having your child wear an identification bracelet, alerting neighbors and first responders that your child may wander, teaching your child to stay close to you, and teaching your child to swim.

For more detailed information and additional resources, please see the Autism Speaks Autism Safety Project (www.autismspeaks.org/family-services/autism-safety-project/safety-resources)

and the National Autism Association's Big Red Safety Tool Kit (<http://nationalautismassociation.org/docs/BigRedSafetyToolkit.pdf>)." Tips provided by Ella Vanderbilt-Adriance, Ph.D. Licensed Clinical Psychologist at the UW Autism Center.

Recommended Readings

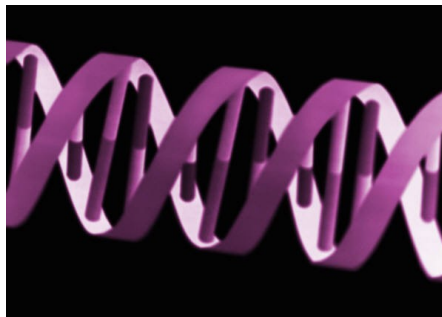
Looking for a book gift for a friend? Want to increase your own knowledge of autism and medicine? Autism Science Foundation and Autism Speaks have a list of recommended books. There is also a list of books for children. More information can be found at

<http://www.autismsciencefoundation.org/autism-science/recommended-reading> and <http://www.autismspeaks.org/family-services/resource-library/books>.



More Evidence that Genome Sequencing Can Improve Autism Diagnosis and Care

A new study adds to research showing that genomic sequencing can provide useful information to guide diagnosis and personalized treatment of neurodevelopmental disorders including different subtypes of autism. The researchers conclude that the benefits of genomic sequencing outweigh the costs and should become a routine part of evaluating children suspected of having a neurodevelopmental disorder. "We've shown that genomic sequencing can often end the diagnostic odyssey and have an immediate impact on patient care," says lead author Sarah Soden. Dr. Soden is a developmental pediatrician with the Center for Pediatric Genomic Medicine at Kansas City's Children's Mercy Hospital. "Now we're hopeful that we can show that the most powerful use of this technology will be in improving the course of development by enabling earlier diagnosis and treatment," she adds. Dr. Soden and her colleagues performed genomic sequencing on 119 children with neurodevelopmental disorders that included autism. Such sequencing goes far beyond conventional genetic testing, which scans a predefined set of genes already associated with a disorder. Before enrolling in the study, the children (average age 7) had already undergone exhaustive but largely unsuccessful testing to identify the cause of their symptoms. The authors calculated the average cost of previous diagnostic testing totaled \$19,100 per child. Their genomic sequencing identified a genetic cause and clear diagnosis in 53 children. More importantly, perhaps, the sequencing resulted in changed treatment plans for half the 119 participants. It led to new medicines or diets in some and the discontinuation of unnecessary treatments in others. "This study provides a first glimpse into the health and economic impact of genome sequencing in neurodevelopment disorders, and I look forward to other studies to further explore these interesting findings," comments Stephen Scherer, director of Autism Speaks whole genome sequencing program. Dr. Scherer was not directly involved in the new study. Last year, he led the first sizable study to use genomic sequencing to investigate autism. That study focused on 32 families affected by autism. It identified associated gene changes in half of the participants and provided medical guidance for several families. To read the entire article, please visit <http://www.autismspeaks.org/science/science-news/more-evidence-genome-sequencing-can-improve-autism-diagnosis-and-care>



Give Back This Holiday Season

Whenever you have an occasion to shop, choose gifts that give back through support of Autism Speaks. Support the companies that support the autism community: Toys“R”Us, The Home Depot, TJMaxx, Zales, and The Gap Stores are just a few. Please visit www.autismspeaks.org/ways-give/corporate-sponsors/meet-our-corporate-partners to view a full list of retailers.



Winter Safety Resources

Seattle Children's has a number of safety resources for all families. At www.seattlechildrens.org, go to the heading Safety and Wellness. A variety of resources can be found including information on helmets for Winter sports including how to choose and fit a helmet. Helmets for winter sports have different standards based on the type of activity. On the webpage, you can find specific recommendations about the standards your child's helmet should meet for their winter sports.



Local Resources for Parents

King County Birth to Three Program. Provides free developmental assessments and services for children ages 0-3 years. (206)-284-0331

Seattle School District. Provides free developmental assessments and preschool services who are eligible for children ages 3-5 years. (206) 252-0010

University of Washington Autism Center. Provides assessment and services for autism and related disorders. (206)-221-6806

Seattle Children's Autism Center. Provides assessment and services for Autism and related disorders. (206)-987-8080.

As she continues her role of Clinical Director for SPARCS, **Dr. Karen Toth, Licensed Psychologist**, now has a private practice office in Seattle! If you have questions regarding your SPARCS visit please contact Dr. Toth at (206) 884-1374 or karen.toth@seattlechildrens.org. If you are interested in learning more about other assessment and treatment services for children of all ages. please contact Dr. Toth at (360) 220-6040 or karentoth22@gmail.com.



Seattle Children's Researchers in the Media:

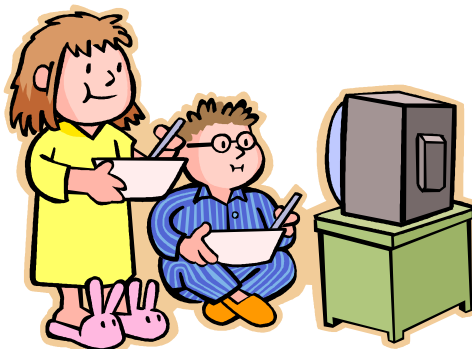
Tech issue or health issue? Pediatricians struggle to guide parents and teens: 08.09.14 - The Seattle Times. Your teen's pediatrician can talk about a good diet, exercise and even tricky stuff like alcohol and safe sex. But what about smartphones, Snapchat and Facebook? Dr. Megan Moreno, the director of the social-media research team that put on the SMAHRT conference to address such popular topics, knows all about it. See the full article at <http://blogs.seattletimes.com/monica-guzman/2014/08/09/tech-issue-or-health-issue-pediatricians-scramble-to-guide-parents-and-teens/>.



All aboard! Bike train research tackles childhood obesity: 06.11.2014 - KOMO 4 News Dr. Jason Mendoza noticed a dramatic drop in the number of kids who ride their bikes to school. Now he hopes to change the trend by encouraging kids to hop aboard the bike train. We caught up with the bike train in a Hillman City park. One of the adult leaders was calling out instructions, saying, "Okay you guys, we're taking a new route this morning," and with calls of "let's do this!" See the full article at <http://www.komonews.com/news/local/All-aboard-Bike-train-research-tackles-childhood-obesity-262789971.html?tab=video&c=y>.



Children and Media: Dimitri Christakis is a pediatrician, parent, and researcher whose influential findings are helping identify optimal media exposure for children. See his TED talk here http://www.youtube.com/watch?v=BoT7qH_uVNo&list=PLF4540D73A1245390&index=4&feature=plpp_video.



Other Research Studies:

How do brains respond to rewards? A new research study for children with ASD to learn how the brain responds to different kinds of rewards and how that relates to social and communication skills for children with or without ASD. Who Can Participate? 8-12-year-old children with or without an Autism Spectrum Disorder. What will the study involve? For children: measuring brain activity during a computer game, plus other games and activities. For parents: questionnaire packets and phone calls. How long will it take? One lab visit of 3 to 4 hours, plus questionnaires and phone calls at the start of the study and at a later time point. What is the compensation? \$40 for the visit and \$10 for the follow up phone interview. This study is conducted at the Seattle Children's Research Institute. To learn more, contact our research coordinator Dr. Emily Neuhaus, Ph.D Postdoctoral Research Fellow at 206-884-8256 or emily.neuhaus@seattlechildrens.org.

"Study of Oxytocin in Autism to Improve Reciprocal Social Behaviors (SOARS-B) is looking for children ages 3-17 years with ASD. The purpose of this research study is to learn about the effects of intranasal oxytocin as a supplemental treatment for improving social difficulties in children with ASD. This study will also provide additional information about the safety and tolerability of intranasal oxytocin. During the first six months of the study, participants will be randomly assigned to take either placebo or active oxytocin. During the second six months, all participants will take active oxytocin. Study participants will come to Seattle Children's for visits once a month for 12 months with one follow-up visit at 18 months. Please contact Christine Rubery at 206-884-1318 or christine.rubery@seattlechildrens.org for more information."

The ZEBRA Study: Zeroing in on the Examination of Brain and Behavior Research in Autism Study Goal: The University of Washington is looking for subjects to participate in a new study exploring how different genetic events impact behavior and electrophysiology in children with an Autism Spectrum Disorder. Participation criteria: We are seeking participants ages 8-17 with an Autism Spectrum Disorder or who are typically developing. Parents will be asked a series of short questions to make sure their child is eligible to participate. What is involved: For children: The study involves two 4-hour visits to the University of Washington. Subjects will participate in a neurocognitive assessment, EEG, and blood draw. For parents: Parents will provide a detailed developmental history through interviews over the phone and during the visit as well as fill out questionnaires about their child. Other information: Expenses related to the study visits (meals, lodging, parking and mileage) will be covered by the study and subjects will be reimbursed \$100 for their participation. Interested in participating? Please contact our research coordinator at (206) 616-2889 or rablab@uw.edu to learn more about the study and see if your child may qualify. To learn more about our research team, please visit our website at: <http://depts.washington.edu/rablab/Home.html>.

Your 6-7 year-old child can help science and receive a free developmental evaluation! Researchers at the University of Washington (Annette Estes, PhD, PI) are working in collaboration with UC Davis (Sally Rogers, PhD, PI) on a project to examine play, language, and social skills in 6-7 year-old children. We are looking for children 6-7 years of age who do NOT have autism, suspected autism or siblings with autism and who have English as a primary language. Eligible children will receive a free developmental assessment at the University of Washington Autism Center, a written report documenting their skills, referrals for services in the community (if appropriate) and a total of \$25 for their participation. Please contact our project staff at 206-616-9566 or esstudy@uw.edu for more information.

GENDAAR Study Dr. Sara Webb is looking for girls and boys with ASD between the ages of 8-17 years old to participate in a new study exploring gender differences in autism spectrum disorders. The study involves two to three half-day visits to Seattle Children's, which will include: Functional magnetic imaging (fMRI) to take pictures of your child's brain, a blood draw for DNA analysis, EEG to record the electrical signals of your child's brain, assessment of your child's cognitive, language and social skills. We will also ask you to answer questions regarding your child's behavior and development. You will receive payment for your participation. This study is being conducted by a collaboration of researchers at Seattle Children's Research Institute, Yale University, UCLA and Harvard University, and is funded by the National Institutes of Health (NIH). Contact: Email Desiree Gulliford or call 206-884-7814.

SHIP Study You're invited to participate in a research study about childhood sleep. Researchers at Seattle Children's want to learn more about the healthy development of children with sleep problems and find ways to help their families. This study might be a good fit if your child is 2 1/2 - 5 years old, has sleep problems, such as resisting bedtime, having a hard time falling asleep, waking up during the night, not getting enough sleep, or feeling tired during the day. To see if your family is eligible, visit <http://www.shipstudy.org> and complete the online survey. You may also call a member of the study team at 206-987-SHIP for more information. What will happen if we take part in the study? During this 3-year study, a member of the study team will visit your home once and talk with you on the telephone to provide free parent education materials and problem-solve ways to keep your child healthy and developing well. 5 times during the study, a study interviewer will visit your home to complete some assessments with you and your child, you will be asked to complete some surveys and a diary of your child's activities, and your child will be asked to wear an actigraph watch on their wrist. Families who participate in this study may receive up to \$180 in gift cards to thank them for their time. The principal investigator of this study is Dr. Michelle Garrison, with the Center for Child Health, Behavior, & Development at Seattle Children's Research Institute.

The READi Lab at the University of Washington is conducting a study to evaluate ImPACT (Improving Parents as Communicative Partners), a parent-implemented intervention designed to improve children's social and communication skills. Our study will examine the effectiveness of ImPACT for infants at familial risk for autism. We are seeking families who live within 20 miles of UW and have a child with autism and an infant under 15 months old. Participating families will be assigned to either the Treatment group or an Assess-and-Monitor group and will all make 6 visits to UW for an evaluation of their infant's social communication skills. Families in the Treatment group will also receive in-home training 2 times per week for 12 consecutive weeks. We will begin seeing families in February 2015. Compensation will be provided. If you are interested in learning more about this study, please contact us at readilab@uw.edu or 206-543-2823.

The READi Lab at the University of Washington is conducting a study to evaluate a new web-based training tutorial that provides parents with strategies for increasing their child's participation in everyday home routines. We are seeking parents of children with autism between 18 and 60 months of age who are willing to: (1) fill out questionnaires before and after viewing the tutorial, and (2) provide short videos of a home routine using camera-mounted eyeglasses. No visits to UW are required. Compensation will be provided. If you are interested in learning more about this study, please contact us at readilab@uw.edu or 206-685-4304.