

## My Journey - CNA to LPN to DDC

by Nyla Adair, LPN,DDC

I am so thankful for this wonderful opportunity to share with you why I feel that I am truly blessed and how being a DD nurse has made this possible.

I began working as a CNA (Certified Nursing Assistant) in nursing homes in 1974. I absolutely loved it. I had so many “grandparents” and endless storytellers. I felt the challenge of trying to please them all and seeing them each as the individuals they were and not just a bunch of old people. Each of them had their own unique qualities, likes, dislikes, behaviors, and beliefs.

I became an LPN in 1984 and remained mostly in the geriatric field where I felt comfortable. In a part-time capacity I worked for a woman whose husband was brain-injured. This was very intriguing to me, so when she opened a small facility specifically for people with brain injuries I stayed on board. I was fascinated with the different abilities and levels of knowledge and functioning that each of the clients had. They all suffered from some form of brain injury but were all so different.

A friend of mine told me about a different type of nursing. It was with adults and children who were mentally/physically challenged, in many different ways and on many different levels. She also informed me of a place that was a school and adult day care, which also had some group homes that cared for these people, either just during the day or for 24 hours a day. Well, this sounded so challenging, fascinating and different from what I had been doing that I just had to investigate it further.

In May of 2003, I began working at the facility caring for individuals with developmental disabilities. The first year that I was employed at the facility, I worked in the ICF/MR clinic. I thoroughly enjoyed this and learned a lot about the types of individuals that this facility served. After a year I decided that I wanted to work more closely with these individuals and be involved in their day-to-day activities, instead of the short time I spent with only a few of the people we served when they came to or were brought to the clinic.

I was totally in awe of this facility and the programs offered, but mostly with the individuals that we served. The unconditional love they very openly displayed all the time was just astounding. They also were not afraid to show or tell you if they were emotionally hurt or upset. I also learned how extremely different each individual was, and that even though

these individuals were or are mentally challenged, or as some people say, “retarded,” they were or are not stupid!

My supervisor told me about an organization called DDNA, and invited me to several meetings. I was so blown away that I could hardly comprehend what it was all about. I, as well as the other nurses employed at this facility were encouraged by many people, especially my supervisor, to become members of DDNA and to sit for the CDDN/DDC exam to become certified. Well, in 2007 I became a DDNA member and also became certified as a DDC. I had a lot of help in obtaining this and am so very grateful to everyone involved.

I was amazed. I actually knew the symptoms of people’s diagnoses, understood most of their behaviors and usually why they acted certain ways at times, or did some of the things they did. I also learned the best way for me to help, encourage and teach them, as well as myself. I also came to understand what the families of these individuals must deal with on a daily basis and how strong, knowledgeable and nurturing these families truly are.

Eventually, I moved to another state, so I sadly left the previous mentioned facility. I was very unhappy when I left, because I thought that I would never find another facility at which I not only truly enjoyed being part of a team, but also where I would learn new and different things on a daily basis.

Much to my surprise, I have been lucky enough to find another type of DD nursing that is very intriguing, challenging and different for me. I am currently employed at Foundation for Blind Children (FBC). This scope of nursing is also very rewarding, as well as extremely life changing to the individuals we serve along with their families.

FBC has many different programs that help/assist as many blind or visually impaired people at various ages and/or stages of their lives as possible. Some of the programs and/or services FBC provides are listed below along with a short description of them:

**Infant Program** - Infants with visual impairments, as well as their families, need professional services or guidance. This program focuses on how the child learns and how parent(s)/families also learn to help and have a better understanding of the situation. In addition, it deals with the impact or effect of having at least one disability on the child, as well as the families and their feelings. The infant has to “see” the world,

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# From the Executive Director's Desk

Dear DDNA Members,

The September letter from the Executive Director is usually focused on gearing up for the annual conference next May. Fall is the time of year when we ask members to suggest conference topics about which they are interested and to recommend speakers who are excellent educators and experts in their particular field in the care of persons with I/DD. So start thinking about topics and speakers as you read the rest of this letter and the rest of the newsletter . . .

September is also when summer ends and school starts back up again. Some of you may be busy now buying backpacks and figuring out school bus schedules for your kids. Or you may be starting classes yourself as you continue to pursue your educational goals. Last week my son, Jim, began his first year as a special education teacher. His students are profoundly affected by autism. Many of you have met Jim at DDNA conferences, where he has helped out over the years. You may or may not know that he himself has Aspergers Syndrome. To say that I am proud of him for graduating with his Master's degree in Special Education with a 3.98 GPA, and that he is also completing his final course for becoming a certified applied behavioral analyst -- well, that is the understatement of the year! As I have seen him bonding with his students, planning lessons to meet their specific needs, and coming home excited when a student masters a new skill, it really takes me back to my first days as a beginning nurse. I realize that teaching children with I/DD and I/DD nursing are two different professions, but all helping professions share commonalities. Do you remember your first day as a developmental disabilities nurse? From talking with DDNA members, it seems to me that, in most cases, your first day on the job made a large impression. You realized that you did know some things about caring for people with I/DD . . . but you didn't know everything (and might have felt a twinge of nervousness about that!), but you could learn and you did! And that is exciting!

This past August, I took my first vacation in five years. Boy, vacations are great and I'll probably take more in the future! I traveled to visit relatives and friends in Lithuania and France. While in Lithuania, I was privileged to stay with Dr. Arvydas Seskevicius, a cardiologist, who became the first Dean of the School of Nursing at Kaunas University when Lithuania gained its freedom from Russia in 1991. He successfully created a nursing school that today is graduating doctoral students in nursing, and its current dean is now a nurse, not a physician! I visited the main hospital in Kaunas and had an opportunity to meet cardiac, ICU, and pediatric nurses. Interestingly, if you have a heart attack in Lithuania, you will spend two weeks in the hospital, and then four weeks inpatient in a cardiac rehabilitation "convalescent" center. Arvydas explained to me that they found if you send people home quickly after a heart attack without providing them with these weeks of inpatient cardiac rehabilitation, they revert to their previous bad habits of not exercising and overeating. Hmmm . . . can't see the American health insurance companies being on board with such a long hospital stay, but it does make you wonder what a study might show about patient compliance with post-cardiac instructions in Lithuanian vs. in the United States, where you are out of the hospital door four days after your bypass surgery!?

I also had the pleasure of having dinner with the Dean of the Nursing School at Vilnius University, Dr. Danute Kalibatiene. I asked her what nursing students in Lithuania were learning about the care of people with developmental disabilities. Her response was the same as the response of most deans of nursing schools in the United States -- students are not learning very much about I/DD. I gave Danute a set of audiotapes from the DDNA 2010 Reno conference and a copy of Dr. Tyler's new book on developmental disabilities. I am also making the HealthSoft courses on developmental disabilities nursing available to the nursing students in Lithuania.

The rest of my vacation was full of amazing old churches, castles, museums, and cities that have been there from as early as the 11th century, wonderful food, meeting relatives for the first time (my grandfather had 11 brothers and sisters!) . . . and then a week in Paris. The food was wonderful and everywhere you looked . . . there were more churches, history, and art . . . and did I mention the wonderful food? I came back to work with my mind stimulated and refreshed, a couple of new pounds around my middle, and a fresh perspective on what really matters in life. The pounds I hope to lose soon. The memories I hope to keep. If you haven't taken a vacation in a while, take one. I used to think that getting away from it

DDNA News Network is published quarterly to specifically address the issues of nurses who serve persons with developmental disabilities.

DDNA News Network accepts unsolicited articles, press releases, and other pieces for consideration as editorial material. Submissions by deadline date does not ensure publication in any issue.

Members are welcome to send articles for the newsletter, as well as correspondence to specific officers, committee members, and liaisons. Please send mail to the DDNA national office at P.O. Box 536489, Orlando, FL 32853-6489. Correspondence may also be faxed to: (407) 426-7440 or emailed to mawillis@ddna.org.

## Directory of Contacts

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**DDNA**

Developmental Disabilities Nurses Association

"Networking to care, advocate, and educate"



# President's Message

Hello DDNA Members -

I hope your summer has been enjoyable. Unbelievably, fall is just around the corner, and yes - it's already time to begin thinking about next year! Just four months ago, we were planning for DDNA's 2010 conference and four months from now, we will be welcoming in a new year. Time seems to pass at the speed of light these days, as we all try to *keep up* in the increasingly challenging I/DD health care environment.

The Board is working to plan next year's conference, which will be held in Hartford, Connecticut in May 2011. The conference program will include a full day of pre-conference, followed by two and a half days of conference sessions, and the conference is shaping up to be another excellent educational program. The 2011 conference sessions will focus on the clinical issues DD Nurses face when providing health support to persons with intellectual and developmental disabilities (I/DD), with ample opportunities for members to network with one another available throughout the conference. We are seeking nurses to present their clinical expertise during the conference, so we encourage all members to submit a speaker application and be a part of the 2011 DDNA conference! See "*Speaker Application*" under the Conference tab on the DDNA website at [www.ddna.org](http://www.ddna.org).

At the 2011 conference - and "back by popular demand" - the *Overview of DD Nursing and Certification Review Course* will be offered again as a "one-day" program prior to the start of the conference. This program will provide an overview of DD nursing for nurses who are "new" to the specialty. The program will also provide an excellent review for nurses who have been practicing in the field for some time or for those planning to take the certification examination.

The Board and the Medication Management Task Force continue to work on DDNA's Medication Management initiative. The Task Force continues to review the issue and work toward developing the Association's position paper. Representatives from the National Council of State Boards of Nursing (the Council) were in attendance at DDNA's Pre-Conference in May 2010. DDNA provided information to the

Council representatives about the concerns with medication management for persons with I/DD and the results from the survey DDNA conducted on this issue. The Council representatives presented these concerns to the Council's national Board of Directors in July and have reported that our concerns were very apparent to the national Board members. The Council has committed to continuing to work with the Medication Management Task Force and the DDNA Board and Task Force welcome the Council's input and support as we address this critical health issue. The DDNA Board will provide more information on the status of this initiative and the work completed in subsequent newsletters and at the 2011 conference.

So, most of us gladly say goodbye to the dog days of summer and look forward to cooler weather and autumn colors - and we hope for a less hectic pace as we strive to provide quality health support to the people with serve. Your continued commitment to persons with I/DD, to each other, and to our association continues to epitomize the very best that DD nursing has to offer - and to each of you, I offer my very best regards.

Best wishes to you all -

S. Diane Moore, BSN, RN, CDDN  
President - DDNA Board of Directors

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*Executive Director's letter* (continued from page 2)

all was over-rated. It is not! It balances your priorities and expands your horizons.

Speaking about expanded horizons -- DDNA is actively looking for speakers, sponsors, and exhibitors to help expand our educational horizons at the May 2011 conference in Hartford, CT. This year, we are specifically looking for topics of clinical interest to nurses. If there is a topic about which you want to learn, tell us so we can seek out someone with the expertise needed to speak on that topic. If you have information to share with other members, consider being a speaker yourself. Conference registration fees are waived for speakers, and speaking at a national conference looks great on your resume or CV. If you have a suggestion for a speaker, please email me at [mawillis@ddna.org](mailto:mawillis@ddna.org) with the speaker's contact information and we will follow up on it. Or, you may give a potential speaker the following link to directly submit a speaker application to DDNA at: [www.ddna.org/apply/speaker](http://www.ddna.org/apply/speaker).

If there is anything that we can do for you here at DDNA, don't hesitate to email or call.

Enjoy the last golden days of summer and have a wonderful autumn.

Mary Alice Willis, MSN RN  
Executive Director

## The NADD 27th Annual Conference

*Ascending the Summit: Mental Health in Autism and Other Developmental Disorders (ID/MH)*

### FEATURING

Pre-Conference Symposium • Keynote Addresses • Concurrent Sessions • Breakfast Consultations with the Experts

*The brochure and online registration will be available in September.*

For information: (Mail) NADD, 132 Fair St., Kingston, NY 12401  
(Phone) (800) 331-5362 • (E-mail) [info@thenadd.org](mailto:info@thenadd.org)  
(Web) [www.thenadd.org](http://www.thenadd.org)

# Certification News

DDNA Members,

Certification. Certification. Certification.

How many ways can I say it? Only one - GET CERTIFIED! In these days of trying times economically and professionally, one way to make your employer sit up and take notice is to be a step above the next person. How do you do that? GET CERTIFIED.

When jobs are scarce or employers are looking for ways to balance their budgets, they will likely look twice before letting someone go who is CERTIFIED.

When regulatory agencies are doing their surveys and they know that the nurse is CERTIFIED, they have more confidence in the agency because they know that they have taken that extra step to get a nurse that is CERTIFIED.

When that nurse who signs CDDN or DDC after her name looks in the mirror, she knows she has gone that extra step.

CERTIFICATION can help you gain more respect among peers and other professionals; it also can potentially help you earn more.

It can show that you are growing in your nursing career.

CERTIFICATION is not difficult to attain. We have practice questions on the web site. We have a list of resources on the web site. We have close to 500 CDDNs and DDCs who would be glad to encourage you to take the leap.

Testing centers are located all over the country at PROMETRIC TESTING CENTERS. The availability of the testing centers allows you to take the test when you feel you are ready.

DDNA offers a full-day DD overview at the Conference, which allows you to get that last minute bit of info and confidence before taking the test.

The test is always offered at our annual Conference.

Check with your local Chapters/Networks and see whether there is any interest in forming a study group. We can always help you find your Chapter/Network, if you don't know where it is.

After CERTIFICATION, get your pin and wear it proudly. You will have earned and it is a way of letting everyone know... YOU DID IT!

Kathleen A Brown, RN, CDDN  
Certification Chairperson  
President Elect DDNA

*Interested in becoming certified? For a complete guide on preparing and taking the CDDN or DDC exam, please visit [www.ddna.org/pages/certification](http://www.ddna.org/pages/certification).*

## CERTIFICATION PIN ORDER FORM

Pins are \$25 each, which includes shipping within the continental US and Canada. For orders outside of these areas, please call the DDNA office at (800) 888-6733 for additional shipping prices before placing your order. You may order with a credit card by phone or online on the DDNA website from the Products page ([www.DDNA.org/store](http://www.DDNA.org/store)) or by mail with check or money order in US\$.

*I would like to order the following:*                      Quantity

CDDN Certification Pin(s) - \$25 each                      \_\_\_\_\_

DDC Certification Pin(s) - \$25 each                      \_\_\_\_\_

**Please send my order to:**

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

DDNA Membership Number: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Certification Number: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

**MAIL ORDERS TO: DDNA Certification, P O Box 536489, Orlando, FL 32853-6489**



# Supporting an Individual with Terminal Cancer

By Richanne F. Cunningham, RN, CDDN

Johnny was a 48-year-old man who had lived in a group home for most of his adult life and in an institution before that. Johnny had cerebral palsy and was a functional paraplegic. He loved to play jokes on staff and was the group home's social greeter. He always had a smile ready to give and brighten your day.

In November 2006, Johnny was on a short vacation. While putting deodorant on Johnny, his direct support person (DSP) noticed a small lump in Johnny's right armpit. The lump was smaller than a pea. Upon John's return to the group home after vacation, the DSP notified the nursing staff of her finding. Nursing staff assessed the lump, and it was indeed smaller than a pea and causing him no pain. They scheduled an appointment for Johnny to see a local general surgeon to have it evaluated. The physician told the staff that he did not think that the lump was anything to worry about, but at their insistence he did a fine needle biopsy. The next month was a very long wait for the staff at Johnny's home. The reason the wait was so long was because the local pathologist noted an abnormality and sent the biopsy to the Mayo Clinic for diagnosis. Johnny had cancer that was already Stage IV, but the axilla was not the primary site. Over the next month, Johnny underwent test after test to try to find the primary site of his cancer so that it could be treated appropriately. Unfortunately, the tests were unable to show the primary cancer.

The interdisciplinary team (IDT) met to discuss the options that were now available to Johnny. One option was full body radiation to try to get the cancer into remission; however, Johnny was not the type of person to sit still for long and the only way to get him to lay still would be with heavy sedation. No one wanted to see him go through that. The decision was made that we would make sure that Johnny was comfortable and not in pain. The doctors could not tell us how long Johnny had to live.

Hospice was called in to support Johnny and the staff, who were the only family that he had ever really known. The hospice nurse told the group home staff that Johnny was expected to live for about a month. Through all of this, Johnny did not seem to understand what was going on. Staff was concerned that he seemed to be more quiet than usual. The hospice nurse recommended that he be started on pain medications, but staff was concerned that we would be sedating him and causing his death to come prematurely. The hospice team attended a weekly staff meeting at the group home to address these concerns. They assured staff that the purpose of the medications was not to sedate Johnny, but to keep him comfortable so that he could continue to live his life to the fullest. Johnny was started on Roxinol. His dosage was increased based on behavioral observations, because he never complained that he hurt. With each dosage increase we would see him trying to give us smiles and play jokes on us.

By the end of the first month of hospice care, it was evident that the hospice nurse was right that we would soon be losing him to cancer. All the individuals who lived with him came to his room to say their goodbyes. There was a non-stop parade of people sitting in his room so that he would not be alone when he died. Johnny died exactly one month after he was admitted to hospice care. He died peacefully in his sleep and he was not alone.

We had only four months with Johnny from the time that the nodule was found by the very vigilant DSP until his death. Direct support personnel are often our front line eyes and ears. They provide nurses with insight into our individuals' lives and can often tell us something is wrong just by the way the individuals are behaving. We need to make sure that we commend our competent direct support personnel, because they are some of the lowest paid people in the country and we expect so much from them!

## Calendar of Upcoming Events



### October 4-5, 2010 - Albany, NY

NYS ID/DD Nurses Annual Conference will be held at the Marriott Hotel in Albany. For details, visit [www.nysmrdna.org](http://www.nysmrdna.org).

### October 13, 2010 - Lancaster, PA

PADDNN 2010 Annual Conference at Eden Resort in Lancaster. Contact [mwolf@heionline.org](mailto:mwolf@heionline.org) for details.

### October 22, 2010 - Devens, MA

MADDNA 2010 Annual Conference at Devens Common Center. Dual Dx - Seizure Disorders & Psychiatric Conditions and Medications. For information, contact Sherrill Hayter at [Sherrill.Hayter@state.ma.us](mailto:Sherrill.Hayter@state.ma.us) or Ann Smith at [asmith4@comcast.net](mailto:asmith4@comcast.net).

### November 3-5, 2010 - Seattle, WA

NADD 27th Annual Conference. "Ascending the Summit: Mental Health in Autism and Other Developmental Disorders (MH/ID)." Details on [www.thenadd.org](http://www.thenadd.org).

### November 12, 2010 - Albuquerque, NM

NM DDNA Chapter state wide conference - "Childhood to Adult - Environmental/Medical Issues Affecting Those with DD." For information, contact Lauren DeCarlo at [lstobie@arc-a.org](mailto:lstobie@arc-a.org).

### May 13-17, 2011 - Hartford, CT

National DDNA 2011 Annual Conference at Hartford Marriott in Hartford, Connecticut. Details will appear on [www.ddna.org](http://www.ddna.org).

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and that is why FBC begins working with the child and his/her family both in the home and in the classroom.

**Preschool** - This is a very critical developmental stage in a child's life. FBC, along with its specialized teachers, counselors and therapists, work together along with the parent(s)/family on planning a program for each child it serves. The learning and development of a child during this time has lifelong benefits.

**Primary Education Program (PEP)** - This is a program that helps prepare each individual by teaching them in ways that are specific to their needs. This helps to prepare them for when they enter the public school system or other placement. It helps them to learn (at times) in different yet equal ways to their sighted peers.

Numerous techniques are taught and used for these individuals. Each is tailored to their needs and abilities, because some of these children have other disabilities along with being blind or visually impaired.

The certified teachers, specialized therapists, and numerous others provide an intensive sensory curriculum to integrate the remaining senses so that they not only better receive but also process and use the information. These curriculums are tweaked for each child based on how and what they have learned, how receptive they are to learning more or learning in different ways, and how they apply what they have learned.

**Elementary and Secondary Program** - Specialized teachers visit the classrooms and work with the teachers and child to help develop individual programs. Braille, tactile materials, and instructions are introduced to the children and used in a variety of ways in the classrooms.

**Adaptive Recreation Program (SHARP)** - This program is year round and mostly on weekends, except during the summer. The students have numerous opportunities to participate in many different activities and/or sports. There may be forms of art, such as painting, sculpting, and making or building something. They may also gain experience with housekeeping and daily activities, such as sweeping, vacuuming, preparing meals and cooking them. Sports activities may include bowling, swimming, rock climbing and golfing. The previously mentioned activities are just a few experiences and/or activities that are presented and taught to the students.

**Adult and Transition Services (ATS)** - This program is designed to assist people preparing to enter college and/or the work area. It focuses on individual needs in different areas, like daily living, Braille, independent mobility, etc.

**Orientation and Mobility Training** - Children must use all of their senses to learn to be mobile and function independently. FBC has specialists who work with the individuals to teach and assist in these areas.

**Independent Living Training Programs** - This program works mostly, but not always, with high school students. It teaches the students skills in a variety of daily living areas. Some of these areas are as follows: money management, cooking, shopping, street crossing and use of community resources.

To learn more about FBC and its programs and services, please visit their website at: [www.seeitourway.org](http://www.seeitourway.org). You will not be disappointed!

Currently, I have the great pleasure of being one of the nurses involved in the preschool and PEP programs. Once a week infants are brought to FBC for music therapy, and the parents receive counseling and/or information. I get to be present then, too!

The students have their own doctors (some have numerous doctors). We administer medications and/or treatments as ordered for the students. Providing these services has given me the ultimate opportunity to observe and assist these students. Through the teachers, para-educators, therapists, families and many others, I have learned a lot about these children. They are just amazing and so special. We all know that children are like sponges as they quickly soak up information, especially when it is presented in such fun and enjoyable ways.

The children at FBC not only learn things that sighted children learn, but they have to learn how to obtain this knowledge in different ways. It is so awesome not only to be a small part of this, but also to watch the children. The abilities that they have and learn are just astounding.

I had worked around and with blind or visually impaired people, but not to this extent. I had never realized how much of our daily activities we do without putting much thought into it. Sometimes we struggle with simple daily activities, and we do not even have to struggle with any disabilities. The blind or visually impaired individual learns how to perform these things and so much more; they are able to make you forget they have even one disability. Well, maybe not totally forget, but you are so fascinated and in awe that you do not really notice the disability, let alone consider the individual to be challenged.

FBC is strictly devoted to blind or visually impaired individuals; in fact, some of the staff also have this disability, so they know what these students are going through and what hurdles or obstacles they must overcome. To watch this is just, just... mind blowing. I cannot even put into words how I feel. I do know that if you ever get the opportunity to at least visit a facility like this, please do so. You will understand why I feel so blessed.

## Works Cited

Foundation for Blind Children - [www.seeitourway.org/ProgramsServices/programsServices.html](http://www.seeitourway.org/ProgramsServices/programsServices.html)

## Elections for the Board of Directors

If you are considering running or nominating someone for a position on the Board of Directors, please review the following information:

Current nurse members who wish to submit a nomination for office must submit the required application and credentials to the office of DDNA postmarked on or before March 31st. Nomination forms are available on the DDNA website at [www.ddna.org/downloads/nominationform.pdf](http://www.ddna.org/downloads/nominationform.pdf).

Once approved by the Board of Directors, each candidate's campaign information and activities shall be limited to the information displayed in the space provided by the association on the website, in the newsletter, and during the time allotted at the annual general membership meeting. Each candidate is expected to conduct himself in a positive, professional manner throughout the nomination, campaign and election processes. The election is for a Board position for the association and is not a public, political election. No active campaigning (i.e., handouts, give-aways, campaign signage, etc.) is allowed.

Candidates will be given five minutes at the general membership meeting at the annual conference to present their platform and to introduce themselves. Candidates will also be able to meet with members at the National Conference during exhibit time on Monday afternoon at the "Nominee Table" in the exhibit area.

### Elections Schedule

- Call for nominations by January 1st.
- Close of nominations March 31st.
- BOD approves the slate of candidates by April 30th.
- Slate of candidates is announced at annual conference and in June newsletter.
- Voting opens July 1st.
- Voting closes July 31st.
- Results announced in the September newsletter and on the website.
- There are two seats open for election in 2011, President-Elect and Treasurer.

For additional information about the DDNA elections, including nomination forms, visit [www.ddna.org/pages/elections](http://www.ddna.org/pages/elections).

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## Silent Auction!

At DDNA's Annual Conference  
May 2011 in Hartford, CT

100% of auction proceeds will be used to support the activities of DDNA's Medication Management Task Force



It is no secret that issues related to medication management for people with I/DD are of significant concern to licensed nurses who work in our field. The challenges nurses face as they work to ensure that medications are administered properly, very often by minimally trained and unlicensed direct support personnel, raise questions of legal liability for nurses and safety for individuals with cognitive and physical disabilities, many of whom take multiple medications each day. On behalf of DDNA's membership, DDNA's newly formed Medication Administration Task Force has already begun efforts to address these issues by surveying members' concerns, working on developing aspirational standards for medication management, evaluating various DSP training and monitoring programs, and seeking input from members and the National Council of State Boards of Nursing. Much more work needs to be done to create high-quality resources that I/DD nurses can use to assure that they are managing medication administration properly and legally, to develop materials for teaching medication administration skills to non-licensed caregivers and, most importantly, to assure that individuals with I/DD receive their medications appropriately and safely to maintain optimal wellness.

The activities of the Task Force require a significant amount of work and expense. All Task Force members volunteer their time. Money is needed, however, to fund travel and lodging costs for Task Force meetings and for other costs associated with research, collaboration with other stakeholders, and creation and dissemination of medication management information and materials.

A successful silent auction is a way DDNA can raise money for the Task Force. And conference attendees can have fun bidding on items (and winning!). DDNA is asking Chapters, Networks, and individual members to consider donating an item for the silent auction. Items are placed on a table for viewing and attendees write their bid down for each item on a list near the item. The highest bidder wins the item! And the Task Force also benefits.

Please remember that many attendees are traveling by plane to the conference, so consider the weight and size of the donated item. Need some suggestions for a donation? How about a unique item from your chapter/network's location, gift cards for stores and restaurants, handmade items, fancy candies, a nice bottle of wine, items and books of interest to nurses, gift baskets, jewelry, items for pets (also kids and grandchildren!), gift certificates for internet shopping sites . . . the sky's the limit -- as long as attendees can fit what they win into their suitcase, ship it home easily, or use it at the conference. So no baby grand pianos, please!

If you would like to donate an item for bid or if you have any questions about the auction, please email [admin@ddna.org](mailto:admin@ddna.org), or call DDNA 9-5 ET at 800-888-6733.

## Dear DDNA and Chapter/Network Members

### Are you getting ready for the 2011 Conference?

Believe it or not, it IS already time for your Chapter or Network to start planning for the 2011 DDNA Conference in Hartford because we want to encourage more involvement! Here's what you can do:

1. Select and plan to send a Chapter or Network Representative to the conference.
2. Create a unique Chapter or Network name badge representing your state or region that your Chapter Representative can wear throughout the Conference. This representative will be invited to participate in registration activities and will be the "go to" person for attendees who want to make Chapter /Network connections at the conference. Each Chapter Representative should also plan to attend the Chapter Leadership Luncheon on the last conference day.
3. Create a Chapter or Network poster presentation that illustrates the "story" and current activities of your Chapter or Network. During exhibit times, we encourage your Chapter or Network Representative and other members to be present at your poster and share information with attendees. You may even give away "freebies" or have a prize drawing. Be creative and have fun with it! Check out the DDNA website and submit a Chapter/Network 2011 Poster Presentation Registration form soon!

### Join a DDNA Committee!

The DDNA Education Committee is busily at work on the 2011 Conference Program. If someone in your Chapter or Network is interested in being involved, please contact Linda Tupper, Education Chairperson, at [education@ddna.org](mailto:education@ddna.org). Other Committees forming are:

**Membership** - Richanne Cunningham, Chairperson  
Email: [membership@ddna.org](mailto:membership@ddna.org)

**Certification** - Kathy Brown, Chairperson  
Email: [certification@ddna.org](mailto:certification@ddna.org)

**Chapter/Networks** - Judy Stych, Chairperson  
Email: [chaptersandnetworks@ddna.org](mailto:chaptersandnetworks@ddna.org)

We encourage each Chapter or Network to consider having a representative on

*Chapter/Network Liaison's Letter continued next page*

## The Arizona Chapter of DDNA

For information, visit the website at [www.ddna.org/chapters/arizona](http://www.ddna.org/chapters/arizona) or contact Sharon Atwood at (623)935-4032 or email: [sharonnurseatwood@yahoo.com](mailto:sharonnurseatwood@yahoo.com).

## Northern California DDNA Network

For NCCDDNA membership information, our next meeting date, to be included on our mailing list, or for a copy of our newsletter, please contact Elaine Rawes, RN, at (707)447-6034 or email: [queene1@comcast.net](mailto:queene1@comcast.net)

## Inland Empire of Southern California DDNA Network

For information on the Inland Empire of Southern California Network, contact Angelique Carter, RN, BSN at (951)318-0312 or email: [cartera883@aol.com](mailto:cartera883@aol.com).

## Colorado Association of Nurses for the Developmentally Disabled

For information about our organization, contact Nancy DeKlyn RN, CDDN, at (303)775-8471 or email: [ndeklyn@imaginecolorado.org](mailto:ndeklyn@imaginecolorado.org).

## Connecticut DDNA

For information, contact Patricia Vibert, RN, CDDN, at (860)675-5215; email: [vibertp@ciboakhill.org](mailto:vibertp@ciboakhill.org).

## The District of Columbia Chapter of DDNA

For information, contact Constance Reese, RN, at (301)588-5220 ext. 13 or email [CnstncRees@aol.com](mailto:CnstncRees@aol.com).

## The Mid-Florida Chapter of DDNA

For information regarding the Mid-Florida Network of DDNA, contact Jan Schlaier at [jschlaier@yahoo.com](mailto:jschlaier@yahoo.com) or call 352-428-9286.

## North Florida DDNA Nurse Network

For information, contact Carolyn Munroe, BS, MEd, RN, C, CDDN, at (352)955-5759.

## Georgia DDNA Network

The Georgia DDNA Network is currently in need of leadership. If anyone is interested in helping to reorganize and lead the Georgia Network, please contact Diane Tebbel at (678)793-2603 or email: [dtebbel@yahoo.com](mailto:dtebbel@yahoo.com).

## Central Illinois DD Nurse Network

For information, contact Debra Davis, RN, BSN at (309)224-0797 or email: [nurses@ciddna.com](mailto:nurses@ciddna.com).

## The Northern Illinois Chapter of DDNA

For information about NIDDNN, contact Sandy Ott, RN, CDDN, at (847)624-1993 or email: [sandyorn@yahoo.com](mailto:sandyorn@yahoo.com).

## Central Indiana DDNA

For information please contact Georgia Swank, RN, at (502)645-1226 or email: [gswank@palrx.com](mailto:gswank@palrx.com)

## Southern Indiana DD Nurse Network

For information contact Kathy Auberry, RN, MS, CDDN, at (812)988-1257 ext. 222 or email: [auberry@christole.org](mailto:auberry@christole.org).

## Iowa DDNA

For information, contact Brenda Behrens at 563-652-2848 ext. 13 or by email at [bbehrens@dacincorp.com](mailto:bbehrens@dacincorp.com). Please visit the website at [www.iddna.org](http://www.iddna.org)

## The Kansas Chapter of DDNA

For information on the Kansas Network, please contact Amy Root, BSN, RN, at (620)429-1212 x129 or email: [amy.root@classld.org](mailto:amy.root@classld.org).

one of these Committees. This representative must be a DDNA member. For the Certification Committee, the representative also must be a certified DD nurse (CDDN or DDC). Representatives are asked to send an email to [contact@ddna.org](mailto:contact@ddna.org) to provide their contact information (name, title(s), email address and phone number).

Re: the Chapter/Network Committee, we are currently planning to develop a Chapter Handbook as a single resource for all things you ever want to know about becoming and being a DDNA Chapter. What questions or issues did you encounter as you developed your Chapter? What information would have been helpful? If you're interested in promoting successful Chapters then this may be just the Committee for you. Sign up soon by emailing me at [chaptersand-networks@ddna.org](mailto:chaptersand-networks@ddna.org).

## FYI - Chapter/Network annual report

We have now combined the Chapter/Network Annual Report and Information Update into a single annual Organizational Report for chapters and networks. There is one form designated for chapters and one for networks. The respective forms can be accessed on the DDNA website; click on "Chapters" or "Networks." This single Organizational Report is due by February 1 of each year. If your Chapter or Network has not yet submitted any report to DDNA for 2009, please do so as soon as possible. We want to assure that the latest contact information is on record. Thanks so much!

*Chapter/Network Liaison's Letter continued next page*

## Kentucky Network

For information, contact Phyllis Fogarty at (859)313-5042 or email: [pfogarty@rescare.com](mailto:pfogarty@rescare.com).

## The Louisiana Chapter of DDNA

For network information, contact Gloria Bradford, RN, CDDN, at (318)827-9456 or email: [rrnmom6@bellsouth.net](mailto:rrnmom6@bellsouth.net).

## Maine Developmental Disabilities Nurses Network

For information regarding MEDDN, please contact Claudia Stanley at (207)782-1371 ext 15 or email: [cstanley@gbccinc.org](mailto:cstanley@gbccinc.org).

## The Massachusetts Chapter of DDNA

Greetings from Massachusetts. It is finally voting time for President Elect and Treasurer of MADDNA (Deadline September 1, 2010). The following nurses have been nominated for MADDNA President-Elect and Treasurer:

President-Elect:

- Sue Ann Poitras, RN, BSN, CDDN

Treasurer:

- Phyllis Schoof, LPN, DDC
- Shirley Michael, RN, CDDN

Please note: only MADDNA members (who also must be members of DDNA) are eligible to vote. If you have any questions regarding

your membership status, please contact Ann Smith, [asmith4@comcast.net](mailto:asmith4@comcast.net).

Membership for MADDNA:

If you are interested in joining MADDNA and are renewing your DDNA membership, please include an additional \$20 for our chapter dues. Please enclose a note with your membership form designating MADDNA chapter dues.

MADDNA 2010 Annual Conference - "Brainstorming" Is it neurological or behavioral? Join us for a day of problem-solving to be held on October 22, 2010 at the new location this year - Devens Conference Center in Devens, Massachusetts. Our presenters will be Dr. Sheldon Benjamin, neuropsychiatrist from U Mass Medical Center, who will be presenting during the morning session, and Carol Mitchell-Boudreau, FNP-BC, MSN, MCP, Assistant Director of Health Services from The New England Center for Children, who will be presenting in the afternoon. Ms Mitchell-Boudreau will talk about behaviors and ruling out a non-psychiatric cause and then an overview of use of psychotropics. We plan to finish the day with an overview of the Rogers Monitor process to be presented by Jay Geenty, Esq. DDS Legal North Central Area Office. Be sure to look for our brochure (coming soon) on the MADDNA web site.

For more information about the Massachusetts chapter, visit [www.ddna.org/chapters/massachusetts](http://www.ddna.org/chapters/massachusetts).

For more information contact either Sherrie Hayter, RN, CDDN email [Sherrill.Hayter@state.ma.us](mailto:Sherrill.Hayter@state.ma.us) or Ann Smith, MSN, RN, CDDN email [asmith4@comcast.net](mailto:asmith4@comcast.net).

## DDNA of SE Michigan

For information please contact Lillian Durecki, RN at (734)407-2500 ext. 315 or email: [DDNAofSEMI@aol.com](mailto:DDNAofSEMI@aol.com).

## The Minnesota Chapter of DDNA

Hi from hot and humid Minnesota! Our chapter takes the summer off, but we are now gearing up for our September Kick-off! Looks like we'll have a great speaker again this year (thanks to Patty Flaherty at Geritom!)

Many providers, including nurses, fought the legislature for 'no cuts' and we won many of the battles! What a great step for our I/DD providers. Next, we need to get our nurses in the budget!

We are always on the move to provide the best care possible to our consumers.

Visit Minnesota Metro's website at [www.mnmetroddna.org](http://www.mnmetroddna.org) and for more information, contact Wendy Herbers, RN, QMRP, at (952)401-4841 or email: [wherbers@tandemresidential.com](mailto:wherbers@tandemresidential.com).

## Nebraska DDNA Nurse Network

For information, email Mary Scherling, MSN, RN, CDDN at [RS11051@alltel.net](mailto:RS11051@alltel.net) or phone (402)228-4258.

## Developmental Disabilities Nurses of New Hampshire

For information about the DDNNH, please contact Jennifer Boisvert, RN, MS by email at [jboisvert@resresources.com](mailto:jboisvert@resresources.com); phone: (603)225-5870; or visit the website at: [www.dhhs.nh.gov/DHHS/BDS/DDNNH](http://www.dhhs.nh.gov/DHHS/BDS/DDNNH).

## Northern New Jersey DDNA

For information on Northern New Jersey DDNA contact Donna Sykes, RN, BSN, CDDN, CPN, at (908)234-0011 ext775 or email: [dsykes@matheny.org](mailto:dsykes@matheny.org).

## The Southern New Jersey Chapter of DDNA

For the latest news and information, contact Ann Yusko, RN, BSN, CDDN at [ayusko@ddna.com](mailto:ayusko@ddna.com) or (856)-875-2190 x 14.

## Share the news about your Chapter on the DDNA website!

Do you know that, as a DDNA benefit, each Chapter can create its own free one-page website? Contact DDNA for several templates from which you can choose. After making your template selection, decide on your content and forward this information to Mary Alice Willis at [mawillis@ddna.org](mailto:mawillis@ddna.org). Your webpage will be created absolutely free and posted on the DDNA website. Please encourage your Chapter to get on board soon! You have nothing to lose and everything to gain - free publicity about your Chapter for members and potential members!

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When the chips are down, DD nurses rise to the challenge! Keep the spirit! You're the best!

Warm regards -

Judy Stych, BS, RN, CDDN  
Vice President and Chapter Liaison

## The New Mexico Chapter of DDNA

The NM DDNA Chapter will be hosting their state wide conference on November 12th 2010 in Albuquerque NM. This year's conference will highlight an overview of medical issues impacting behaviors of the I/DD client and the impact they have had on health and developmental stages from "Childhood to Adult." The title of the conference is Childhood to Adult-Environmental/Medical Issues Affecting Those with DD. Guest speakers will include expert physicians along with family members to share experiences. CEs will be available. For further information, please contact Vice Chair Lauren DeCarlo RN at [lsto-bie@arc-a.org](mailto:lsto-bie@arc-a.org) or (505) 450-7209.

For information, contact Judi Murphy, RN, CDDN, at (505)332-6820 or email: [jmurphy@arc-a.org](mailto:jmurphy@arc-a.org).

## NYS ID/DD Nurses Association Network

For more information about the NYS ID/DD Nurses Association, visit [www.nysmr.ddna.org](http://www.nysmr.ddna.org) or contact Cathy Engel RN, BSN, CDDN, at (716)375-4751 ext. 452 or email [cengel@rehabcenter.org](mailto:cengel@rehabcenter.org)

## North Dakota DDNA

For information, contact Bernadette Vetter, RN, CDDN, at (170)663-0379 or email: [berniev@hitinc.org](mailto:berniev@hitinc.org).

## Oklahoma DDNA Nurse Network

For information on OKDDNA, please contact Phil Parker, RN, CDDN, at (405)413-4480; email: [okddna@cox.net](mailto:okddna@cox.net). The OKDDNA address is PO Box 94073; Oklahoma City, OK 73129. All OKDDNA meetings are open to all nurses working with individuals with developmental disabilities.

## East Tennessee DDNA

For information, visit our website at [www.etddna.com](http://www.etddna.com) or contact Melinda Hendon RN, BSN, CDDN. Phone: (423) 308-1168; email: [etddna@hotmail.com](mailto:etddna@hotmail.com)

## West Tennessee DD Nurses Network

For information on the network and quarterly meetings, please contact Susan Hatfield, RN, CDDN, LNHA, at (901)266-7276 or email: [shatfield@csnwt.org](mailto:shatfield@csnwt.org).

## DDNA of North Texas

For more information, please contact: Gwen Weiss, RN, CDDN at 214-476-4575 or [GwenLWeiss@aol.com](mailto:GwenLWeiss@aol.com).

## DDNA Network of Central Virginia

For information, contact Linda Coley, RN, CDDN, at (434)947-2274 or email: [arva.coley@cvtc.dmhmrsas.virginia.gov](mailto:arva.coley@cvtc.dmhmrsas.virginia.gov).

## DDNA Northern Virginia Network

For information, contact Deborah Tatum-Johnson at (703)323-4097 or email: [deborah.tatum@nvtc.dmhmrsas.virginia.gov](mailto:deborah.tatum@nvtc.dmhmrsas.virginia.gov).

## The Wisconsin Chapter of DDNA

For information on W.DDNA, contact Judy Stych, BS, RN, CDDN, at (608)266-8783 or email: [judith.stych@dhs.wisconsin.gov](mailto:judith.stych@dhs.wisconsin.gov).

## Pennsylvania Developmental Disabilities Nurses' Network

For information, contact Kimberly Cahill at (717)835-2277. Email [kimc@theadvocacyalliance.org](mailto:kimc@theadvocacyalliance.org)

## Rhode Island DDNA

For information, contact Christine Gadbois, RN, at (401)765-3700 ext. 223; email: [cgadbois@thgri.org](mailto:cgadbois@thgri.org)

### Our voices:

“ I am an RN working for United Cerebral Palsy Foundation for more than 30 years. No matter what goes on outside of work whenever I enter our group homes, I get unconditional love in the form of smiles and hugs. I know in my heart that I'm a much better person today because of my very special patients who are also my teachers. I've been humbled and honored by them and the lessons learned are immeasurable. It is still a thrill and privilege to work here. Thank you for letting me share.

”

- Linda Brown, RN

# Web Sightings

## Access to Medical Care for Individuals With Mobility Disabilities

Please view this new technical assistance document from the Department of Justice:

[www.ada.gov/medicare\\_mobility\\_ta/medcare\\_ta.htm](http://www.ada.gov/medicare_mobility_ta/medcare_ta.htm)

Please share this with your hospitals, healthcare facilities, community partners and anyone else who might be interested!

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## CDC Features - Tourette Syndrome: Involuntary Motor and Vocal or Phonic Tics

Did you know that 79% of children diagnosed with Tourette Syndrome also have at least one additional mental health or neurodevelopmental condition. Learn more about Tourette Syndrome from the CDC at: [www.cdc.gov/Features/Tourette-Syndrome/](http://www.cdc.gov/Features/Tourette-Syndrome/).

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## Spina Bifida Facts - NCBDDD

[www.cdc.gov/NCBDDD/spinabifida/facts.html](http://www.cdc.gov/NCBDDD/spinabifida/facts.html)

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## Aicardi Syndrome

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/aicardi-syndrome>.

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## Learning About Down Syndrome

From the National Human Genome Research Institute: [www.genome.gov/19517824](http://www.genome.gov/19517824)

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## About Masturbation Behaviors

Learn about the differences between healthy and unhealthy masturbation behaviors and when it may be necessary to intervene. [www.intelihealth.com/IH/ihtPrint/WsiHW000/9105/28955/266765.html?d=dmContent&hide=t&k=basePrint](http://www.intelihealth.com/IH/ihtPrint/WsiHW000/9105/28955/266765.html?d=dmContent&hide=t&k=basePrint)

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## Leaders with Developmental Disabilities in the Self-Advocacy Movement

Learn more about leaders with developmental disabilities in the self-advocacy movement from the Regional Oral History Office at the Bancroft Library at the University of California at Berkeley.

[http://bancroft.berkeley.edu/ROHO/collections/subjectarea/ics\\_movements/self\\_advocacy.html](http://bancroft.berkeley.edu/ROHO/collections/subjectarea/ics_movements/self_advocacy.html)

## Public Health Resources in the U.S.

From the CDC, here is a link to all the U.S. State Health Departments and public health resources in each state.

[www.cdc.gov/mmwr/international/relres.html](http://www.cdc.gov/mmwr/international/relres.html)

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## Accommodation and Compliance: Employees with Epilepsy

From the Job Accommodation Network, this is part of a n accommodation and compliance series designed to help employers determine effective accommodations and comply with Title I of the Americans with Disabilities Act (ADA).

<http://askjan.org/media/epilepsy.html>

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## Spina Bifida: Common Objects Containing Latex and Alternatives

This list provides a guide to some of the most common objects containing latex and offers some alternatives. It is not meant to be a comprehensive listing.

[www.spinabifidaassociation.org/atf/cf/%7bEED435C8-F1A0-4A16-B4D8-A713BBCD9CE4%7d/LatexList09.pdf](http://www.spinabifidaassociation.org/atf/cf/%7bEED435C8-F1A0-4A16-B4D8-A713BBCD9CE4%7d/LatexList09.pdf)

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## Aicardi-Goutieres syndrome

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/aicardi-goutieres-syndrome>

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## Epilepsy Foundation-Seizures: Types, Triggers, Causes & Syndromes

[www.epilepsyfoundation.org/about/types/](http://www.epilepsyfoundation.org/about/types/)

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## Addressing Health Disparities

From the CDC: [www.cdc.gov/Healthyouth/healthtopics/disparities.htm](http://www.cdc.gov/Healthyouth/healthtopics/disparities.htm)

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## GM1 gangliosidosis

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/gm1-gangliosidosis>

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## The Office of Developmental Primary Care

The Office of Developmental Primary Care is a program within the Department of Family and Community Medicine at the

# Web Sightings

University of California, San Francisco. It is dedicated to improving health outcomes for people with developmental disabilities across the lifespan. Dr. Clarissa Kripke, MD, FAAFP, a colleague from the American Academy of Developmental Medicine and Dentistry, is the Director of this Center. Gerri Collins-Bride, RN, MS, ANP, a member of DDNA, is the Center's Director of Training & Clinical Education

<http://developmentalmedicine.ucsf.edu/odpc/>

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## Learn More About Fragile X Syndrome

From the CDC: Information about Fragile X Syndrome: [www.cdc.gov/Features/FragileX/](http://www.cdc.gov/Features/FragileX/)

Video: [www.cdc.gov/ncbddd/single\\_gene/video/Fragile%20X-4.html](http://www.cdc.gov/ncbddd/single_gene/video/Fragile%20X-4.html)

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## Epilepsy and mood

Presented in a pdf form from the American Academy of Neurology: [www.neurology.org/cgi/reprint/75/4/e12](http://www.neurology.org/cgi/reprint/75/4/e12)

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## Scabies

Scabies - small mites that burrow under the skin - are contagious from person-to-person and can be a problem in facilities for people with I/DD. This article presents easily understandable information for DSPs about scabies and includes links to more information for health care professionals.

[www.cdc.gov/scabies/faq\\_public.html](http://www.cdc.gov/scabies/faq_public.html)

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## MicrobeWorld - Why is Handwashing Important?

Do you need to teach and emphasize to DSPs or clients about the important of handwashing and how to wash hands properly. Here are some fun and easy to understand resources.

[www.microbeworld.org/index.php?option=com\\_content&view=article&id=171&Itemid=62](http://www.microbeworld.org/index.php?option=com_content&view=article&id=171&Itemid=62)

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## Neurofibromatosis

Here are several links to information presented by the Children's Tumor Foundation about Neurofibromatosis:

Part 1: About Neurofibromatosis - [www.ctf.org/pdf/brochures/NF1-Brochure.pdf](http://www.ctf.org/pdf/brochures/NF1-Brochure.pdf)

Part 2: About Neurofibromatosis - [www.ctf.org/pdf/brochures/About%20NF2%20Brochure%20Printer%20Friendly.pdf](http://www.ctf.org/pdf/brochures/About%20NF2%20Brochure%20Printer%20Friendly.pdf)

Children with NF1 - [www.ctf.org/images/pdf/childwithnf1.pdf](http://www.ctf.org/images/pdf/childwithnf1.pdf)

## CDC Grand Rounds: Additional Opportunities to Prevent Neural Tube Defects with Folic Acid Fortification

This is another in a series of occasional CDC Grand Rounds reports. These reports are based on grand rounds presentations at CDC on high-profile issues in public health science, practice, and policy. Information regarding CDC Grand Rounds is available at [www.cdc.gov/about/grand-rounds](http://www.cdc.gov/about/grand-rounds).

[www.cdc.gov/mmwr/preview/mmwrhtml/mm5931a2.htm?cid=mm5931a2\\_e](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5931a2.htm?cid=mm5931a2_e)

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## Are epilepsy surgery guidelines being followed?

Most patients with epilepsy have good control of seizures using medications. However, up to 1/3 of epilepsy patients still have seizures despite trying several medications. Evidence has shown that surgery can be an effective way of treating temporal lobe epilepsy (TLE) that does not respond to medications. In 2003, this led the American Academy of Neurology (AAN) to recommend that patients with TLE whose seizures did not respond to drug treatment should consider surgery. They released a clinical practice guideline (CPG) to alert doctors to this information.

Full details and information are available from the American Academy of Neurology: [www.neurology.org/cgi/content/full/75/8/e41](http://www.neurology.org/cgi/content/full/75/8/e41).

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## Cyber Disclosure for Youth with Disabilities

This document is a supplement to The 411 on Disability Disclosure: A Workbook for Youth with Disabilities which helps youth learn about disability disclosure and what it means for them. Since the toolkit was written in 2005, there have been many advances in technology that have changed what youth need to know about disability disclosure.

Search sites like Google, social networking sites like Facebook, and micro-blogging sites like Twitter have added a new element to disclosure. Now it is possible to disclose a disability on the internet without even being aware of it. This can be as simple as a picture of someone using a wheelchair, a comment on a friend's blog about disability, or a profile posted on a disability organization's website. The goal of this document is to provide suggestions about how to make an informed decision about disability disclosure and to manage disclosure.

[www.ncwd-youth.info/cyber-disclosure](http://www.ncwd-youth.info/cyber-disclosure)

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## Autism Speaks Official Blog

<http://blog.autismspeaks.org/category/science/>

## Imaging Reveals Abnormal Brain Growth in Toddlers with Fragile X

Differences in brain growth patterns between preschool-aged boys with Fragile X syndrome (FXS), the most common cause of inherited intellectual disability, and their healthy peers suggest that the disorder may affect brain development both before and after birth, according to NIMH-funded researchers. In addition, their findings indicate ages 1-5 are an important window for better understanding the effects of FXS on brain development. The study was published May 18, 2010, in the Proceedings of the National Academy of Sciences.

### Background

In addition to its association with intellectual disability, FXS is the most common known specific genetic risk factor for autism spectrum disorders (ASD). FXS results from mutations on a gene that creates a protein called FMRP. The mutations, in effect, turn off the gene. Relatively little is known about how these mutations affect brain development in early childhood.

Allan Reiss, M.D., of Stanford University, in collaboration with colleagues from Stanford and the University of North Carolina, used magnetic resonance imaging (MRI) to examine changes in brain volumes in 69 boys, first assessed at ages 1-3 and then again an average of two years later at ages 3-5. Of the participants, 41 had FXS, 21 had typical development, and seven had some form of developmental delay.

### Results of the Study

The researchers found that some brain regions were similar between the boys with FXS and those without FXS at both times they underwent MRI. Other regions were abnormal among those with FXS at the first time point and remained that way at the second time point, suggesting that the gene mutations responsible for FXS begin to alter brain development early in life, possibly even before birth.

Furthermore, some brain regions were similar among all the participants at the start of the study but showed major differences by the second MRI at ages 3-5.

“This third category is the most interesting because it suggests that we have captured a critical development window of brain development that is significantly affected by fragile X,” said Reiss.

### Significance

The same mutations that cause FXS are also strongly linked to ASD. Thus, FXS is considered a model condition for informing research on ASD.

This study provides greater insight into how FXS mutations affect early brain development, which may one day serve as targets for the development and evaluation of new interventions for FXS and related disorders.

### What's Next

The researchers note that their study provides only preliminary information and that it will be crucial to follow the study participants as they enter their school age years, a time when the greatest number and severity of ASD behaviors tend to appear.

Future studies should include larger control samples, track development from an earlier age, and follow participants for a longer period of time. Studies comparing FXS population with those affected by other specific genetic risk factors, such as those occurring in Williams syndrome, may be useful as well.

Source: [www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x.shtml](http://www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x.shtml)

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## Slightly early births linked to autism, dyslexia

Babies born just 1 or 2 weeks before their 40-week gestation due date are more likely to develop learning difficulties such as autism or dyslexia, according to a British study.

The findings show that even babies born at 39 weeks -- the point at which many women who choose to have a Caesarean section delivery -- have an increased risk of a developing a learning disability compared with babies born a week later at 40 weeks.

Scientists in Scotland, analyzing the birth history of more than 400,000 schoolchildren, found that while babies born at 40 weeks have a 4 percent risk of learning difficulties, those born at 37 to 39 weeks of gestation have a 5.1 percent risk.

“There was an increasing risk of special educational needs as the gestation date fell, so as deliveries got earlier, the risk went up,” said Jill Pell, an expert in public health and health policy Glasgow University, who led the study.

“Even being just a week early put the risk up.”

It is already known that a baby born prematurely -- for example at 24 weeks of gestation -- is more likely to have learning difficulties. But the risks for babies born in the 24 to 40 week range had not previously been studied.

According to the World Health Organization, more and more women worldwide are delivering by caesarean section and a “significant proportion” of these surgical procedures are performed without any clear medical need.

Around a third of babies are born between 37 and 39 weeks of gestation, either by caesarean section or natural vaginal delivery.

Rates of autism have also been rising, with worldwide prevalence estimated at between 1 to 2 people in every thousand, although experts say this may be partly due to better diagnosis.

Pell noted this rise but said it would be “a leap too far” to link her findings directly to rates of autism, since autism was only

one of a range of learning difficulties considered.

Pell, whose study was published in the Public Library of Science Medicine journal, stressed that caesarean sections were not the only factor behind early-term births, since some women go into labor naturally before 40 weeks of gestation.

But she said doctors and women should consider the risks of learning difficulties when thinking about a caesarean.

“It is now normal policy (in caesarean section) to deliver women a week early,” she said in a telephone interview. “But if you make a decision...for an elective pre-term delivery, then it has to be a balance, weighing up the risks and potential benefits.”

“What this study shows is that special education needs are another factor that need to be considered.”

Children with special educational needs may have either a learning difficulty such as dyslexia or autism, or a physical difficulty such as deafness or poor vision.

Pell found that although the risk of educational difficulties was much higher in preterm than in early term babies, the absolute numbers of children with difficulties in the 37 to 39 week group were higher, because many more babies are born at this time than before 37 weeks.

In her study, early term births accounted for 5.5 percent of cases learning disabilities, while preterm deliveries accounted for only 3.6 percent of cases.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_99748.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_99748.html)

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## Gene Copy Aberrations May Help Drive Autism

The genetic background to autism may have gotten a little clearer.

Scientists say they have pinpointed certain types of genetic abnormalities that are unusually prevalent in individuals with the disorder. These are either segments of DNA entirely missing from the genome or the same segment repeated several times, known to geneticists as “copy number variations” (CNVs).

“We knew genetics were involved through twin studies and family studies, but the majority of studies focused on common variations in probably a few genes,” explained study author Stephen Scherer, director of the McLaughlin Center and the Center for Applied Genomics at The Hospital for Sick Children and the University of Toronto in Canada. “We found dozens, if not hundreds, of genes involved and each autism family may have their own genetic form of autism. The variations are quite rare.”

“This validates and confirms a hypothesis long held by researchers in this community that autism, instead of having

just one or two genetic risk factors, is likely to have hundreds, and these are usually identified by these sudden deletions or insertions in the genome called copy number variants,” added Andy Shih, vice president of scientific affairs at Autism Speaks, which helped fund the study. Shih served as key facilitator of the Autism Genome Project Consortium, a collaboration of institutions around the world that conducted the study.

The study findings are published in the June 10 issue of Nature.

The researchers compared the genomes of nearly 1,000 people with autism spectrum disorder (ASD) and about 1,300 healthy controls.

On average, participants with ASD had 19 percent more CNVs than the controls. Most of the CNVs were inherited from parents while others appeared for the first time in the autistic individual.

“About 6 percent of these occur as new CNVs in autistic individuals but the vast majority are rare, inherited CNVs,” Scherer explained.

“With autism, there’s a higher likelihood of having CNVs in their genes, especially genes related to intellectual disability,” Shih stated.

About 40 percent to 50 percent of kids with autism also have intellectual disabilities, Scherer pointed out.

There were also commonalities with other disorders, including schizophrenia, Shih said.

When researchers mapped all the genes affected by CNV deletions, they found many overlaps.

“We were able to link hundreds of these candidate genes together in the same pathway and these molecules include the known autism genes,” Scherer said. “We identified known groups of genes but also entirely new collections.”

These links between genes may prove important in looking for treatments.

“Now that we have a good outline of the network of molecules involved, that’s what we can use to start designing rationally targeted therapeutics,” Scherer said. “We didn’t really have that before.”

In some cases, there may even be drugs already out there that would affect some of these genes, he said.

Many of the CNVs identified were in areas of the genome already known to be associated with autism. Others were in areas involved with neuron (brain cell) signaling, also in line with previous research.

But some of the aberrant areas were involved in other areas also linked to brain development.

“That’s exciting . . . because it could mean even more targets for treatment,” Shih said, although the road to actual treatments could be a long one.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_99778.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_99778.html)

## Epilepsy Drug Linked to Serious Birth Defects

The offspring of women who took the epilepsy drug valproic acid during the first trimester of pregnancy are much more likely to have serious birth defects affecting the brain, heart and limbs, a new study finds.

Babies whose mothers took valproic acid during the first trimester were 12.7 times more likely to have spina bifida, in which the spinal cord and backbone fail to develop or close properly, compared to babies whose mothers did not take the drug.

Babies whose mothers took valproic acid were also 2.5 times more likely to have an atrial septal defect (a heart defect); about five times as likely to have a cleft palate (a defect of the upper lip and roof of the mouth) or hypospadias (a penis abnormality); more than twice as likely to be born with an extra digit on the hand (polydactyly); and nearly seven times more likely to have craniosynostosis (premature fusion of the skull during fetal development that restricts skull and brain growth).

While valproic acid (brand names include Depakene and Depakote) was associated with a higher relative risk of the six birth defects, the absolute risk of having a baby with any of the defects remains small, the researchers noted. For example, the risk of having a baby with spina bifida was 0.6 percent, or six in 1,000, among women who took the drug compared to five in 1,000 of babies born to mothers who didn't take any epilepsy medication.

Yet given mounting evidence of the risks of valproic acid to fetuses, researchers urged women of childbearing age to try other drugs to control their seizures.

"These findings provide further evidence to avoid valproic acid, if possible, in pregnant women and [for doctors] to discuss with girls and women of childbearing potential the risk of the drug for the unborn child," said senior study author Lolkje T.W. de Jong-van den Berg, of the University of Groningen in the Netherlands.

Dr. Kimford Meador, a professor of neurology at Emory University in Atlanta, echoed that warning.

"This drug should not be used as a first-line drug for epilepsy in women of childbearing age," Meador said. "There are multiple types of malformations that can be associated with valproic acid."

The review was published in the June 10 issue of the *New England Journal of Medicine*.

In the review, researchers first looked at eight studies that included nearly 1,600 births and identified some 14 birth defects that seemed to be much more common among the children of women who took valproic acid early in pregnancy.

Researchers then took that information and analyzed data from a large European study that included nearly 4 million

births and 98,000 birth defects. They found women who took valproic acid in early pregnancy had two to 12 times the risk of having a baby with one of six specific birth defects compared to women who took no epilepsy drugs. The findings were similar when birth defect rates among those taking valproic acid were compared to the rates for women who took other epilepsy drugs, leading researchers to conclude it was the valproic acid, not some other epilepsy drug, that was to blame.

Among those who took valproic acid during early pregnancy, the chances of having a baby with any of the defects was less than 1 percent -- cleft palate (0.3 percent), hypospadias (0.7 percent), polydactyly (0.2 percent), craniosynostosis (0.1 percent).

Previous research has also linked valproic acid to spina bifida, other birth defects and cognitive problems in children, Meador noted. In April 2009, Meador was the lead author of a study that appeared in the *New England Journal of Medicine* that linked exposure to valproic acid in the womb to lower IQ scores in children at age 3.

The American Academy of Neurology recommends avoiding the use of valproic acid in pregnant women, according to background information in the article. Yet since up to half of pregnancies are unplanned, according to the study, all women of childbearing age should be warned about the dangers, researchers said.

Despite such concerns, valproic acid is often still prescribed, Meador said. In 2006, valproic acid was the second most commonly prescribed epilepsy drug, he noted.

Valproic acid is also prescribed to prevent migraines and for bipolar disorder, he added.

Despite the risks, valproic acid can be a very effective drug and may be the best choice for some patients whose seizures are not well-controlled by other medications, Meador said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_99783.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_99783.html)

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## Imaging Reveals Abnormal Brain Growth in Toddlers with Fragile X

Differences in brain growth patterns between preschool-aged boys with Fragile X syndrome (FXS), the most common cause of inherited intellectual disability, and their healthy peers suggest that the disorder may affect brain development both before and after birth, according to NIMH-funded researchers. In addition, their findings indicate ages 1-5 are an important window for better understanding the effects of FXS on brain development. The study was published May 18, 2010, in the *Proceedings of the National Academy of Sciences*.

### Background

In addition to its association with intellectual disability, FXS is

the most common known specific genetic risk factor for autism spectrum disorders (ASD). FXS results from mutations on a gene that creates a protein called FMRP. The mutations, in effect, turn off the gene. Relatively little is known about how these mutations affect brain development in early childhood.

Allan Reiss, M.D., of Stanford University, in collaboration with colleagues from Stanford and the University of North Carolina, used magnetic resonance imaging (MRI) to examine changes in brain volumes in 69 boys, first assessed at ages 1-3 and then again an average of two years later at ages 3-5. Of the participants, 41 had FXS, 21 had typical development, and seven had some form of developmental delay.

## Results of the Study

The researchers found that some brain regions were similar between the boys with FXS and those without FXS at both times they underwent MRI. Other regions were abnormal among those with FXS at the first time point and remained that way at the second time point, suggesting that the gene mutations responsible for FXS begin to alter brain development early in life, possibly even before birth.

Furthermore, some brain regions were similar among all the participants at the start of the study but showed major differences by the second MRI at ages 3-5.

“This third category is the most interesting because it suggests that we have captured a critical development window of brain development that is significantly affected by fragile X,” said Reiss.

## Significance

The same mutations that cause FXS are also strongly linked to ASD. Thus, FXS is considered a model condition for informing research on ASD.

This study provides greater insight into how FXS mutations affect early brain development, which may one day serve as targets for the development and evaluation of new interventions for FXS and related disorders.

## What's Next

The researchers note that their study provides only preliminary information and that it will be crucial to follow the study participants as they enter their school age years, a time when the greatest number and severity of ASD behaviors tend to appear.

Future studies should include larger control samples, track development from an earlier age, and follow participants for a longer period of time. Studies comparing FXS population with those affected by other specific genetic risk factors, such as those occurring in Williams syndrome, may be useful as well.

Source: [www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x-sht-ml](http://www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x-sht-ml)

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## The Fight Against Autism Goes High Tech

From iPods to robots to avatars, people with autism are increasingly taking advantage of cutting-edge technologies to improve their social skills and, in the process, break the isolation of their condition.

“We use them as a bridge to develop communication skills people with autism don’t have, like social referencing [for example, making eye contact],” explained Katharina Boser, president of Individual Differences in Learning of Howard County, Maryland, and co-chair of the Innovative Technology for Autism (ITA) committee at one of the nation’s leading autism advocacy groups, Autism Speaks. “There are a range of devices that can support people at different levels,” she said.

Several of these technologies were demonstrated recently at the International Meeting for Autism Research (IMFAR) in Philadelphia, which was sponsored by Autism Speaks and the International Society for Autism Research.

Among other things, the very predictability of robots, toys and computer-generated avatars are a low-threat way for autistic children to learn new skills, Boser explained.

“People are unpredictable,” she said. “Robots are more predictable. They’re not going to jump at you like a person might.”

Furthermore, “people with autism are hugely engaged by things, objects,” Boser added. “It’s a big motivator.”

In that respect, a child who won’t engage with a person might just engage with a “robot that cares,” she explained. A toy dinosaur that nods his head and purrs when he’s stroked is “mechanical and that will help people smile and engage in a way they normally wouldn’t with people,” Boser said.

Experts have noted that with this type of practice, children with autism can begin looking at a parent or a peer when speaking with them.

For example, a turtle named “Crush,” part of the “Turtle Talk with Crush” interactive attraction featured at several Disney theme parks, has turned out to be helpful for low-verbal, low-functioning kids, Boser said. After participating in a show and a “meet and greet,” children were more likely to smile, repeat words uttered by Crush, clap and laugh, according to a study presented at IMFAR.

People with Asperger’s syndrome (on the “lighter” end of the autism disorders spectrum) can also now wear a sensor on their wrist that measures their heart rate and gives them concrete data on their internal, physical state. According to Boser, this can provide an opportunity to connect their physical response (which is literal and concrete and therefore understandable to people with Asperger’s) with their feelings, and start to understand which behaviors are appropriate for different situations.

"It helps them become more mindful about what they do," Boser said.

Another innovation: A GPS mobile "app" that acts as a "proximity indicator," helping autistic people understand how close they can appropriately stand next to another person if they're a friend or if they're someone less familiar.

G. Richmond Mancil, executive director of the Kentucky Autism Training Center at the College of Education and Human Development at the University of Louisville, has also adapted an iPod touch to help upper elementary, middle school and high school students with autism communicate better.

The device uses pictures of everyday things to help the person better communicate. Mancil is now expanding the application to include videos of how one is supposed to interact in particular situations.

Kids who used the device had less screaming, hitting, biting and other behaviors associated with frustration, he said.

The iPod has the added advantage of the "coolness factor," Mancil pointed out. "It's much more socially acceptable."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_100143.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_100143.html)

## Down Syndrome Cases at Birth Increased

**The total number of cases at birth in the US increased by 24.2% from 1979-1983 to 1999-2003 in 10 regions.**

From 1979 to 2003, the prevalence (total number of cases of a disease in a population at a specific time) of Down syndrome (DS) at birth increased by 31 percent, from 9 to 12 per 10,000 live births in 10 US regions. Within the 10 regions, birth prevalence of DS ranged from a low of 9.7 in Arkansas to a high of 13.7 in Utah during 1997-2003.

The number of infants born with DS was almost 5 times higher among births to older mothers (38.6 per 10,000) than among births to younger mothers (7.8 per 10,000).

In 2002, DS was found to be present in about 1 of every 1,000 children and adolescents aged 0 to 19 living in 10 chosen regions of the United States, which means that approximately 83,000 children and adolescents with DS were living in the United States during that year. Prevalence of DS by age group was the highest in 0-3 year olds at 11.1, declining to 10.3 among 4-7 year olds, 9.8 among 8-11 year olds, 8.3 among 12-15 year olds, and 6.0 among 16-19 year olds.

Also in 2002, the lowest prevalence of DS aged 0 to 19 among race/ethnic groups was seen among Non-Hispanic black individuals, at 7.3. Hispanic individuals had the highest prevalence at 12.3, followed by Non-Hispanic white individuals at 10.2 and individuals of other races/ethnicities at 8.9.

More male (prevalence 10.8) than female children and adolescents aged 0 to 19 (prevalence 9.7) had DS in 2002.

Moreover, the 2002 prevalence of individuals with DS who also had major congenital heart defects (CHDs) was lower (4.7) than that of individuals without major CHDs (5.6).

Source: [www.cdc.gov/Features/dsDownSyndrome/](http://www.cdc.gov/Features/dsDownSyndrome/)

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## Predicting Alzheimer's Risk in Patients With Cognitive Problems

New research suggests the combination of a memory test and a brain scan may best predict the likelihood that an individual with mild cognitive problems will go on to develop Alzheimer's disease.

Mild cognitive impairment (MCI), is a condition "in which a person has problems with memory, language or another mental function severe enough to be noticeable to other people and to show up on tests, but not serious enough to interfere with daily life," according to the Alzheimer's Association.

Although not everyone with MCI will go on to develop Alzheimer's, the team of researchers noted that some ultimately will. And using these tests in tandem, they said, could increase early intervention among those most at risk.

"Even though it's true that there aren't preventive treatments for Alzheimer's, there are good reasons to want to know early [whether you are developing it]," explained study author Susan M. Landau, a research scientist with the Helen Wills Neuroscience Institute at the University of California at Berkeley and the Lawrence Berkeley National Laboratory.

"Basically, there are a number of really exciting drugs in the pipeline now that are being tested," she explained. "It's overconfident to say it's just a matter of time, but there's a huge amount of money and effort going into vaccine-type drugs, drugs that treat the symptoms and all kinds of different mechanisms. So, there's a lot of promise. And as soon as we have a drug that works, we also hope to have the ability to tell who's going to benefit from that drug."

Landau and her colleagues reported the findings in the June 30 issue of *Neurology*.

The study authors spent 1.9 years following the cognitive health of 85 patients participating in the Alzheimer's Disease Neuroimaging Initiative, taking place at 50 medical centers across the United States and Canada.

All had been diagnosed with mild cognitive impairment but were free of any other major neurological disease, and all were between the ages of 55 and 90.

The team conducted a number of Alzheimer's assessments that had already been shown to be helpful individually in identifying signs of the disease. For example, an "episodic memory test" that measured patients' ability to recall a list of words was administered, in addition to MRI brain scans that measured

the size of each patient's hippocampus (the brain region that controls learning and memory).

Levels of beta-amyloid -- a protein linked to Alzheimer's -- were tallied, and the researchers performed PET brain scans to look for metabolic irregularities also thought to be associated with the disease. Finally, a genetic analysis was conducted to identify which type of APOE gene each patient carried, given that a specific form of the gene has been linked with an increased risk of developing Alzheimer's. (The researchers noted that they didn't include all the exams and tests, such as the Mini-Mental State Examination, that are used to look for signs of Alzheimer's.)

Landau and her team observed that none of the patients reverted to their pre-MCI healthy cognitive state during the course of the nearly two-year study. In fact, 28 of the patients went on to develop Alzheimer's in that timeframe.

The authors found that PET scans and episodic memory tests turned out to be very effective at predicting Alzheimer's. In fact, patients with abnormal results on both tests were 12 times more likely to develop the disease than those with normal results.

However, an accompanying editorial -- co-authored by Dr. Carol Lippa, director of the Clinical Memory Disorders Program at Drexel University College of Medicine in Philadelphia -- pointed out that while the current efforts "dispel some of the mystery" regarding Alzheimer's progression, it does so by touting the diagnostic benefits of prohibitively expensive PET scans, which are unlikely to be a realistic option for many patients.

Landau agreed that cost is definitely an impediment to widespread PET scan use.

"However, we think where it might be feasible to use imaging is in the process of selecting participants for clinical trials for potential Alzheimer's drugs," she said. "Because we want to identify the right people who can ideally benefit from these drugs. So, that's one possible way it might be a very useful tool."

"Outside of that, people have imaging done, even though it's expensive, for lots of medical conditions," Landau noted. "So if it's useful enough, it could be promising nevertheless."

On the latter point, Dr. Gary J. Kennedy, director of the division of geriatric psychiatry at Montefiore Medical Center in New York City, was not so optimistic.

"I'd agree that the PET scan may have applications for the research studies, but for clinical day-to-day diagnosis it's going to be a rare individual that we send to get it done," he said. "But the episodic memory test is easy to administer, and it's not terribly cumbersome. So, it reinforces the value of cognitive testing."

"But I'd also caution that both tests appeared very, very effective at predicting Alzheimer's because they were used

among a group of selected people among whom you would expect it to be effective," Kennedy noted. "So if you look at patients visiting the average physician's office, that predictive power would probably fall off considerably."

"But it is certainly very important to identify these kinds of tests that have this kind of predictive ability," he added. "Because even though we don't currently have much to slow the disease process down at this point, I'd say that a lot can be done as far as helping a person plan ahead."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_100571.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_100571.html)

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## New Autism Genes Discovered: Autism Speaks and The World's Leading Autism Experts Announce Phase 2 Results of the Autism Genome Project

Autism Speaks, the world's largest autism science and advocacy organization, and an international consortium of researchers, along with participating families, joined together to announce new autism genetic discoveries from the second phase of its collaborative study: the Autism Genome Project. The results were published in the journal *Nature*, one of the world's most respected peer-reviewed scientific publications.

The Autism Genome Project (AGP) is an international autism genetics research consortium co-funded by Autism Speaks, the Medical Research Council, Canadian Institutes of Health Research, Health Research Board (Ireland), Genome Canada, the Hilibrand Foundation and Autistica. Based on analysis of high-density genotyping data collected from 1,000 individuals with autism spectrum disorder (ASD) and 1,300 without ASD, the AGP reported that individuals with autism tend to carry more submicroscopic insertions and deletions called copy number variants (CNV) in their genome than controls. Some of these CNV appeared to be inherited, while others are considered *de novo*, or new, because they are found only in affected offspring and not in the parents. Taken together, more of the CNVs disrupt genes, previously reported to be implicated in intellectual disability without autism or in autism, than expected by chance.

The new AGP study also identified new autism susceptibility genes including SHANK2, SYNGAP1, DLGAP2 and the X-linked DDX53-PTCHD1 locus. Some of these genes belong to synapse-related pathways, while others are involved in cellular proliferation, projection and motility, and intracellular signaling, functional targets that may lead to the development of new treatment approaches.

These findings further support an emerging consensus within the scientific community that autism is caused in part by many "rare variants" or genetic changes found in less than one percent of the population. While each of these variants may

only account for a small fraction of the cases, collectively they are starting to account for a greater percentage of individuals in the autism community, as well as providing insights into possible common pathogenic mechanisms. The overlap between autism susceptibility genes and genes previously implicated in intellectual disabilities further supports the hypothesis that at least some genetic risk factors are shared by different psychiatric developmental disabilities. Finally, identification of these biological pathways points to new avenues of scientific investigation, as well as potential targets for the development of novel treatments.

“Piece by piece, we are discovering genetic mutations that can cause autism. These findings will provide answers for families about what contributed to their autism,” said Andy Shih, Ph.D., Autism Speaks vice president for scientific affairs. “Furthermore, as we have learned from examples involving other genetic risk factors of autism (e.g., Fragile X, Rett, TSC), these genetic findings help us understand the underlying biology of autism, which can lead to the development of novel treatments.”

The AGP consists of 120 scientists from more than 60 institutions representing 11 countries who formed a first-of-its-kind autism genetics consortium. The AGP began in 2002 when researchers from around the world decided to come together and share their samples, data, and expertise to facilitate the identification of autism susceptibility genes. This continuing collaboration and its unique scientific assets (e.g., large sample set and multidisciplinary expertise) created scientific opportunities that otherwise would not exist. The AGP is well positioned to build on these extraordinary assets as the field of autism genetics further investigates rare variants, requiring larger sample sets to identify more CNV. Additional support for Phase 2 of the AGP was provided by the National Institutes of Health. The first phase of the AGP, the assembly of the largest-ever autism DNA collection and whole genome linkage scan, was funded by Autism Speaks and the National Institutes of Health and completed in 2007.

Source: [www.autismspeaks.org/press/autism\\_genome\\_project\\_nature.php](http://www.autismspeaks.org/press/autism_genome_project_nature.php)

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## Fertility treatment tied to risk of cerebral palsy

A new study confirms that children conceived via infertility treatment may have a higher-than-average risk of cerebral palsy -- explained largely by their higher rates of multiple births and preterm delivery.

The study, of nearly 590,000 children born in Denmark between 1995 and 2003, found that those conceived through assisted reproduction were about twice as likely to be diagnosed with cerebral palsy as children who were conceived naturally.

The findings, reported in the journal *Human Reproduction*, confirm those from a number of past studies. They also

suggest that the increased risk of cerebral palsy can be largely attributed to the heightened odds of twin or higher-order births, as well as preterm delivery, with assisted reproduction.

However, the absolute risk of having a baby with cerebral palsy is still quite low for couples undergoing infertility treatment.

In the U.S. and Europe, it's estimated that two or three of every 1,000 babies are affected by the disorder. So even with a relatively increased risk, the vast majority of children born via assisted reproduction techniques will not have cerebral palsy.

Still, researchers say their findings offer an argument for implanting women with only one embryo at a time, in order to cut the odds of multiple births and preterm delivery.

Cerebral palsy refers to a group of conditions, usually present at birth, that permanently impair movement, balance and posture. The impairments range from mild -- some children have only relatively minor problems with movement -- to more severe, with some children being unable to walk or having additional impairments, such as mental retardation or vision and hearing problems.

The precise cause of cerebral palsy is unknown, but it is believed to involve a disruption in normal fetal brain development. Premature and low-birthweight infants are known to have a higher risk than full-term, normal-weight babies.

For the new study, researchers led by Dr. Dorte Hvidtjorn, of the University of Aarhus in Denmark, examined national data on all 588,967 children born in the country between 1995 and 2003. That included 33,139 children conceived via in-vitro fertilization (IVF) or with the help of fertility drugs to stimulate the ovaries to produce eggs.

IVF, the most technologically advanced of assisted reproductive technologies, involves removing an egg cell from a woman's body, fertilizing it in the lab, and placing it in the woman's womb. It can cost up to \$15,000 per “cycle” of medications and procedures, with successful pregnancies often requiring several cycles.

Overall, 0.2 percent of all children were diagnosed with cerebral palsy. The risk was more than doubled among children in the IVF group, and 55 percent higher among those conceived using fertility drugs, compared with children conceived naturally.

When the researchers factored in the effects of multiple births and preterm delivery, the link between fertility treatment and cerebral palsy disappeared -- indicating that those two factors are likely responsible for the connection.

In fact, the researchers found no increased risk of cerebral palsy among singletons born via IVF.

The findings, according to Hvidtjorn's team, indicate that the risk of cerebral palsy among children conceived through assisted reproduction is “strongly associated” with their

high proportion of multiple births and premature deliveries. In this study, 63 percent of children conceived through assisted reproduction were premature, versus 33 percent of those conceived naturally.

Similarly, 54 percent of births in the assisted-reproduction group were twins or triplets, compared with 7 percent of births among children conceived naturally.

As it stands, doctors often transfer more than one embryo to a woman's uterus during an IVF procedure, with the goal of boosting the chances that at least one will successfully implant and result in a birth.

However, Hvidtjorn's team writes, the current findings make an argument for transferring only one embryo at a time.

Recent research also suggests that women implanted with one embryo during IVF have a similar success rate as those who receive two embryos. A Swedish study published last year in the *New England Journal of Medicine* found that among 661 women implanted with either one or two embryos during their first IVF attempt, 53 percent and 57 percent gave birth, respectively.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_100685.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_100685.html)

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## Obstructive sleep apnea linked with later risk of heart disease

*Individuals with I/DD, especially those with Down syndrome, can experience sleep apnea. Studies show that sleep apnea significantly contributes to the development of cardiac disease. Your nursing assessment of individuals with I/DD should include questions about sleep problems and whether significant snoring or sleep apnea problems exist.*

Severe obstructive sleep apnea (OSA) raised the risk of heart failure for middle-aged and older men – and significantly raised the risk of coronary heart disease in men up to age 70, according to research reported in *Circulation: Journal of the American Heart Association*.

After adjusting for known heart risk factors, researchers found that men with the most severe OSA faced a 58 percent higher risk of developing heart failure than those without OSA. And those ages 40 to 70 with the most severe OSA had a 68 percent higher risk of developing coronary heart disease than those without OSA.

“The Sleep Heart Health Study is the first to demonstrate prospectively that sleep apnea is associated with an increased incidence of heart failure,” said Daniel J. Gottlieb, M.D., M.P.H., lead study author and associate professor at Boston University's School of Medicine. “It's also the first large community-based study specifically designed to examine the association of sleep apnea with either coronary heart disease

or heart failure. Previous work has focused more narrowly on patients receiving care at sleep clinics.”

In obstructive sleep apnea, the airway collapses during sleep, leaving patients struggling to breathe.

In the study, researchers defined severe apnea as an hourly average of 30 or more breathing interruptions causing oxygen depletion and lasting at least 10 seconds. This can cause blood oxygen to drop and can rouse people from sleep with a burst of adrenaline that increases blood pressure, which may contribute to vascular problems.

OSA is common, affecting 24 percent of adult men and 9 percent of adult women, said Gottlieb, who is also director of the Sleep Disorders Center at VA Boston Healthcare System.

Research from the Sleep Heart Health Study also breaks ground because it included many women, Gottlieb said. However, researchers found no link between OSA and heart problems in women. Women are about half as likely as men to have sleep apnea, making it difficult to detect an apnea-heart disease link. This is an area for further study, he said.

The 1,927 men and 2,495 women were 40 or older and free of heart problems when the study began. Twenty-four percent of the men and 11 percent of the women had at least moderately severe obstructive sleep apnea. Researchers assessed participants' health for a median follow-up of 8.7 years.

The ages of the study subjects may have limited researchers' ability to detect a stronger link between apnea and coronary heart disease, Gottlieb said. Coronary heart disease risk from sleep apnea may be greatest at a relatively young age, with previous research suggesting increased risk of cardiovascular related death from sleep apnea in individuals ages 30 to 50.

Furthermore, sleep apnea is typically diagnosed years or decades after its onset. So, the requirement that study subjects be free of heart problems at enrollment would have excluded people who already suffered heart disease consequences that might be linked to long-term apnea, Gottlieb said.

By contrast, heart failure tends to occur more frequently in elderly people. Heart failure is a chronic weakening of the heart, leaving it unable to pump enough blood to meet the body's needs. Coronary heart disease is a narrowing of the coronary arteries that reduces blood flow to the heart.

The study didn't include enough minorities to detect trends for specific racial or ethnic groups, Gottlieb said.

Given the evidence that men 40 to 70 years old with obstructive sleep apnea face a higher risk of coronary heart disease, “it's really time for us to perform clinical trials to assess whether coronary heart disease risk can be reduced in patients with severe sleep apnea by treating the apnea,” he said.

The most common treatment, called continuous positive airway pressure, involves the use of a machine that forces air into the airways to prevent breathing interruptions.

“The take-away from our study is that obstructive sleep apnea is a serious condition that warrants medical treatment,” said Gottlieb. “Many patients don’t experience symptoms of obstructive sleep apnea, such as daytime sleepiness, or if they do, don’t mention it during routine medical exams. It’s important for anyone who suspects they have obstructive sleep apnea to discuss it with their primary care physician.”

Co-authors are: Gayane Yenokyan, M.D., Ph.D.; Anne B. Newman, M.D., M.P.H.; George T. O’Connor, M.D., M.Sc.; Naresh M. Punjabi, M.D., Ph.D.; Stuart F. Quan, M.D.; Susan Redline, M.D., M.P.H.; Helaine E. Resnick, Ph.D., M.P.H.; Elisa K. Tong, M.D., M.A.; Marie Diener-West, Ph.D.; and Eyal Shahar, M.D., M.P.H. Author disclosures are on the manuscript.

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Source: [www.newsroom.heart.org/index.php?s=43&item=1077](http://www.newsroom.heart.org/index.php?s=43&item=1077).

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## Autistic Kids Often Fussier Eaters, but Nutrition OK

As many parents of autistic children can attest, youngsters with the disorder are often slower to eat solid foods and become pickier eaters as they get older, new research shows.

However, the good news from the study is that the nutrition and growth of these kids typically doesn’t seem to suffer.

Problems with eating can emerge as early as infancy in children with autism and can become more pronounced with age, the study authors found.

Researchers collected data on the eating habits of nearly 13,000 children born in southwest England in 1991-92. Children were tracked from birth, and their parents filled out questionnaires about their youngsters’ eating habits.

About 80 children were later diagnosed with an autism spectrum disorder, a neurodevelopmental condition that appears in the first three years of life and is characterized by impaired social interaction and communication and restricted or repetitive behavior.

Parents of children later diagnosed with autism were more likely to report their children had feeding difficulties between 15 months and 54 months old, including being “very difficult to feed,” “very choosy,” or eating non-food objects, a disorder called pica.

For example, parents whose children were later diagnosed with autism reported that at 6 months of age their children had later acceptance of solid foods and took longer to eat than children without the disorder.

As kids reached 15 months, about 8 percent of parents of autistic kids reported their children were “very difficult to feed,” compared to about 3 percent of kids without autism.

And for kids between the ages of 4 and 5, about 26 percent of

parents said their autistic children were very difficult to feed, compared to 10 percent of youngsters without the disorder.

Autistic kids were also pickier eaters. At 15 months old, 9.5 percent of parents of kids later diagnosed with autism considered their children “very choosy,” compared to 5.4 percent of parents of kids without autism.

Between 4 and 5 years old, 37.5 percent of parents of autistic kids said their child was “very choosy,” compared to about 14 percent of the parents of other kids.

Yet despite the challenges parents may face in getting their autistic children to eat a balanced diet, researchers found no differences in the height, weight or body mass index (BMI) of kids with autism compared to their non-autistic peers at age 7.

Autistic children ate fewer vegetables, salads and fresh fruit than other children, but they also consumed fewer sweets and soda, the study team found.

And an analysis of reported food intake showed autistic children and non-autistic children consumed similar amounts of calories, fats, proteins and carbohydrates.

Aside from small differences in levels of vitamins C and D, autistic and non-autistic children were getting similar amounts of important nutrients. Autistic children’s levels of hemoglobin, or iron, in the blood were slightly lower, but not enough to be statistically significant.

Taken together, parents of children with an autism spectrum disorder should breathe easier about their child’s eating habits, said study co-author Pauline Emmett, a nutritionist at University of Bristol in England.

“Although children with autism spectrum disorders are more difficult to feed and they eat less variety of foods, this is not affecting the nutrients of their diet, their height, weight or BMI,” Emmett said. “There doesn’t seem to be any major cause for concern.”

The study is published in the July 19 online issue of Pediatrics.

Experts who treat children with autism often hear stories of parents having trouble around mealtime, said Geraldine Dawson, chief science officer for Autism Speaks. The problem is so prevalent most autism centers have a nutritional expert who evaluates kids’ eating habits.

One challenge is that many autistic children have a strong need for consistent routine or “sameness,” Dawson said, which can cause anxiety when asked to try new foods. Children with autism can also have sensory sensitivities, causing aversions to certain textures or tastes.

Some autistic children have motor delays that can cause problems eating or swallowing.

And although the underlying causes are poorly understood, autism is also associated with gastrointestinal problems, such as constipation and diarrhea, leading some kids to avoid eating.

In the study, some 8 percent of parents reported that their

children were on a special “allergy” diet, compared to about 2 percent of other kids. Though there was no other information collected about what the allergy might be, many parents put their children on diets free of gluten (wheat) and casein (dairy). There is little evidence it helps ease symptoms, according to recent studies.

One strength of the findings, Dawson said, is that parents were queried about their children’s diets prior to an autism diagnosis, reducing the chances of bias in describing their child’s behavior. The median age of diagnosis was just under 4 years.

“The eating difficulties appear to start very early and seem to be pretty inherent in the syndrome for many kids,” Dawson said.

Dawson agreed with the researchers’ suggestion that children who have persistent feeding difficulties may need to be screened for autism.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101211.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101211.html)

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## Voice Recorders Seem to Help Detect Autism

An analysis of soundtracks from a recording system worn by young children might detect differences in vocalization and help researchers identify those children who may have autism or language delays, a new study suggests.

“This automated application makes it possible to monitor development in a completely objective way,” said lead researcher Dr. D. Kimbrough Oller, a professor at the University of Memphis.

For the study, Oller and his team attached recorders in the chest pockets of children’s clothing. The device recorded the children in their natural environments during the course of a day.

They analyzed nearly 1,500 soundtracks from the recordings of 232 children, aged 10 months to 4 years.

Then, an automated system separated sounds made by the children and by their environment. The sounds and utterances were classified and rated, using established vocal development theory guidelines.

From that, the researchers found consistent differences between typically developing kids and those previously diagnosed with autism or those with language delays.

They also could predict a normally developing child’s age.

What was different between the groups? “The biggest difference appears to be the extent to which the kids performed well-formed syllables,” Oller said.

The research is published in the July 19-23 online edition of the Proceedings of the National Academy of Sciences.

Oller was previously a paid consultant for the company that

made the recording device. That company was then dissolved and reconstituted as the not-for-profit LENA Foundation, for which Oller is now an unpaid consultant.

One expert calls the new research promising. “We’re at the early stage of looking at this as one potential way to screen for the language delay in autism,” said Geraldine Dawson, chief science officer for Autism Speaks.

“I think it’s promising, but it would be important to continue to do further studies and replicate the findings,” she added.

One of the pluses of the recording device, she said, is that it can be used in the home.

But it won’t identify all children on the autism spectrum, Dawson said, which includes children with classic autism and other, milder developmental disabilities. “Not all children on the autism spectrum have language delays. The majority of children with autism do show some delay in the onset of language or early vocalization,” she said.

“This could be a potentially useful screening tool,” she added. Before the automated system, she said analysis of vocalization was mostly observational.

Experts do agree, Dawson said, that many children who go on to develop autism are not uttering those early vocalizations, known as communicative babbling.

“Having this automated system makes [the analysis] more objective,” she noted.

About one in 110 U.S. children are on the autism spectrum, according to the U.S. Centers for Disease Control and Prevention. The spectrum includes a host of developmental disorders that involve communication, social and behavioral challenges.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101221.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101221.html)

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## Giving Kids Booze, Medicines Can Be Child Abuse

The malicious use of alcohol and medicines is an under-recognized form of child abuse, according to a new report.

The U.S. study reviewed cases of pharmaceutical-related child abuse reported to the National Poison Data System between 2000 and 2008. The cases included the use of alcohol, painkillers, cough and cold medicines, sedatives, sleeping pills and antipsychotic medicines.

The findings are scheduled to be published in an upcoming issue of the Journal of Pediatrics.

The review included over 1,400 cases, and nearly 14 percent led to moderate or major consequences for children, including death. In about half of the cases, children were given at least one sedative. On average, 160 cases of pharmaceutical abuse, including two deaths, were reported each year.

Motives for this type of child abuse included punishment, amusement, or a desire for a break from childcare responsibilities, the researcher pointed out in a news release from the journal's publisher.

The findings highlight a serious problem, according to study author Dr. Shan Yin, of the University of Colorado and the Rocky Mountain Poison and Drug Center at Denver Health.

"The malicious administration of pharmaceuticals should be considered an important form of child abuse," Yin stated in the news release.

Pediatricians and emergency medical personnel should be on alert for this type of child abuse, and comprehensive drug screening should be used for children who are suspected victims of abuse, Yin added.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101371.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101371.html)

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## Imaging Reveals Abnormal Brain Growth in Toddlers with Fragile X

Differences in brain growth patterns between preschool-aged boys with Fragile X syndrome (FXS), the most common cause of inherited intellectual disability, and their healthy peers suggest that the disorder may affect brain development both before and after birth, according to NIMH-funded researchers. In addition, their findings indicate ages 1-5 are an important window for better understanding the effects of FXS on brain development. The study was published May 18, 2010, in the Proceedings of the National Academy of Sciences.

### Background

In addition to its association with intellectual disability, FXS is the most common known specific genetic risk factor for autism spectrum disorders (ASD). FXS results from mutations on a gene that creates a protein called FMRP. The mutations, in effect, turn off the gene. Relatively little is known about how these mutations affect brain development in early childhood.

Allan Reiss, M.D., of Stanford University, in collaboration with colleagues from Stanford and the University of North Carolina, used magnetic resonance imaging (MRI) to examine changes in brain volumes in 69 boys, first assessed at ages 1-3 and then again an average of two years later at ages 3-5. Of the participants, 41 had FXS, 21 had typical development, and seven had some form of developmental delay.

### Results of the Study

The researchers found that some brain regions were similar between the boys with FXS and those without FXS at both times they underwent MRI. Other regions were abnormal among those with FXS at the first time point and remained that way at the second time point, suggesting that the gene mutations

responsible for FXS begin to alter brain development early in life, possibly even before birth.

Furthermore, some brain regions were similar among all the participants at the start of the study but showed major differences by the second MRI at ages 3-5.

"This third category is the most interesting because it suggests that we have captured a critical development window of brain development that is significantly affected by fragile X," said Reiss.

### Significance

The same mutations that cause FXS are also strongly linked to ASD. Thus, FXS is considered a model condition for informing research on ASD.

This study provides greater insight into how FXS mutations affect early brain development, which may one day serve as targets for the development and evaluation of new interventions for FXS and related disorders.

### What's Next

The researchers note that their study provides only preliminary information and that it will be crucial to follow the study participants as they enter their school age years, a time when the greatest number and severity of ASD behaviors tend to appear.

Future studies should include larger control samples, track development from an earlier age, and follow participants for a longer period of time. Studies comparing FXS population with those affected by other specific genetic risk factors, such as those occurring in Williams syndrome, may be useful as well.

Source: [www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x.shtml](http://www.nimh.nih.gov/science-news/2010/imaging-reveals-abnormal-brain-growth-in-toddlers-with-fragile-x.shtml)

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## Sniffing Device Allows Disabled to Write, Run Wheelchairs

An Israeli research team has harnessed the power of the sniff to help severely disabled people play computer games, express themselves through writing and even move around in wheelchairs.

The experimental "sniff controller" takes advantage of the fact that cranial nerves in disabled people are often not damaged and are still able to send messages to the soft palate (the back of the roof of the mouth). The device registers changes in nasal pressure as the soft palate is being moved. Those changes are translated into electric signals that then communicate to the device.

The researchers, whose findings are published online this week in the Proceedings of the National Academy of Sciences, postulated that the experimental device could help quadriplegics and those suffering from "locked-in syndrome," which is when the patient is aware of their environment but can't respond or move.

“It’s a pretty brilliant idea,” said Paul Sanberg, distinguished professor of neurosurgery and director of the University of South Florida Center of Excellence for Aging and Brain Repair in Tampa. “It’s really a mechanical thing that allows people that don’t have other ways to communicate to use sniffing. It gives people who have significant disabilities another option.”

Many of these people can only communicate using eye movements, although scientists have been working on different brain-computer or brain-machine interface technologies to expand their abilities, but these are in various stages of development.

As part of the study, one 51-year-old woman, locked in for seven months due to a stroke, was able to use the sniff device to write a message to her family, the first since she had been stricken.

Similarly, a 42-year-old man who had been locked in since a car accident 18 years earlier, wrote messages by sniffing when particular letters were highlighted. It took him only 20 minutes to write his name after first being introduced to the sniff controller.

The first participant was able to “write” at a rate of three letters per minute and the second at 1.5 letters per minute, the researchers said.

And although this might seem slow, the researchers pointed out that Jean-Dominique Bauby wrote the memoir *The Diving Bell and the Butterfly* using only blinks of his left eye to sort out letters. This worked out to about one word every 2 minutes. Bauby was locked in as the result of a stroke suffered during his 40s.

The device also enabled quadriplegic individuals to write and even to navigate the Internet and write e-mails.

Sniffing also equaled mobility for many participants in the trial. Both healthy controls and disabled people were able to navigate a 115-foot path, including several turns, using a series of simple commands: forward was two sniffs in; backward was two sniffs out; left was sniffs out then in; and right was sniffs in then out.

Often, it took only 15 minutes of practice to “drive” successfully.

The researchers believe that most people can breathe independently of sniffing, ruling out the possibility that an accidental breath might activate the wheelchair commands and cause a disaster.

But, even so, the device can be programmed with “safety breaks,” for instance, adding extra commands so as to minimize the possibility that the wheelchair would be activated accidentally. It’s just that such controls would slow things down.

The authors are now planning to test the sniff controller in other types of patients, including those in a vegetative state.

The Weizmann Institute in Israel, which conducted the trial, has applied for a patent on the technology.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101487.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101487.html)

## Not All Epilepsy Drugs Raise Suicide Risk: Study

Since 2008, the U.S. Food and Drug Administration has required that all epilepsy drugs bear a warning label about an increased risk of suicidal behaviors, but German doctors report that only certain medications may increase the risk of self-harm.

However, some epilepsy researchers are skeptical of the findings and say the paper raises more questions than it answers.

The study of more than 44,000 epilepsy patients in the United Kingdom revealed that those who took relatively new antiepileptic drugs with a higher risk of causing depression, such as levetiracetam (Keppra), topiramate (Topamax) and vigabatrin (Sabril), were three times more likely to harm themselves or attempt suicide than those who weren’t taking any epilepsy medications.

The researchers found that patients who took conventional epilepsy medications, such as divalproex (Depakote, Depakote ER, Depakene) or phenytoin (Dilantin), or newer drugs with a low risk of depression, such as gabapentin (Neurontin) or lamotrigine (Lamictal), faced no increased risk of self-harm of suicidal behavior.

“These potential adverse effects should be considered in the selection of antiepileptics and during monitoring of the effects of these medications in epilepsy patients,” said study author Dr. Frank Andersohn, of the Medical Center in Berlin. “Patients with epilepsy who are currently taking an antiepileptic drug that might increase the risk of depression and/or suicidal behavior should, however, not abruptly stop or change their medication but should discuss this issue with their physician.”

Andersohn and his colleagues examined data on 44,300 patients in the United Kingdom General Practice Research Database who had epilepsy and had at least one prescription for an epilepsy drug from 1989 through 2005. Participants were followed for an average of five-and-a-half years. During that time, 453 patients had harmed themselves or attempted suicide, and 78 people died at the time or within four weeks of the initial attempt. The 453 patients were compared with 8,962 others who had not harmed themselves or attempted suicide. Six of the 453 people, or 1.3 percent, who harmed themselves or attempted suicide were taking the newer drugs with the higher risk of depression, compared with 45 of the 8,962 people, or 0.5 percent, of those who didn’t harm themselves.

The findings were published in the July 27 issue of *Neurology*.

An accompanying editorial notes several weaknesses of the study. For one thing, the results were based on a very small number of cases. Also, those taking the newer drugs with the higher risk of depression may have been more likely to have chronic and severe epilepsy, and these patients are known to have a higher risk of suicide, noted the editorial authors.

The FDA added the suicide warning to epilepsy drugs after an

agency review of 199 studies found that patients taking the drugs had about twice the risk of suicidal behavior compared with patients taking a placebo. The absolute risk amounted to about one added case of suicidal thoughts or behaviors for every 500 patients taking the antiepileptic drugs vs. placebo.

Dr. Josemir Sander, co-author of the editorial, said he doubted these new findings would prompt doctors to reconsider what drugs they prescribe. "I think that most physicians will use good sense and see that there are far too many problems with [the study] and not make knee-jerk reactions," said Sander, of the University College London's Institute of Neurology.

One expert agreed that the findings are far from conclusive. "Although some antiepileptic drugs may pose a risk to increasing suicidal behavior, this study does not prove that," said Dr. Orrin Devinsky, director of the New York University Comprehensive Epilepsy Center. "However, it strongly speaks to the need for more information."

Devinsky added that it's important to consider the real risks of epilepsy vs. a possible small increased risk of suicide. "Epilepsy can be a progressive and deadly disorder, especially for those with chronic and severe seizures. The dangers of epilepsy far exceed the dangers of the possible small increase in suicidal behavior risk from some medications."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101482.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101482.html)

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## New health policy: encouraging friendships?

Having good social relationships -- friends, marriage or children -- may be every bit as important to a healthy lifespan as quitting smoking, losing weight or taking certain medications, U.S. researchers reported on Tuesday.

People with strong social relationships were 50 percent less likely to die early than people without such support, the team at Brigham Young University in Utah found.

They suggest that policymakers look at ways to help people maintain social relationships as a way of keeping the population healthy.

"A lack of social relationships was equivalent to smoking up to 15 cigarettes a day," psychologist Julianne Holt-Lunstad, who led the study, said in a telephone interview.

Her team conducted a meta-analysis of studies that examine social relationships and their effects on health. They looked at 148 studies that covered more than 308,000 people for their analysis, published in the Public Library of Science journal PLoS Medicine at [www.plosmedicine.org](http://www.plosmedicine.org).

Having low levels of social interaction was equivalent to being an alcoholic, was more harmful than not exercising and was twice as harmful as obesity.

Social relationships had a bigger impact on premature death

than getting an adult vaccine to prevent pneumonia, than taking drugs for high blood pressure and far more important than exposure to air pollution, they found.

"I certainly don't want to downplay these other risk factors because of course they are very important," Holt-Lunstad said. "We need to start taking social relationships just as seriously."

## PEOPLE INCREASINGLY ISOLATED

Government policies to encourage social relationships will not necessarily be easy, Holt-Lundstad said. "Air pollution and the clean air act -- that is simple policy," she said.

But she has some ideas -- such as making it easier for friends or relatives to take part in medical care, and city planning that encourages interaction.

The different studies measured social interaction in different ways, so the researchers said it was impossible to precisely define positive social interaction.

It equally difficult to study systematically, as it is impossible to randomly assign people to have friends or not have friends. But Holt-Lundstad said there is some evidence that assigning caretakers does not help improve people's health.

"Naturally occurring relationships may be different than support received from someone who is hired for that purpose," she said.

Her team found some troubling evidence that Americans are becoming more isolated, and thus losing the support and care that love and friendship provide.

"For instance, trends reveal reduced intergenerational living, greater social mobility, delayed marriage, dual-career families, increased single-residence households, and increased age-related disabilities," they wrote.

"More specifically, over the last two decades there has been a three-fold increase in the number of Americans who report having no confidant," they added.

"Such findings suggest that despite increases in technology and globalization that would presumably foster social connections, people are becoming increasingly more socially isolated."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101556.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101556.html)

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## FDA Approves Drug for Chronic Drooling

The U.S. Food and Drug Administration approved Cuvposa (glycopyrrolate) Oral Solution to treat chronic severe drooling caused by neurologic disorders in children ages 3 years to 16 years.

Drooling is normal in infants. But a significant proportion of the developmentally disabled population experiences drooling caused primarily by neuromuscular dysfunction that makes it hard to swallow. Cuvposa reduces drooling by lowering the volume of saliva produced.

Glycopyrrolate was approved decades ago to treat peptic ulcers and reduce salivation in patients under anesthesia. Until now, glycopyrrolate has been used on an off-label basis to treat drooling in the developmentally disabled population, but in a different dosage form than the approved product. A drug is said to be used off-label when a physician prescribes its use in a different way than described in the FDA-approved drug label.

In 2001, the FDA held an advisory committee meeting to discuss how best to develop products for drooling with ethically and scientifically sound trials in children who have neurological disorders. Utilizing the advice provided, the FDA has been able to move forward in addressing the needs of this population.

For more information, please visit: [www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm220444.htm](http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm220444.htm)

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## Story-Telling More Difficult for Brain-Injured Children: Study

Children with brain injuries tend to be able to acquire the same language abilities as other children but have greater difficulty developing story-telling skills, a new study shows.

“Our findings suggest that there may be limitations to the remarkable flexibility for language functions displayed by children with brain injuries,” study author and University of Chicago researcher Ozlem Ece Demir said in a university news release.

The study included a control group of 20 typically developing children and 11 children with brain lesions (areas of damaged tissue) that are mainly caused by a stroke. This type of brain injury occurs in about one in 4,000 infants.

All the children, whose median age was 6, were asked to tell a story after they were given a line that suggested a narrative, such as, “Once there was a little boy named Alan who had many different kinds of toys.” As the children told their story, they were prompted by questions such as “anything else?” until they said they were done.

Compared to those in the control group, the children with brain injuries produced shorter and less complex stories, even though they had similar vocabulary and sentence comprehension abilities.

The study appears in the current issue of the journal *Developmental Science*.

Story-telling is a more complex activity than learning words and sentence structure because it requires flexibility in using words. That means that story-telling may be more likely to be affected by developmental delays than other areas of language learning, the researchers explained.

Previous research has shown that parents can improve the story-telling skills of children by engaging them in conversations

around narratives. The new findings add to evidence suggesting that parents of children with brain injuries should spend extra time helping their children create narratives during their preschool years, Demir and colleagues said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101633.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101633.html)

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## Vitamin D linked to cancer, autoimmune disease genes

Scientists have found that vitamin D influences more than 200 genes, including ones related to cancer and autoimmune diseases like multiple sclerosis -- a discovery that shows how serious vitamin D deficiency can be.

Worldwide, an estimated one billion people are deficient in vitamin D, and a team of scientists from Britain and Canada said health authorities should consider recommending supplements for those at most risk.

“Our study shows quite dramatically the wide-ranging influence that vitamin D exerts over our health,” said Andreas Heger of the Functional Genomics Unit at Britain’s Oxford University, who led the study.

Vitamin D effects our DNA through something called the vitamin D receptor (VDR), which binds to specific locations of the human genome. Heger’s team mapped out these points and identified more than 200 genes that it directly influences.

Vitamin D deficiency is a well-known risk factor for rickets, and some evidence suggests it may increase susceptibility to autoimmune diseases such as multiple sclerosis (MS), rheumatoid arthritis and type 1 diabetes, as well as certain cancers and even dementia.

With this in mind, the group looked at disease-associated regions of the gene map to see if they had higher levels of VDR binding. They found VDR binding was “significantly enriched” in regions linked to several common autoimmune diseases, such as MS, type 1 diabetes and Crohn’s disease, as well as in regions associated with cancers such as leukemia and colorectal cancer.

### “SUNSHINE VITAMIN”

Sreeram Ramagopalan, of the Wellcome Trust Center for Human Genetics at Oxford University, said the results, published on Monday in the journal *Genome Research*, showed “just how important vitamin D is to humans, and the wide variety of biological pathways that vitamin D plays a role in.”

Most Vitamin D is made by the body as a natural by-product of the skin’s exposure to sunlight. It can also be found in fish liver oil, eggs and fatty fish such as salmon, herring and mackerel, or taken as a supplement.

Some experts say that up to half the world’s population has

lower than optimal levels of vitamin D, and that about one billion people are actually vitamin D deficient. The problem is getting worse as people spend more time indoors.

A study published in March found that vitamin D is vital for activating the immune system's killer cells, known as T cells, which remain dormant and unaware of threats from infections if vitamin D is lacking in the blood.

Ramagopalan said the latest study suggested vitamin D played a role "in susceptibility to a host of diseases" and that health authorities should consider giving supplements to pregnant women and young children as a preventative measure.

"Vitamin D supplements during pregnancy and the early years could have a beneficial effect on a child's health in later life," he wrote. "Some countries such as France have instituted this as a routine public health measure."

There are no definitive studies on the optimal daily dose of vitamin D but some experts recommend 25 to 50 micrograms.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_102507.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_102507.html)

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## Quick brain scan could screen for autism

A 15-minute brain scan could in future be used to test for autism, helping doctors diagnose the complex condition more cheaply and accurately.

British scientists said on Tuesday their rapid test had proved more than 90 percent accurate in adults and there was no reason why it should not work equally well in children.

It could be a boon for patients and their doctors by reducing reliance on time-consuming and emotionally trying assessments based on interviews and behavioral observation.

Autism is a complex brain disorder characterized by difficulties in social interaction and communication, ranging from mild to profound impairment.

The new scanning method -- which picks up on structural changes in the brain's grey matter -- could be ready for general use in a couple of years. The next goal is to test it in children.

"What we are working on now is to see if we find the same results in younger people," research leader Declan Murphy, professor of psychiatry at the Institute of Psychiatry, King's College London, said in an interview.

"We would hope that it would work just as well ... there is no reason why not."

### TREATMENT

The ability to base a diagnosis on an objective biological test, rather than having to rely on personality traits, should mean patients get treatment more quickly, he added.

Cognitive behavioral therapy and educational treatment can

be highly effective for some patients and the impact of a more certain prognosis would be especially beneficial for children.

Murphy and colleagues, who published their findings in the *Journal of Neuroscience*, studied 20 healthy adults and another 20 individuals previously diagnosed with autism spectrum disorder, which also includes Asperger syndrome.

The accuracy of the scan in predicting autism was so high that the results were strongly significant, despite the small number of patients involved.

Experts not involved in the research applauded the research but cautioned further study was still needed.

"Although this method is not ready for normal diagnostic situations, any step to easier diagnosis is welcome," said Terry Brugha, professor of psychiatry at the University of Leicester.

Murphy said he envisaged that in future autism specialists would use a scan alongside interviews, in much the same way as doctors monitoring diabetes look at blood test results alongside patient histories.

The new system works by analyzing variations in the shape and structure of brain regions linked to language and social behavior, using standard magnetic resonance imaging (MRI) machines made by companies like General Electric, Siemens and Philips.

The speed of the test makes it some 20 times cheaper than traditional tests, which can take a team of doctors four to eight hours to conduct. The actual brain scan costs around 100 pounds (\$157.5).

Autism spectrum disorders are diagnosed in one percent of the population in Britain and the United States, and the condition affects four times as many boys as girls. Researchers agree there is a strong genetic component.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_102044.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_102044.html)

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## Little evidence antidepressants helpful for autism

While antidepressants are commonly given to people with autism, there is no evidence from clinical trials that the drugs are helpful for children with the disorder, and only limited evidence that they benefit adults, a new research review finds.

The analysis, reported in the *Cochrane Database of Systematic Reviews*, adds to doubts about the use of antidepressants known as selective serotonin reuptake inhibitors (SSRIs) in autism.

Last year, a U.S.-government-funded study found that the SSRI citalopram (Celexa) was no better than a placebo at improving repetitive behaviors in children with autism. At the time, experts expressed surprise at the lack of benefit and said the

results illustrated the need to test antidepressants against placebos in people with autism.

For the new review, researchers evaluated the findings of the Celexa study, along with those of six other -- much smaller -- clinical trials in the medical literature.

Overall, they found no evidence that SSRIs were better than placebos at improving repetitive behaviors or other symptoms in children with autism. And there was only limited evidence from two small clinical trials that certain SSRIs might improve anxiety, depression and other symptoms in autistic adults.

On the whole, there is no basis for recommending the routine use of SSRIs in treating autism, according to the researchers, led by Dr. Katrina Williams, a pediatrician at the University of New South Wales and Sydney Children's Hospital in Australia.

However, the researchers are not recommending that people with autism who are already on an SSRI and doing well stop taking their medication.

As it stands, no medications are specifically approved for treating autism spectrum disorders (ASDs), a group of developmental disorders that hinder people's ability to communicate and build relationships. The conditions range from severe cases of "classic" autism to the relatively mild Asperger's syndrome.

Behavioral and educational therapies that target the social, developmental and communication problems are the mainstay of autism treatment. But SSRIs are often prescribed to aid with certain symptoms; by one estimate, up to 40 percent of children with autism have been treated with an antidepressant.

In the U.S., three SSRIs - sertraline (Zoloft), fluoxetine (Prozac) and fluvoxamine (Luvox) -- are FDA approved for children older than seven.

Part of the rationale for SSRI use in ASDs is that the drugs can be effective for anxiety and obsessive-compulsive disorder, conditions whose features are similar to some behaviors seen in autism. For example, repetitive behaviors -- such as repeating specific words or actions, or obsessively following a routine or schedule -- are a main feature of autism.

In addition, SSRIs enhance levels of the brain chemical serotonin, and serotonin is thought to influence sleep, mood, aggression and other brain processes that are often altered in autism, Williams told Reuters Health in an email.

But few clinical trials have been done to test the drugs' effectiveness in improving the symptoms of children or adults with autism.

Williams and her colleagues were able to find only seven small, short-term trials where people with autism were randomly assigned to take an SSRI or a placebo for comparison.

The Celexa study, by far the largest, included 149 children with ASDs who were given either the SSRI or a placebo for three months. Roughly one-third of the children in each group showed improvements in repetitive behaviors during the study

period, with no advantage from the antidepressant.

All of the other studies Williams and her colleagues found were quite small, with the largest including 39 children. None went beyond three months.

Overall, the five studies that focused on children and teenagers showed no benefits of SSRI treatment, according to the researchers; the trials tested the drugs fluoxetine, fluvoxamine, and, in the two oldest studies, fenfluramine -- a medication that has since been pulled from the U.S. market.

Two studies included adults, with one testing fluoxetine and the other fluvoxamine. The trials found improvements in SSRI users' obsessive behaviors, anxiety, depression and aggression versus placebo users. However, the studies were very small -- one included six participants, the other 30 -- and treatment lasted eight to 12 weeks.

Moreover, SSRIs can have side effects, and concerns about adverse effects are greater with children and teens. In the citalopram study, one child given the drug developed seizures that required hospitalization, and continued to have repeat seizures after being taken off the drug. Children on the drug were also more likely than placebo users to show impulsive behavior, sleep problems and difficulty concentrating.

No increased risk of side effects was seen in children given Prozac; the study that looked at Luvox provided little information on side effects, according to Williams' team.

Given the lack of effectiveness and potential for side effects, SSRIs cannot be recommended for children with autism, the researchers say.

For adults, Williams told Reuters Health in an email, there is "preliminary information that suggests effectiveness" for alleviating depression, anxiety, obsessive-compulsive behavior and aggression. Decisions on whether an adult with autism should try an SSRI should be made on a case-by-case basis, according to Williams.

That said, some people with autism currently on an SSRI may be doing well.

"If children or adults are on an SSRI or other antidepressant and it has improved the problem that it was prescribed for and is not causing side effects, they should continue on the medication," Williams said.

Larger, well-conducted trials of SSRIs in the treatment of autism are still needed, according to Williams. That includes studies of other SSRIs that have yet to be put to the test in clinical trials but are being prescribed to people with autism -- such as sertraline and paroxetine (Paxil).

Larger studies, Williams and her colleagues point out, might allow researchers to find out whether certain subgroups of people with autism respond better to SSRIs than others.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_102002.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_102002.html)

## Gene scan finds link across array of childhood brain disorders

Mutations in a single gene can cause several types of developmental brain abnormalities that experts have traditionally considered different disorders. With support from the National Institutes of Health, researchers found those mutations through whole exome sequencing – a new gene scanning technology that cuts the cost and time of searching for rare mutations.

“This is going to change the way we approach single-gene disorders,” said lead investigator Murat Gunel, M.D., who is chief of the Neurovascular Surgery Program and co-director of the Program on Neurogenetics at Yale University in New Haven, Conn. Whole exome sequencing can be applied to dozens of other rare genetic disorders where the culprit genes have so far evaded discovery, he said.

Such information can help couples assess the risk of passing on genetic disorders to their children. It can also offer insights into disease mechanisms and treatments.

The research is funded in part by a \$2.9 million stimulus grant from NIH’s National Institute of Neurological Disorders and Stroke (NINDS) made possible by the American Recovery and Reinvestment Act.

“This study demonstrates a powerful new tool for discovering the cause of tough-to-crack genetic disorders,” said NINDS director Story Landis, Ph.D. “It also exemplifies how Recovery Act support to the NIH community is successfully driving biomedical technology and innovation.”

The study appears in *Nature*, and focuses on children with malformations of cortical development (MCD). These are severe abnormalities of the cerebral cortex, the brain’s outermost layer, which normally contains complex folds that are densely packed with brain cells. In MCD, the cortex is smaller and its folds are less complex. Affected children have severe intellectual disabilities and may not reach developmental milestones.

Different types of MCD are recognized based on anatomy. They carry names like microcephaly (small brain and head), schizencephaly (fluid filled clefts in the brain), pachygyria (a cortex with thicker, fewer folds) and polymicrogyria (cortex with many small folds). These conditions reflect a failure of brain cells to grow and reach their proper places during development. They can result from prenatal exposure to alcohol, drugs and some viruses. In many cases, the cause is genetic, but the specific genetic lesion is often unknown.

Through whole exome sequencing, the new study found a single gene at the root of seemingly distinct types of MCD in children from multiple families. Rather than scanning a person’s entire genome for mutations, this technique focuses on the protein-coding bits of DNA, or exome, which makes up about 1.5 percent of the genome.

Genetic forms of MCD occur worldwide and in all kinds of families, but the highest incidence is among children born

to parents who are related. Dr. Gunel and his colleagues at Yale teamed up with investigators in Turkey to study Turkish families with MCD. The country has a tradition of first- and second-cousin marriages, and thus a relatively high incidence of MCD.

The study began by focusing on two related children who were diagnosed with microcephaly. Whole exome sequencing revealed that both children had mutations in a gene called WDR62. As the study grew to include children from other families with microcephaly, many of the children were found to have mutations in the same gene. Unexpectedly, brain imaging revealed that the children also tended to have other types of MCD, superimposed with microcephaly. In all, the investigators found 6 unique mutations in the WDR62 gene among 30 families.

Those results show that a single gene “is required for strikingly diverse aspects of human cortical brain development,” said Dr. Gunel.

No one knows precisely what WDR62 does, but related proteins are known to regulate the processing of RNA (the intermediate between DNA and protein). The researchers found that in the developing mouse and human brain, WDR62 is enriched in a band of brain tissue that contains neural stem cells. They plan to explore the exact functions of WDR62 in mouse studies. Meanwhile, they will use their Recovery Act grant to extend whole exome sequencing to hundreds of additional families with MCD.

The technology should prove to be quick and cost effective for identifying the roots of other rare genetic disorders too, according to Dr. Gunel. In his laboratory, whole genome sequencing takes several weeks and costs about \$50,000, while whole exome sequencing takes 9 days and costs about \$3,500, he said.

In addition to NINDS, other support for the study came from a Clinical and Translational Science Award from NIH’s National Center for Research Resources, and from NIH’s National Institute of Mental Health.

Source: [www.nih.gov/news/health/aug2010/ninds-22.htm](http://www.nih.gov/news/health/aug2010/ninds-22.htm)

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## How Parents Come to Accept Down Syndrome Diagnosis

The negative feelings parents first experience when told their child has Down syndrome in most cases will eventually turn into joy and resilience, U.S. researchers report.

The study authors have released preliminary findings of an online survey of parents of children with Down syndrome. The survey, begun in October 2009, drew more than 500 responses.

There were many similarities in how parents felt when they learned their child had Down syndrome, said the researchers at Kansas State University and Texas Tech University.

“The majority said it was very devastating, and went through periods of depression, grief, mourning and shock, and felt scared, angry, disappointed or helpless,” Briana Nelson Goff, associate dean for academic affairs in the College of Human Ecology and a professor of family studies and human services at Kansas State, said in a university news release.

However, many parents said those initial feelings were later replaced by positive emotions.

“Several parents said the time to bond with their child was one of the most important keys to their resilience. They had to take that time to realize what they were facing, which then helped their adjustment,” Goff said in the news release.

While parents weren’t directly asked about their dealings with medical professionals, about 20 percent said they’d had negative experiences. These included medical professionals discussing abortion as the only option or parents feeling they were being pressured into making a decision to abort, the survey participants explained.

“This was the biggest surprise to come from the results. I would expect this answer from parents who had their child 20 years ago, but not from parents who had their child within the past five years,” Goff said.

She and colleague Nicole Springer of Texas Tech plan to publish a book that includes information from the survey and interviews with selected parents. Both researchers are parents of a child with Down syndrome.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101937.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101937.html)

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## Epilepsy Drugs Don’t Raise Suicide Risk, Study Shows

In 2008, the U.S. Food and Drug Administration required epilepsy medications to bear a warning label about an increased risk of suicidal behaviors. The move came after an agency review of 199 studies that found patients taking the drugs showed about twice the risk of suicidal behavior.

But now a study of more than 5 million patients contradicts the FDA’s findings. It suggests that the increased risk of suicide has more to do with the conditions for which these drugs are prescribed than the medications themselves.

For the study, researchers in Spain and the United States evaluated the health records of primary care patients in England. They found that people with epilepsy who currently use an antiepileptic drug are at no greater risk of suicide-related events than those who aren’t taking the medications.

“In our opinion, in the long term, it is not the drugs themselves that raise the risk of suicide, but the underlying disease for which these drugs are prescribed,” said study author Dr. Alejandro Arana, an epidemiologist and managing partner

at Risk MR Pharmacovigilance Services, in Zaragoza, Spain. “Treatment with antiepileptic drugs [AEDs] helps to control the psychiatric syndromes that are at the root of suicidal behavior in these patients.”

At least one epilepsy expert said the new findings, published in the Aug. 5 issue of the *New England Journal of Medicine*, are powerful enough to prompt the FDA to consider reversing its decision.

“The warning on AEDs and suicide was never justified, and this data strongly argues for its removal,” said Dr. Orrin Devinsky, director of the New York University Comprehensive Epilepsy Center.

“This study examined a much larger and more meaningful ‘real-life’ group of patients on antiepileptic drugs than the FDA study did,” added Devinsky, who noted that a major flaw of the FDA analysis was that many of the people studied had more severe cases of the condition, and these patients are known to have a higher risk of suicide to begin with. Another benefit of Arana’s study is that patients were followed for an average of six years, rather than the 24 weeks’ follow-up in the FDA analysis.

These new findings come on the heels of two other epidemiological studies that are also at odds with the FDA’s findings. Those studies, one by Harvard researchers and the other by scientists in Germany, suggested that some antiepileptic medications raise the risk of suicide, while others do not.

Arana and his colleagues studied a total of 5,130,795 patients who were seen in a general practitioner’s office for at least six months between July 1988 and March 2008. First, they identified how many patients were diagnosed with epilepsy, depression or bipolar disorder (since antiepileptic medications are often given to patients with one or more of these conditions). Then they looked at how many people had received an antiepileptic medication that was included in the FDA’s agency review and was also available in the U.K.

The medications studied were carbamazepine (Carbatrol, Equetro, Tegretol, Tegretol XR), gabapentin (Neurontin), lamotrigine (Lamictal), levetiracetam (Keppra), oxcarbazepine (Trileptal), pregabalin (Lyrica), tiagabine (Gabitril), topiramate (Topamax), valproate (Depakote, Depakote ER, Depakene) and zonisamide (Zonegran). Participants were followed for an average of six years. During the study period, 8,212 people attempted suicide, and 464 of these patients died as a result of their injuries.

Two subgroups of patients taking these medications were found to have an increased risk of suicide: people diagnosed with depression, and those who were prescribed an antiepileptic drug for a condition other than epilepsy, depression or bipolar disorder. Patients in the latter group were roughly two and a half times more likely to attempt or commit suicide than those who didn’t take an antiepileptic medication.

The researchers weren't able to determine why patients were taking an antiepileptic medication even though they didn't have epilepsy, depression or bipolar disorder. However, they noted that it may have been for chronic pain, which has been associated with an increased risk of suicide.

One possible reason for the increased risk seen among these two groups, the authors concluded, may be that "the use of antiepileptic drugs in these patients is a marker of severe depression or the presence of another condition that may be associated with an increased risk of suicide-related events."

"Research is dialogue, and our study is just another brick in the wall of knowledge," said Arana, who noted that the study was funded by an unrestricted grant from drug maker Sepracor. "There is still the need to fine-tune the role of antiepileptic drugs in indications other than epilepsy, to study the risk in the initial period of treatment compared to the use afterwards, and to compare individual antiepileptic drugs when used to treat patients with identical types of epilepsy."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101841.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101841.html)

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## Signs of Autism May Show in Early Infancy

Signs of autism may show up in babies as young as 1 month old, a new study shows.

But the tip-offs are not the usual red flags, such as a lack of eye contact or smiling, the researchers noted.

Instead, they found babies who needed neonatal intensive care and were later diagnosed with an autism spectrum disorder were more likely to have abnormal muscle tone and differences in their visual processing than babies who went on to develop normally after time in the neonatal intensive care unit (NICU).

The differences, which were subtle and probably not something parents would easily spot, were picked up by trained experts closely observing babies, said study co-author Ira Cohen, chair of the psychology department at the New York State Institute for Basic Research in Developmental Disabilities.

Still, "any parent concerned about the development of their child should have the child evaluated," Cohen said.

Autism is a neurodevelopmental disorder characterized by problems with social interaction, verbal and nonverbal communication and restricted interests and behaviors.

If the study findings are borne out by future research, they might lead to earlier identification and treatment of autistic children, experts say.

For the study, published in the September issue of *Pediatrics*, researchers identified 28 babies who spent time in the NICU and were later diagnosed with an autism spectrum disorder.

They matched them by gender and gestational age with 112 babies who did not have autism.

Babies' behavior and development was tested at 1 month old, 4 months and periodically until they were about 2.

At 1 month, infants later diagnosed with autism were more likely to show "persistent neurobehavioral abnormalities" after hospital discharge than other babies. About 40 percent of babies later diagnosed with autism showed abnormalities in the way they visual tracked objects compared to about 10.5 percent of babies who did not get an autism diagnosis.

More than half of babies later diagnosed with autism had abnormal arm tone -- either too floppy or too rigid -- compared to 22 percent of babies that developed normally.

At 4 months, infants later diagnosed with autism preferred higher amounts of visual stimulation than other babies their age. To test this, researchers showed infants flashing lights at varying speed. Children were given a choice of gazing at a monitor with more or less visually stimulating lights. Researchers determined preference by measuring how long the infant gazed at each monitor.

"It fits in anecdotally with what we see later on," Cohen said. "Kids with autism like looking at moving things in front of their eyes, such as flapping hands or following contours."

At 7 to 10 months, babies later diagnosed with autism also showed a decline in their thinking and motor skills, perhaps as a consequence of the very early sensory and motor signs. By about 13 months, the development of children with autism started to diverge markedly from those without, according to the study.

"The rationale for trying to identify kids sooner is that you can start intervention sooner, and the data indicate the sooner you start intervention the better children do," Cohen said.

Intervention by age 2 offers the best outcome, the authors wrote.

Researchers stressed that this research was done on babies from the NICU. More research is needed to confirm if babies born full-term and healthy who are later diagnosed with autism show similar types of abnormalities early on, Cohen said.

Recent estimates put the number of U.S. children with the disorder at one in 110, a number that has climbed steadily since the 1980s, according to background information in the study.

Previous research has found children born prematurely or of low birth weight are more likely to develop autism, though most kids with autism were not preemies, said Dr. Rebecca Landa, director of the Center for Autism & Related Disorders at Kennedy Krieger Institute in Baltimore.

Landa said medical professionals taking care of post-NICU babies should pay more attention to muscle tone abnormalities.

"One of the big take-home messages in this study is the researchers are reporting on muscle tone and visual system,

things that are not what one would maybe look at or expect to be precursors to autism,” Landa said. “We are now thinking it’s not the obvious old standbys like facial expression and eye contact that will be the main signs of autism in an infant.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_101788.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_101788.html)

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## Early and late birth ups cerebral palsy risk

Full-term babies born a bit on the early or late side are at higher risk of cerebral palsy, according to a new study in nearly 1.7 million Norwegian children.

“It is important to emphasize that the absolute risk is still very low and the vast majority of children being born some weeks away from 40 weeks (full-term) will not develop cerebral palsy,” Dr. Dag Moster of the University of Bergen in Norway, one of the study’s authors, told Reuters Health.

Cerebral palsy is a collective term for several disorders that involve the brain and nervous system that first appear in early childhood. It is the most common reason for disability in childhood and is thought to occur because the brain has been damaged during fetal development or early infancy.

According to the March of Dimes, two to three out of every 1,000 children born have cerebral palsy; the non-profit group estimates that there are 800,000 children and adults with the condition in the United States.

Preterm birth is well known to increase cerebral palsy risk, but most children with the condition aren’t born prematurely, Moster and his colleagues point out in the latest issue of the Journal of the American Medical Association.

To investigate whether being born later might influence risk as well, they looked at nearly 1.7 million children born in Norway at 37 to 44 weeks’ gestation between 1967 and 2001. A total of 1,938 of these children were known to have cerebral palsy.

The lowest risk of cerebral palsy, the researchers say, was seen in children born at term (40 weeks), with about one in every 1,000 of these children having cerebral palsy.

The risk of having cerebral palsy was higher with earlier or later delivery. The risk for children born at 37 weeks was nearly 2 in 1,000; it was 1.25 in 1,000 for children born at 38 weeks; 1.36 in 1,000 for children born at 42 weeks; and 1.44 for children born after 44 weeks.

The reason for these increased risks at 37 or 38 weeks’ gestation, or at 42 weeks or beyond, are not clear, Moster said.

One possibility is that a newborn’s brain may be more vulnerable if he or she is born shortly before or after the normal 40-week mark. “An alternative explanation may be that fetuses prone to develop cerebral palsy have a disturbance in timing of birth making them more prone to be delivered either early or late,” Moster said.

Until the biological reason for the link between pregnancy duration and cerebral palsy risk becomes clear, the researchers say, “it would be hasty to assume that interventions on gestational age at delivery could reduce the occurrence of cerebral palsy.”

“Women having a normal delivery outside 40 weeks,” Moster said, “still have a very small risk...that their child will develop cerebral palsy.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_102825.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_102825.html)

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Web Sightings (continued from page 12)

## Mucopolysaccharidosis type III

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/mucopolysaccharidosis-type-iii>.

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## Mucopolysaccharidosis type VII

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/mucopolysaccharidosis-type-vii>.

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## Lennox-Gastaut syndrome

From Genetics Home Reference: <http://ghr.nlm.nih.gov/condition/lennox-gastaut-syndrome>.

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## Tourette Syndrome

Tourette Syndrome Association TSA Home Page: [www.tsa-usa.org/index.html](http://www.tsa-usa.org/index.html)