

CenterLines

Center for Disabilities and Development *Useful News for Families*

When you get a chance . . .

Come visit our website at www.uichildrens.org/cdd. We have been changing our look and have added more information for you. You will be able to watch a great video about coming to CDD. We made this video so you would have a better idea of what to expect when you got here. We also have special **Social Stories**. These stories show your child, with words and pictures, what will happen on their visit to CDD. This can help them be more comfortable while they are here.

We have many links to things like

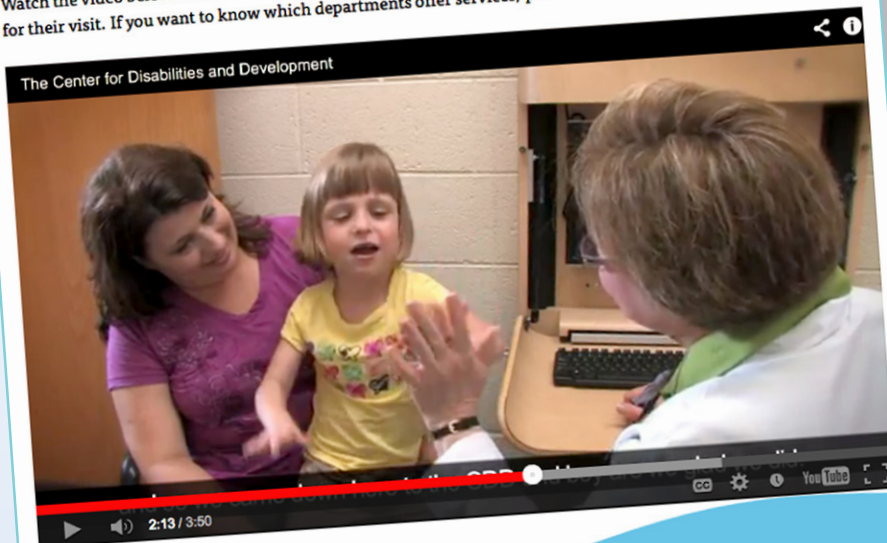
- Our Disability Resource Library (DRL)
- A list of all our clinical services
- Several issues of our *Centerlines for Families* newsletter
- Patient forms
- Local community supports and services



University of Iowa Health Care

Preparing for Your Visit to CDD

Watch the video below to learn more about CDD. Read the [Social Stories](#) to learn ways to help your child get ready for their visit. If you want to know which departments offer services, please check out our [Referral Form](#).



For instance, you can learn that the DRL is a resource for and by people with disabilities of all kinds. The DRL has information on programs like **Prescription to Play**. This is a fairly new program that lends equipment to families who come to CDD. Our staff picked the items that they thought would help promote growth and development. The family gets a "prescription" from the clinic and the DRL checks the item out to the family. The DRL also has the **AT Lending Library** with devices and software you can check out and use at home for communication, school, work, and recreation. Mary Hubbard, the DRL librarian has put together a special **Bibliography on Autism and Asperger's Syndrome**. You can find out more by calling 800-272-7713 (toll-free).

We will keep adding to our website to keep it up-to-date and helpful.

So come visit us online soon and see what we have to offer for you!



Neurofibromatosis

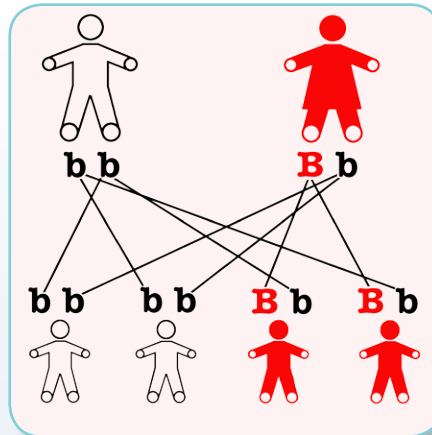
Susan VanWye, A.R.N.P.

Center for Disabilities and Development and Medical Genetics

Neurofibromatosis is a kind of genetic problem that causes tumors to grow along nerves. It can also affect bones and skin. About 1 in 2,500 people have these special freckles called "café au lait spots." About half of these people will have problems with learning disabilities. This condition is called neurofibromatosis. It is a kind of genetic problem that causes tumors to grow along nerves. It can also affect bones and skin.

There are 3 types: NF1, NF2 and schwannomatosis. NF1 is the most common. People with NF1 have lots of café-au-lait spots (CALs) and neurofibromas on or under the skin. CALs are dark spots that are the color of coffee with cream. Neurofibromas are bumps you can see on or feel under the skin. Bones can grow too big or grow wrong. The spine can curve, causing scoliosis. Sometimes tumors can grow in the brain, on cranial nerves, or on the spinal cord. About half of the people with NF1 also have learning disabilities.

NF1 is called an autosomal dominant genetic disorder. Half of the people with NF1 inherited it from a parent who has NF1. In the other half, there was a



change in the sperm or egg cell. If a parent has NF1, their children have a 50% chance of inheriting the gene causing NF1. This is not the same as "Elephant Man disease."

People with NF almost always have six or more café-au-lait spots. The size of the spots can be from 1/4 inch (5 mm) in children and 3/4 inch (15 mm) in adults to several inches or larger. Café-au-lait spots are usually present at birth in children who have NF. If they are not there at birth, they usually show up by two years of age.

Children usually keep getting more and bigger spots. Sometimes even adults can get more. Café-au-lait spots and freckling can show up in the armpit (axilla) and the groin. Most people only get freckles where the sun shines on the skin.

Having a lot of neurofibromas can be a big sign of NF. Neurofibromas are the most common tumors in NF. They are benign growths (not cancer). They usually show up on or just underneath the skin. They can also grow in deeper parts of the body.

Neurofibromas are made of tissue from the nervous system (neuro) and fibrous tissue (fibroma). They usually start growing around puberty, although they may show up at any age. People with NF1 can also have plexiform neurofibromas. Plexiform neurofibromas grow widely under the skin or in deeper areas of the body. This kind of neurofibroma might feel like worms when you touch them.

People with NF1 can also get Lisch nodules in their eyes. Lisch nodules are like freckles in the colored part of the eye. They usually show up around puberty. The eye doctor might need to do a special slit-lamp exam to see them. They don't affect anything other than vision.

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CDD Treatment Services

Our therapists are available to provide treatment services for children of all ages and a variety of diagnoses. Treatment services are provided in our facility to fit around the family's busy schedule. We work together with parents, other local service providers (including AEA therapists and school personnel), and medical staff to meet the child's needs and to help the child be as independent as possible. Treatment areas may be addressed individually or together as a coordinated team, and include the following:



Occupational therapy

- Assistive technology training and use
- Coordination (developmental motor) skills
- Feeding skills
- Activities of daily living, including self-care skills
- Sensory processing (sensory motor) skills
- Fine-motor skills and handwriting
- Neuromuscular Electrical Stimulation
- Constraint Induced Movement Therapy

Physical therapy

- Gait training
- Partial weight bearing therapy (promotes normal walking patterns by controlling weight bearing, balance and posture during walking therapy)
- Gross motor skills
- Equipment and bracing trials and management
- Neuromuscular Electrical Stimulation
- Constraint Induced Movement Therapy

Speech•Language therapy

- Speech and language deficits
- Aphasia therapy (post-stroke therapy)
- Alternative and augmentative communication
- Feeding and swallowing therapy

For more information or to make an appointment:

call: 877-686-0031 (toll-free)
319-353-6900 (local)

email: cddscheduling@uiowa.edu

visit: www.uichildrens.org/cdd

We want to hear from you...

Each year we pick the topics we think will be the most helpful to you. This past year we wrote about some of the services here at CDD, as well as other programs and treatment options. We also had articles on conditions or syndromes that may affect you or someone in your family. We are always looking for input on this newsletter. Let us know if you really liked something. Also, let us know if you have topics you want us to write about in the upcoming year. Just call Amy Mikelson (the editor) at **319-356-1514**. Or please email her at amy-mikelson@uiowa.edu. We look forward to hearing from you in our **10th year** of bringing you the *Centerlines for Families* newsletter!



Crime Victim Compensation: Help for victims of violent crime

Jennifer Luria, LMSW
Center for Disabilities & Development Social Work

At CDD we sometimes meet children or adults who have been the victims of a violent crime such as domestic violence, child abuse, or assault. Some of our readers also may have been victims of a crime, so we want everyone to know of an important resource called the Crime Victim Compensation program. It can help you or a loved one get back on your feet again. You may be eligible if you are:

- A victim of an assault, rape, burglary, or a hit and run accident
- A survivor of someone who was murdered
- Living with a person who was a victim of a violent crime
- A child who has seen domestic violence

- A child who has been the victim of abuse
- An adult who was the victim of child abuse or who witnessed domestic violence as a child

This program can give you money to:

- get new clothes if yours were taken as evidence
- fix a broken window from a robbery, or
- pay you lost wages if you missed work.

You can also get medical care or counseling that isn't covered by insurance.

As an adult victim of child abuse, you may find yourself struggling but may not have insurance to pay for counseling. The Crime Victim

Compensation program would be able to help with that cost.

The program is funded entirely by fines and penalties paid by the criminals.

To qualify you must report the crime to your local police within 72 hours and apply to the program within 2 years of the crime. However, there may be good reasons you couldn't do either. For instance, you were in the hospital after the crime, or you are an adult looking for help now from something that happened when you were a child.

For more information and to get an application for the Crime Victim Compensation program please go to their website at www.iowa.gov/government/ag/helping_victims/services/compensation_program.html.

You can also write or call them:

Iowa Attorney General's Office
Crime Victim Assistance Division
Lucas State Office Building
321 East 12th Street
Des Moines, IA 50319

Phone: 515-281-5044
Toll-Free: 800-373-5044





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Someone might have NF1 if they have two or more of the following:

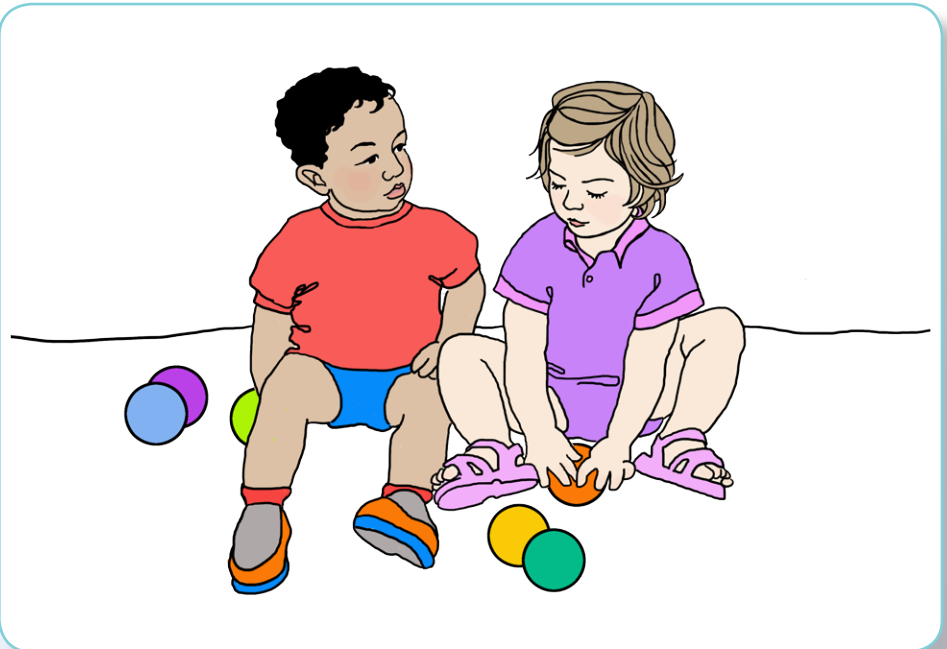
- Family history of NF1
- 6 or more light brown (“cafe-au-lait”) spots on the skin
- Presence of pea-sized bumps (neurofibromas) on the skin
- Larger areas on the skin that look swollen (plexiform neurofibromas)
- Freckling under the arms or in the groin area
- Lisch nodules on the eye
- Skeleton problem like bowed legs or thin bones on x-rays
- Tumor on the optic nerve that may cause vision problems

Laboratory tests can help decide if a person has NF1.

Some people with NF have almost no problems at all. Other people can have serious problems because of NF1. There is no way to know who will have a mild case or who will have problems. Most people with NF (probably 60%) have mild forms of NF. Another 20% have problems that are pretty easy to fix and another 20% have serious and lasting problems.

Complications of NF1

NF1 can cause problems in how people look. Skin neurofibromas grow on the face or on the arms or legs where people can see



them. Plexiform neurofibromas may grow around the eye or eyelid, or change how one side of the face grows. Scoliosis, or curvature of the spine, can be visible when it is severe. Once in a while the skin or bone can grow too much, making one arm or leg bigger than the other.

Learning disabilities are more common in children with NF1 than in other children. Kids with NF1 can also have hyperactivity.

An optic glioma is a tumor of the optic nerve (the nerve that controls vision). This tumor is not very common. It usually shows up in childhood. Often people notice there is a problem because of poor or failing vision or bulging of the eye.

Bone problems can occur in almost any bone. They are seen

most often in the skull, arms and legs. There may be bowing of the long bones because the bone is thinner than normal. If there is a broken bone it can take a long time to heal.

People with NF1 can have hypertension (high blood pressure). This can happen if the artery to the kidney gets blocked. Another kind of tumor called a pheochromocytoma is rare. It is a usually benign tumor of the adrenal gland. It can cause periods of headaches and high blood pressure.

You can find out more from the Children's Tumor Foundation. They are a non-profit medical foundation dedicated to improving the health and well-being of individuals and families affected by NF. You can find them online at www.ctf.org/.

CenterLines

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

CenterLines@uiowa.edu

or by regular mail:

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Centerlines for Families is published quarterly. CDD encourages subscribers to read partner newsletters *Iowa COMPASS News* and *Possibilities in Education and Training*. You can find them all by going to our website at www.uichildrens.org/cdd and then clicking on the link for newsletters on the right.

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

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disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uichildrens.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.