

CenterLines

Center for Disabilities and Development *Useful News for Families*

The CDD Fragile X Clinic

Fragile X is a rare chromosomal mutation. The condition occurs when a mutation on a person's X-chromosome leads to a lack of important proteins in the brain. This deficiency often leads to anxiety problems, sleeping troubles, and impeded sensory development. Males, who only have one X chromosome, tend to suffer more severe effects. According to the Center for Disease Control and Prevention, approximately 1 in 4,000 males and 1 in 6,000 to 8,000 females are diagnosed with Fragile X nationwide. Fragile X is difficult to recognize, but the Fragile X Clinic at CDD will help identify and treat the disorder.

Though Fragile X and autism appear similar, the causes are different. An autistic child may avoid eye contact in social settings because they do not recognize other people are more significant than other objects. Children with Fragile X avoid eye

contact because they feel uncomfortable under someone's gaze.

The National Fragile X Foundation developed the Fragile X Clinical and Research Consortium in 2006, and then added a database and registry for those with the mutation in 2008. The CDD Fragile X Clinic (which opened in 2010) is the first in the state. Fragile X clinics provide customized learning programs for those diagnosed with the condition.

The Clinic had their first open house on April 14. Families got together to compare notes, connect, and have their family portraits taken. Dianne McBrien, MD is the Clinic's Coordinator as well as a Clinical Associate Professor with the Department of Pediatrics at the University of Iowa Children's Hospital.

The clinic offers services provided by a physician, an occupational therapist, a behavioral psychologist, and speech and language pathologist. Jennifer Luria, the clinic's coordinator,



Clinic coordinators – Jennifer Luria and Dianne McBrien

said she often helps families find resources for children with Fragile X in the school system.

The pace of national Fragile X research has quickened in the last 10-15 years. Opportunities for people with Fragile X are an ongoing challenge in Iowa. But with the addition of this clinic, things are getting better and the future is brighter.

For more information contact Jennifer Luria, Coordinator, Fragile X Clinic, 319-384-6208, Jennifer-luria@uiowa.edu



University of Iowa Health Care



Have a Safe Summer!

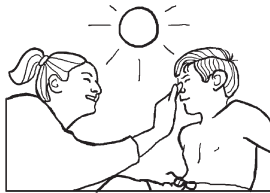
Summer is the time of year to get out, be in nature, and have some fun. Summer is a magical time when school is out and days are endless. So remember to stay safe. Almost half of all serious injuries or deaths for children are due to accidents and happen from May through August.

When we are having fun, we don't always remember things like sun screen, helmets, heat, bugs and water. Keep these things in mind when you are out and about this summer.

Sun and Sunburns

Use sunscreen. It doesn't matter if you burn or not. The sun can hurt everyone.

And it's not just in the summer or only on sunny days.

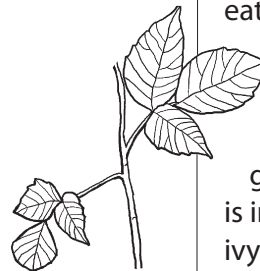


You can get sunburned when it's cloudy. Protect against both UVA and UVB rays. Use sunscreens that are SPF 30 or higher. Make sure it is water resistant. If you get just one blister when you're a kid, it doubles the chances of skin cancer. Put the sunscreen on 15 to 30 minutes before you go outside. Don't skimp, put on a lot. Bug spray should go on after sunscreen. Be sure to wear hats with bills and protective clothing if you know you will be in the sun for a long time. You can also buy summer clothing that has sunscreen protection right in the material.

Heat

Heat-related illness and heat stroke are serious. You can get overheated when you are too active in the hottest part of the day. Kids are more likely to have problems than adults. When you first get overheated you may feel thirsty, tired, and have cramps in your legs or stomach. Heat stroke is more serious. Here is a list of signs of heat stroke:

- Feeling dizzy
- Trouble breathing
- Headaches
- Rapid heartbeat
- Nausea
- Vomiting
- Confusion
- Flushed skin
- Hot and dry with no sweat
- High temperature



If you are out in the sun, stop and take many rest breaks. Avoid sun in the afternoon. Stay in the shade. Stay inside if it is really hot out and wait to go out until later in the afternoon or evening when it cools down. Remember to drink water. Sometimes you can get sick from lack of water or dehydration. Don't wait until you are thirsty. Drink some water every 20 minutes if you are really active. The best things to drink are water and sports drinks with electrolytes. Stay away from soda, juice or other fruit drinks. Make sure the drink doesn't have a lot of sugar.

Food Poisoning

Picnics and cookouts are what summer is about. But don't let the heat ruin it for you. Certain foods need to be kept cool. They are milk, eggs, chicken, and fish or other seafood. They can only be out for about 1 – 2 hours. Raw fruits and veggies can be out, but be sure to wash them. Food poisoning feels and looks like the flu. That can be stomach cramps, nausea, vomiting, and diarrhea. It can be light or mild or severe. So be careful and if you are not sure of food that has been left out – don't eat it.

Poison Ivy

Spring and summer bring growing plants like poison ivy. It is important to learn what poison ivy looks like and stay away from it. Some people don't get a rash the first time or it is a mild one. If you are exposed many times, your reaction will get worse over time. Poison ivy is in the woods but you can find it in your backyard on fences or bushes. All you have to do is touch it. Poison ivy has an oil that spreads. If you touch it with your hand and then touch your face, you will have it both places. You can also get it when you pet your dog or cat. If they have rubbed against it, the oil gets on their fur. You can also get a rash if you burn it or hit it with the weed whacker. If you think you've touched poison ivy, you should:

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- Not touch bare skin
- Wash your hands and any other places it's touched with soap and water
- Remove your clothes and wash them
- Wash work gloves and shoes

If you have a lot of poison ivy growing by your house or if you have a strong reaction to it, you may want to buy special poison ivy soap and keep it on hand. If you do have a strong reaction, go see your doctor for help.

Bugs

Summer also means bugs. You can use bug spray for most bugs. However, here are some things you can do if you can't avoid them:

Ticks carry diseases like Lyme disease. You find them in the woods or tall grass. You can also find them in your yard. If you are out hiking, be sure to wear long sleeves, socks, and hats. If you use bug spray, be sure it works on ticks. Check your clothes and body when you get home. If you find a tick, be sure to remove it right away. Use tweezers to remove them if they are attached. Wash your skin with soap and water, and watch the bite spot. If you get a rash or have any swelling, call your doctor.



Mosquitoes can carry viruses like West Nile, encephalitis, or Bird flu. Don't let kids play out at dusk when mosquitoes are most active.



Remove any standing water in your yard. That is where they lay their eggs. If you live near lakes or ponds, you may want to get special pellets or tablets that float in the water and help kill their eggs. There are also special yard foggers or devices to help with mosquitoes.

Bees can sting which causes pain and sometimes an allergic reaction. They don't want to sting, they do it to protect themselves. Bees are very important to the environment, so you



don't want to kill them. To avoid stings, try not to wear heavy perfume when you are outside. Bees like anything sweet, like fruit or soft drinks. Watch for them landing on plates or crawling in pop cans. Insect repellent doesn't work on them like on other bugs. It is better to leave them alone and avoid them. If you have a severe reaction to a bee sting, talk to your doctor about getting an EpiPen. The medicine in the pen will stop the reaction. You should make sure that the EpiPen has not expired and you should carry one with you at all times. It doesn't do you any good at home. Once you've used the EpiPen, get medical treatment right away.

Swimming and Boating

Be careful when swimming or boating. You could drown or get hurt. Kids should be watched around water all the time. Even baby pools can be dangerous. City pools with lifeguards are safer than

the local pond, stream, or lake. When at the pool obey the rules. Don't run or dive in no-diving zones. If you are swimming at a pond or lake, don't dive into shallow or dark water. Diving accidents can cause a head or back injury. If you are going on a boat, always wear a life jacket.



Helmets

You and your children should wear safety helmets and other protective equipment when you are out bicycling, skateboarding, or roller blading. A helmet can make the difference between a skinned knee and permanent brain damage. Kneepads and elbow pads can prevent painful breaks or other injuries when you fall. When you are out riding be sure to watch out for cars. Not all drivers see you on your bike. Always follow the traffic rules to stay safe.



For more summer safety tips and tips all year round, visit Safe Kids USA on their website at www.safekids.org.



Autism Internet Modules (AIM)

<http://www.autisminternetmodules.org/>

This is a great FREE resource for families and professionals looking for information on evidenced-based treatments and topics related to Autism Spectrum Disorder. The website contains 37 modules that are divided into 5 topic areas. Examples of modules include: functional communication training, discrete trial training, pivotal response training, antecedent interventions, structured teaching, task analysis, visual supports, social skills groups, preparing for the workforce, and supporting successful completion of homework.

Have You Searched the Iowa COMPASS Database Lately?

In November, 2011, CDD's disability information and referral service, Iowa COMPASS, launched its new website design at www.iowacompass.org. The launch included new database software which has shown a dramatic increase in the numbers of information searches completed on the public website. Jennifer Britton, program manager, shared that there has been a 300% increase in the number of completed searches from the same time period last year. According to Katie Conlon Fasselius, database manager, the new online searches are more intuitive and include new search features, such as the ability to search for services by their target populations. Do a search yourself and see if you agree. CDD patients and families are also welcome to take a look. As always, please feel free to contact Iowa COMPASS at 800-779-2001 or iowacompass@uiowa.edu.

Where do you fit in? Asperger's Teen Therapy Group

United Action for Youth (UAY) announces the formation of an evening therapy group serving teens (14 to 18 years) who are navigating the unique challenges of Asperger's Syndrome and adolescence. The group will meet for eight weeks beginning in June. The benefits of the sessions will be to provide support, improve social skills and to offer the opportunity to process personal experiences with peers. The fee for attendance is \$25 per week to be paid in advance of the first meeting. The group will be limited to 12 participants.

Please call UAY for details and to register. 319-338-7518





Mental Health First Aid Training

What is Mental Health First Aid?

You may know CPR and the Heimlich Maneuver. You can call 911. But can you administer first aid in a mental health crisis? Mental Health First Aid is the initial help given to a person showing signs or symptoms of mental illness or in a mental health crisis. Mental Health First Aid is provided until appropriate professional or other help can be engaged.

What will I learn?

- How to support an individual experiencing a mental health crisis until appropriate professional help is available.
- The prevalence of mental illness in the U.S. and the emotional and economic cost.
- The potential warning signs and risk factors for depression, anxiety disorders, trauma, psychotic disorders, eating disorders and substance use disorders.
- A 5-step action plan to help an individual in crisis connect to appropriate professional care.
- Resources available to help someone with a mental health concern.

When can I get trained?

There are three Mental Health First Aid trainings scheduled for Summer 2012 in **Iowa City** hosted by Community Circle of Care. Trainings will be held at the Center for Disabilities and Development, 100 Hawkins Drive, Iowa City, IA in the Rembolt Conference Room. Space is limited to 30 participants at each training. Early registration is highly encouraged.

June 12th & 13th	9am-4pm
July 17th & 18th	9am-4pm
August 13th & 14th	9am-4pm

*Must attend both days to receive your MHFA certification.

Cost: \$60 per participant. Please make checks payable to THE UNIVERSITY OF IOWA and mail checks to Community Circle of Care, 799 Main Street, Nesler Centre Suite 250, Dubuque, IA 52001.

To Register: contact Nancy Papin, Nancy-Papin@uiowa.edu 563-583-5545 ext. 607

Continuing Education Credit
Applications for Social Work, Nursing and Foster Parent Continuing Education will be submitted.

Needed: Male Volunteers

The Muscular Dystrophy Association is recruiting male volunteer counselors for its annual summer camp being held at Camp Courageous in Monticello, IA, on June 24-29, 2012.

Counselor Requirements: Must...

- Be at least 16 years of age
- Work one-on-one with a camper who has a neuromuscular disease (ages 6-17)
- Provide personal care and supervision for camper (training provided)
- Provide companionship at a wide range of recreational and social activities
- Pass a background check, provide 3 references, and get a physical
- Be committed to making this week an amazing experience for all campers

This unique opportunity involves completing over 150 volunteer hours and is an excellent experience for individuals interested in the health care field.

To participate in this life-changing week, call the Muscular Dystrophy Association Summer Camp Coordinator, Ali Maahs, at 319-393-8905 or amaaahs@mdausa.org

CenterLines

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CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uihealthcare.org/cdd. Click on Centerlines for Families.

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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.