

Autism Update

CHRISTIAN SARKINE AUTISM TREATMENT CENTER'S QUARTERLY NEWSLETTER

WHAT IS THE MEDICAID WAIVER?

SPECIAL POINTS OF INTEREST:

- Learn about the Medicaid Waiver
- Discover ways to evaluate treatment options
- Hear about our recent conference and upcoming awareness fair
- Check out our upcoming events and ongoing research opportunities

The Medicaid Waiver Programs are very useful ways to get the most services possible for your child without having to spend money out of pocket for everything. The Medicaid Waiver Programs are controlled by the Family and Social Services Administration (FSSA). The FSSA is a complex system that has 4 divisions: Division of Family Resources (FDR), Division of Mental Health and Addiction (DMHA), Division of Disability and Rehabilitative Services (DDRS), and Office of Medicaid Policy and Planning (OMPP). Divisions are then further divided into bureaus.

More information on the Medicaid Waiver is available on the FSSA website: <http://www.in.gov/fssa/servicedisabl/waivers.html>

You can also contact Lynn Jump, who is the Program Director for DD Services, including the autism waiver: 317-234-2764; lynn.jump@fssa.in.gov

A help line has also been established to answer questions. Email your questions to: BDDShelp@fssa.in.gov

Information specific to your district is available by contacting your district office, see map and accompanying contact information for your specific office.

More information on the FSSA is available on their website: <http://www.in.gov/fssa/>

You can also get additional information by simply calling them at their general information phone number, (317) 233-4454, or by writing them:

Family and Social Services Administration
P.O. Box 7083
402 W. Washington Street
Indianapolis, IN 46207

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AUTISM TIP: HOW TO EVALUATE TREATMENTS

When you are trying to determine the best treatments for your child, it can be difficult to know how to compare one to another. Below are some questions to ask and things to consider during this process.

Question 1: Which behavior(s) does it target?

Consideration 1: Are these behaviors problematic for my child?

Q2: What positive effects should I expect to see (short-term and long-term)

C2: How will I know whether the treatment is working?

Q3: How will the therapist assess the effectiveness of the treatment?

C3: How often will I be given progress reports?

Q4: How long do I have to stay involved before I can expect to see any effects?

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NEWS, UPCOMING PRESENTATIONS, AND INTERESTING RESEARCH FACTS

The HANDS in Autism Program has several new research activities that you can participate in. First, we are conducting a survey of parents/caregivers of children who wander to test a new product called the "Alert-Wear" bracelet.

A second new project is the Indiana Autism Community survey. This survey asks 15 questions about how and where you receive information about autism. The survey is for any parent or professional who interacts with an individual with an Autism Spectrum Disorder and is totally anonymous.

The third project will help us to better target information and services to meet caregiver needs for individuals with a diagnosis of Down Syndrome and Autism Spectrum Disorders. This survey will inform our upcoming conference on March 1, 2008.

To participate in any of these surveys, please visit our website at <http://www.handsinautism.org>

- What are some common types of medication studies?
 - Prospective, open-label: everyone receives medication
 - Randomized controlled trial: assignment by chance to either medication being studied or a control (often a placebo)
- What is a placebo?
 - Inactive substance that looks just like the real study medication.
 - Also called a "sugar pill"
- Who can participate in clinical research studies?
 - Each child is carefully evaluated to see if he or she can participate.
 - This evaluation might include diagnosis, review of treatment history, and a physical exam.
- What happens after the study?
 - The study doctor or study staff often provide recommendations for future care.

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C4: Do I have the resources to stick with this treatment?

Q5: Are there any side effects?

C5: Can this treatment be physically or psychologically harmful to my child?

Q6: What is the cost?

C6: Can I afford this treatment? Will participation in this treatment mean we will have to drop other treatments?

Q7: How much time does it take per week?

C7: Can I devote the required time? Is the treatment compatible with my child's current program?

Q8: Is there scientific validation for this treatment?

C8: What do professionals think about the pros and cons of this treatment?

Q9: Who has used this treatment before and what do they say about it (pros and cons)?

C9: What kinds of experiences have other parents had with this treatment?

Q10: What training and qualifications are needed to provide this treatment?

C10: Does the therapist have the appropriate training and/or credentials?

Q11: Does the therapist belong to a professional organization?

C11: Can the therapist be held accountable to a professional code of ethics?

Q12: What role do parents play?

C12: Will I be taught the skills necessary to help my child?

Q13: How are challenging behaviors handled?

C13: Is there a plan for preventing the occurrence of problematic behaviors?

Be cautious about any treatment that...

...offers a cure for autism.

...promises to be effective for all children.

...claims to improve all of the symptoms of autism.

...requires you to suspend your belief system and adopt theirs (*for example, asks you to "believe" in things that don't make common sense, or tells you that the treatment won't work unless you believe in it.*)

...consists of a general "package" or predetermined curriculum that is not tailored to the needs of the individual child.

...does not provide routine and periodic assessment of the child's progress and the treatment's effectiveness.

...claims to be "the best" treatment for your child or "the only" treatment for your child's needs.

This information has been reprinted with permission by Wendy Stone, Ph.D., Vanderbilt University Center for Child Development, TRIAD.

U P C O M I N G E V E N T S

There are always lots of activities going on here at the Christian Sarkine Autism Treatment Center. This section of the newsletter will help you know what is planned over the next few months. You can also check our website for up-to-date information about all of our events!

J A N U A R Y 2 0 0 8

- 1 – Clinic Closed
- 15 – Next Steps Workshop for Parents
6:00–7:30pm
Advance registration is required, see below*
Clarian North Learning Center, 1st Floor
- 21 – Clinic Closed
- 23 – Make It Take It: Visual Schedules
5:30–7:00pm
Advance registration is required, see below*
Riley Outpatient Center, Ruth Lilly Learning Center

F E B R U A R Y 2 0 0 8

- 20 – Make It Take It: Visual Supports
5:00–7:30pm
Advance registration is required, see below*
Riley Outpatient Center, Ruth Lilly Learning Center

A P R I L 2 0 0 8

- 18–Awareness Fair
11:00am–2:00pm
Registration is not required, so bring your family and friends!
Riley Outpatient Center, Ruth Lilly Learning Center
- 22 – Next Steps Workshop for Parents
5:00–6:30pm
Advance registration is required, see below*
Clarian North Learning Center, 1st Floor
- 23 – Make It Take It: Sensory
5:00–7:00pm
Advance registration is required, see below*
Riley Outpatient Center, Ruth Lilly Learning Center

M A R C H 2 0 0 8

- 1–Autism/Down Syndrome Event
- 19 – Make It Take It: Work Tasks
5:00–7:30pm
Advance registration is required, see below*
Riley Outpatient Center, Ruth Lilly Learning Center

* You can register for these events on our website: www.HANDSInAutism.org. Phone registrations can be done by calling Jessica at 274-8622. **It is critical to cancel prior to the event if you will not be attending. Space is limited and you may be preventing another from attending if you do not relinquish your spot.** Please contact Heather Coates at 317-278-7839 with questions about HANDS events or materials.

Mark your calendar and join us at these great events!



VISIT US ON THE WEB AT
WWW.IUPUI.EDU/~PSYCDEPT/AUTISM/

**CHRISTIAN
SARKINE
AUTISM
TREATMENT
CENTER
QUARTERLY
NEWSLETTER**



Riley Hospital for Children
Christian Sarkine Autism Treatment Center
A Clarian Health Partner

Mission Statement

The Christian Sarkine Autism Treatment Center at Riley Hospital for Children is committed to helping children and adults with autism and related disorders to achieve their potential and to participate as fully as possible in family, school, and community life. Interventions are based on the individual goals and objectives of the family. Interventions typically involve medication management, behavioral strategies, special education consultation, and/or counseling and reflect the most recent and empirically supported approaches to treatment. There is frequent coordination with the occupational therapy services in the hospital. Individuals and families may be offered participation in research projects. Services may be provided in a time-limited or ongoing fashion.

If you would like to receive this newsletter by email, please contact Heather Coates by phone at 317-278-7839 or by email at hands@iupui.edu

ONGOING RESEARCH OPPORTUNITIES!



Atomoxetine in Children and Adolescents with Autism

The Christian Sarkine Autism Treatment Center at Riley Hospital for Children is conducting a research study for children and adolescents ages 6-15 who have autism and who also have symptoms such as: overactivity, impulsivity, and/or inattention. The study involves a non-stimulant medication and clinic visits at no charge. If you would like to find out more about this research study at Riley Hospital for Children, please contact us at (317) 274-1218 or at kidpsych@iupui.edu

A Pilot Study of Oral N-Acetylcysteine In Children with Autism Spectrum Disorders

The Christian Sarkine Autism Treatment Center at Riley Hospital for Children is conducting a Research Study for 4 - 12 year old children who have an Autism Spectrum Disorder (ASD). Autism Spectrum Disorders include Autism, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). If your 4 - 12 year old has an ASD, he or she may qualify for a research study involving study medication and clinic visits with a child psychiatrist and qualified research staff at no charge. The purpose of this study is to find out if the study medication will help to improve some of the behaviors associated with autism spectrum disorders. Participation requirements and risks involved in this study will be disclosed prior to study enrollment. If you are interested in participating or would like more information, please contact us at (317) 274-1218 or kidpsych@iupui.edu.

A Prospective, Open-Label Study of Paliperidone ER in Adolescents and Young Adults with Autism

The Christian Sarkine Autism Treatment Center at Riley Hospital for Children is conducting a Research Study for children and adolescents aged 12 - 21 years old who have Autism. If your 12 - 21 year old has Autism, he or she may qualify for a research study involving study medication and clinic visits with a child psychiatrist and qualified research staff at no charge. The purpose of this study is to find out if the medication, paliperidone ER, is helpful for the treatment of irritability, aggression and/or self injurious behavior improves in adolescents and young adults with autism. Participation requirements and risks involved in this study will be disclosed prior to study enrollment. If you are interested in participating or would like more information, please call (317) 278-6253.



The Neurobehavioral Phenotype of Fragile X Syndrome

The Child and Adolescent Psychiatry Clinic Fragile X Syndrome Clinic at Riley Hospital for Children is conducting a Research Study for individuals age 7 and older with Fragile X Syndrome. Your 7 year or older child with Fragile X Syndrome may qualify for this study involving psychological testing and structured surveys designed to describe behaviors and mental illnesses common to Fragile X Syndrome. Participation requirements and risks involved in this study will be disclosed prior to study enrollment. If you are interested in participating or would like more information, please contact Marianna at (317) 278-6253.

IN OUR NEXT ISSUE:

* Discover more about Autism in our issue devoted entirely to Autism Awareness Month!