

## Supporting the Aging Adult with Cerebral Palsy

by Judith A Stych BS, RN, CDDN

As individuals with intellectual and developmental disabilities experience longer lifespans, there has been expanding interest in understanding and addressing their health care needs as aging adults. Considerable study has surrounded the management of Down Syndrome and the early onset of dementia. I began to wonder, however, about research concerning the needs of the aging adult with Cerebral Palsy (CP). In short, the medical literature on this subject is emerging and offers multiple opportunities for nursing research and development of evidence-based care management by nurses specializing in Intellectual and Developmental Disabilities (I/DD) nursing. It is hoped that this brief overview will stimulate us, as I/DD nurses, to share our best practices and engage in nursing research on this topic.

### Cerebral Palsy (CP) - A Brief Review

Cerebral palsy has been defined as “A group of permanent disorders of movement and posture causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances in sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal disorders.”<sup>1</sup> Essentially, CP is a disorder of the brain that results in miscommunication from the brain to the muscles yielding impairments in muscle tone. Because different areas of the brain can be affected, the type and extent of the muscle tone impairment and any associated conditions will vary from one individual to the next.

The three primary types of cerebral palsy are described in *Table 1* (page 6).

In addition, cerebral palsy is classified according to the area(s) of the body affected:

- Diplegia - only lower extremities affected
- Hemiplegia - one half of body affected (such as, right arm and leg)
- Quadriplegia - all four extremities affected ( may include torso and facial area)

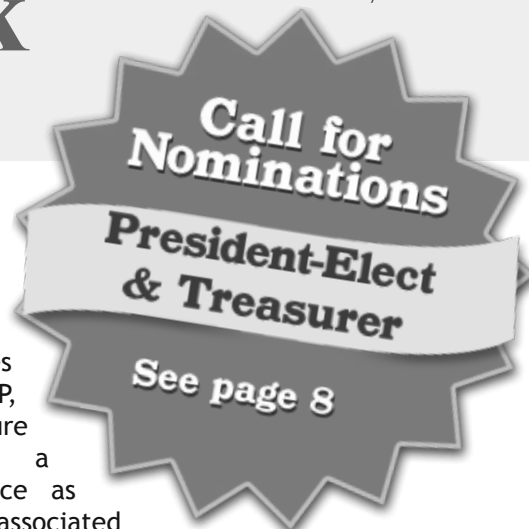
According to the National Dissemination Center for Children with Disabilities, CP occurs in approximately 2 per 1000 births. Coinciding with improved survival rates for low (<2500 grams; < 5lb, 8oz) and very low (<1500 grams; < 3 lbs, 5oz) birth weight babies, 1 in 20 infants with extreme prematurity may have CP.

Full term babies may manifest CP, but premature infants have a higher incidence as a result of associated complications. Deaths tend to be prevalent in infants born with severe brain injury or deformities who would, as a consequence, have been at high risk for CP.<sup>2</sup>

The brain injury that causes CP may occur in the prenatal, perinatal, or postnatal periods. “Seventy to 80% of cerebral palsy cases are acquired prenatally and from largely unknown causes. Birth complications, including asphyxia, are currently estimated to account for about 6 percent of patients with congenital cerebral palsy. Neonatal risk factors for cerebral palsy include birth after fewer than 32 weeks gestation, birth weight of less than 5lb., 8oz. (2,500 grams), intrauterine growth retardation, intracranial hemorrhage, and trauma. In about 10 to 20 percent of [individuals], cerebral palsy is acquired postnatally, mainly because of brain damage from bacterial meningitis, viral encephalitis, hyperbilirubinemia, motor vehicle collisions, falls, or child abuse.”<sup>4</sup>

Generally, CP manifests itself before the age of three years. Typical clinical findings may include prematurity (<1500 grams; <3lbs, 5oz), delayed developmental milestones, spasticity or athetoid movements before the age of 15 months and evidence of a seizure disorder before the age of two years.<sup>8</sup> With ambulation, the child may lack muscle coordination during voluntary movements. The dragging of one foot or leg, toe-walking, and/or a crouched or a “scissored” gait may be noted. Primary treatment approaches for CP include physical therapy, use of orthoses and/or other assistive devices to aid ambulation, and medications to reduce spasticity. Surgical treatment may include selective dorsal rhizotomy, which has been demonstrated to reduce spasticity and improve gross motor function for some individuals. In addition, surgical procedures for complete hip dislocations or subluxations (partial dislocation) are not uncommon.

United Cerebral Palsy estimates that about 764,000 children and adults in the United States manifest one or more of the symptoms of cerebral palsy. Further, it is estimated that about 400,000 are adults. About two-thirds of individuals with CP have an intellectual impairment. A few studies have



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# From the Executive Director's Desk

DDNA News Network, Vol 18, No 3  
Fall/Winter 2010

Dear DDNA Members,

Egad! Winter is starting again. Down here in Florida at DDNA HQ, we have had to break out our sweaters and lightweight jackets. To all of you who are starting to shiver, I do hope that the holiday season warms your hearts. For those of you who just love, love, love the cold, enjoy the lovely wintery weather!!!

Have you had a chance to read about DDNA's 19th Annual Education Conference yet? If not, when you are done reading this newsletter, go to the Conference page of the website to check out the educational sessions, the speakers, special planned events, and other "need to know" about the conference. You also will be getting a brochure in the mail early in 2011. Eli is designing a conference brochure that opens up into a poster that you can hang on the wall (for everyone to see). Definitely something different this year!

Now for a more serious topic that is on my mind for many reasons - bullying. There has been a lot of reporting about bullying in the news here in Orlando. It made the national news, so some of you may have heard or read about it. There was a 13-year-old girl with cerebral palsy who was bullied mercilessly on the school bus - to the point where she did not want to go to school - and her father decided to confront the bus bullies. Unfortunately, he was so distraught about the behavior of the other teenagers toward his daughter that he completely lost control and said some inappropriate things to the bullies. As a parent, I totally understand, yet do not condone his behavior. The father ended up being punished by the legal system; I'm not sure what happened to the bullies. These events raised a fire storm of outrage about bullying in our community and nationally. And our school system has responded. But is this what it takes?

As some of you know, I have an adult son with AS and low-level Tourette syndrome. He is smart, kind, hard-working, and does not have a mean bone in his body. He also was bullied in school, sometimes so cruelly that it was necessary for us to intervene on his behalf. Let's put it this way, I hold the record for number of years as PTA President, because it was important for me to have a continuing presence in the school. The bullying came not only from the other children, but also a few times from teachers. One teacher placed my son's desk in the back of the classroom facing the wall away from the blackboard because his tics were "distracting." My son did not tell me right away, but when I found out, I contacted the school to have that situation corrected immediately. In middle school, other boys would write obscenities and insults in his textbooks, and would hold him down on the playground and spit into his ears. When I found out, I went to the assistant principal and was told that there was nothing that could be done unless the behavior was witnessed. I don't know what part of "Why don't you please go and witness it then . . . because it happens to my son on the playground every day" the principal did not get, but . . . let's just say that was the end of public school for both my kids. If you are the parent of a child who has been bullied or if you ever were bullied, I'm sure you get it. And these days the Internet allows bullying to be anonymous and spread quickly, hurting its victims on their own computers. The recent suicides of young people who were picked on in cyberspace for being different are beyond tragic.

People with DD can be easy targets for bullying and abuse of all kinds. As DD nurses, you likely have taken mandatory classes on recognizing and preventing abuse of persons with DD. Type the word "bullying" into your computer's browser. I get 14,300,000 hits, so it is definitely a major topic of Internet discussion. When I specifically type in "bullying and disabilities," I get 1,970,000 hits. Wow - that is a lot! So if you want to learn more about bullying and disabilities, there is plenty of information out there. Research studies show that bullying causes increased rates of physical and mental illness, not just at the time of bullying, but also in later life. It causes wounds that can stay fresh or reopen under difficult life circumstances. The people for whom you provide care and services may be living with these wounds, which may manifest in health problems. Antecedents to negative behaviors may date back to childhood trauma caused by bullying.

"Eating our young" is a term used in nursing to describe the bullying (or "lateral violence") that can be perpetuated on new nurses in the work place. Google the term . . . I got 20,200 hits. The majority of them relate to nursing. Have you ever been bullied? If you say "yes," it means that it made enough of an impression on you to remember it. Bullies do not always

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.

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**DDNA**  
Developmental Disabilities Nurses Association

"Networking to care, advocate, and educate"



# President's Message

Hello DDNA Members -

As the year draws to a close, the DDNA office and Board is gearing up for the 2011 conference, which will be held in Hartford Connecticut in May. The conference program will include a one-day program providing an *overview* of I/DD Nursing, a full day of preconference focusing on the mental health needs of persons with I/DD, and two and a half days of conference sessions exploring "steps to clinical excellence." The Board also continues to work with the Medication Management Task Force on DDNA's Medication Management initiative and will provide members with an update at the conference. The conference is promising to be another excellent educational program, including ample opportunities for members to network with others, so I hope you will join us in Hartford!

Over the next few months, the Board will begin preliminary planning for the 2012 conference and will begin the call for presentations after the start of the new year. As always, we will be seeking nurses to share their clinical expertise during the conference, so we encourage all members to consider presenting an educational session. Look for more information beginning in January and submit a speaker application to be a part of the 2012 DDNA conference!

The primary mission of DDNA is to advocate for nurses working in the field of Intellectual and Developmental Disabilities (I/DD) - and advocacy comes in many forms. DDNA *advocates* for its members by offering quality education in the specialty, to help assure that I/DD nurses receive current, valuable information and are prepared to meet the health needs of the person with I/DD. During the conference, we try to assure that members have the opportunity to *connect* with others in the field - to share challenges and success stories - and to learn from each other. The Association *advocates* for the specialty of I/DD nursing by educating regulators and other healthcare professionals about the importance of nurses with expertise in the specialty and by promoting professional certification among the greater healthcare community. DDNA also works to demonstrate its appreciation for individual I/DD nurses through recognition events that shed light on the dedication and perseverance of our members.

As most realize, the healthcare industry as a whole is facing many challenges and nurses who work with persons with I/DD are being significantly impacted. Nurses in I/DD are facing the results of federal, state and agency funding cuts each day, with increasing caseloads, less-prepared unlicensed support personnel, and the outright elimination of nursing positions across the industry. In an effort to address these issues, DDNA continues to advocate for and promote I/DD nursing through several channels.

The Association maintains membership in the Nursing Organizations Alliance (*the Alliance*), which enables DDNA to promote

the specialty of I/DD nursing among the nursing profession as a whole. Recently, two DDNA Board members attended the Alliance conference and networked with leaders from other nursing organizations across the healthcare spectrum. Last year, DDNA collaborated with the American Academy of Developmental Medicine and Dentistry (AADMD) in a *Healthcare Disparity Initiative*, to issue a position statement on the disparity in healthcare for persons with I/DD. This initiative involved leaders from advocacy groups as well as the healthcare community, and the outcome focused on the importance of nursing involvement and other healthcare services in the care and support of persons with I/DD. Next year, DDNA will present information about the Medication Management initiative at the American Healthcare Association 2011 conference, and will take the opportunity to promote I/DD nursing to this large healthcare association. In 2009, DDNA participated in a training program for regulators at the Centers for Medicaid and Medicare Services (CMS) and provided training on nursing care for persons with I/DD. DDNA has been asked to provide additional training program to CMS regulators in the coming years, and will continue to "carry the message" about the importance of nursing care for persons with I/DD as regulators consider the *structure* of healthcare services going forward.

DDNA recognizes the increasing difficulty our members face when working in this specialty, and the new year will most certainly bring new obstacles and challenges. Rest assured that regardless of the challenge, this Association will continue to advocate for I/DD nurses and to promote the specialty of I/DD nursing at every opportunity!

I wish you all a wonderful holiday season, absolutely full of blessings, and a great start to the New Year!

Best wishes to you all -

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

## Calendar of Upcoming Events



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

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

If you have events you would like to see listed on this calendar, please contact the DDNA office at [mawillis@ddna.org](mailto:mawillis@ddna.org) and we will include them.

# Certification News

DDNA Members,

It's that time of year again when we all have so much to do and so many things to be thankful for. I want to wish everyone the best holiday season and hope that the upcoming year is the best ever for everyone.

I want to say thanks to Upper Management, the other Board members, the Medication Task Force and especially all the members of DDNA for all the work they do in support of the mission of DDNA. We are an organization like no other nursing organization. Our members are the best there are.

We have added new CDDNs and DDCs this year. Congratulations go out to each and every one of you. Thanks for going that extra mile in our profession.

I also want to thank Nyla Adair for her article in the last newsletter about her journey from CAN to LPN, DDC. I am hoping that we can get more LPNs to sit for the exam, because they are so vital to DD nursing.

Certification has been studied every which way, but the overall finding is that certification leads to better work satisfaction. They have also found that relationships with supervisors and managers are better and the quality of care is higher for those supported. There is also evidence to support that those certified are more confident and make fewer errors.

Those of us who are certified should try to encourage co-workers to obtain certification. If all of us could get just one person to take the exam, we could double our numbers in no time. Think about it. How exciting would that be!

We will be offering the Certification Preparation course again this year in Hartford at the conference. Anyone taking the exam can then schedule a time to take the certification test by appointment during the conference, rather than waiting until the last day. "Take the test while you're fresh" will be my motto in Hartford. You can even use your own computer, so you are even more comfortable!

Nursing is changing. Our roles are becoming more visible in the DD field. Strut your stuff. GET CERTIFIED!

Have a wonderful Holiday Season!

Kathleen A. Brown, RN, CDDN  
Certification Chair

*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\$.

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# Medication Administration Task Force

## List of Curricula for Medication Administration Training

*NOTE: The DDNA Medication Management Task Force is not recommending or endorsing any specific curriculum, but provides this list of available curricula for your review. These are just a few examples, among many available curricula, that contain suggested core components.*

### Administering Medications the Right Way Version 3.1.1

By Margaret Casey-Medeiros, RN Copyright 2005 CC&R Healthcare Solutions

[www.medicationsadministration.com/store](http://www.medicationsadministration.com/store)

#### SECTION 1: The Basics of Medication Administration

Module 1: Administering Medications the Right Way

Module 2: Medications and What You Need to Know

#### SECTION 2: The Techniques of Medication Administration

Module 3: How to Observe and Report Information

Module 4: How to Prevent and Control Infection

Module 5: How to Administer Medications

Module 6: How to Handle Special Situations

#### SECTION 3: The Management of Medication Administration

Module 7: Obtaining Medications

Module 8: Documentation, Recording, and Storage

For more information: contact Sharon Oxx, RN, CDDN at [sharon.oxx@state.ma.us](mailto:sharon.oxx@state.ma.us)

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### Ohio Department of Developmental Disabilities Training manuals

*Certification 1 - Prescribed Medications and Health Related Activities*

[www.odmrdd.state.oh.us/health/documents/PrescribedMedicationHandbookandHealthRelatedActivitiesTrainingManual.pdf](http://www.odmrdd.state.oh.us/health/documents/PrescribedMedicationHandbookandHealthRelatedActivitiesTrainingManual.pdf)

*Certification 2 - Administration of Food and Prescribed Medication per Stable Labeled Gastrostomy tube and Stable Labeled Jejunostomy Tube*

<http://dodd.ohio.gov/health/documents/G-JTubeCert2CurricRevAug09.pdf>

*Certification 3 - Subcutaneous insulin Injection by Nursing Delegation*

<http://dodd.ohio.gov/health/documents/Cert3CurriculumAug2009.pdf>

For more information: contact Kathy Biddlestone RN, BSN, CDDN at [Biddlestone.Kathleen@CuyahogaBDD.org](mailto:Biddlestone.Kathleen@CuyahogaBDD.org).

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### College of Direct Support - web-based learning system

[www.collegeofdirectsupport.com](http://www.collegeofdirectsupport.com)

#### 1. An Overview of Direct Support Roles in Medication Support

#### 2. Medication Basics

Kinds of meds

What is a Med error

Doing a med history

Monitoring for side effects

Reducing med errors

#### 3. Working with Medications

Five rights

Reading med labels

What to do/know when confronted with a new med

Proper med storage

Standard precautions

Proper med disposal

#### 4. Administration of Medications and Treatments

Intro to MAR

Med admin prep

Why do a triple check?

Med admin techniques (5 routes)

What to do when person won't take meds

Methods to help persons understand and use meds correctly

#### 5. Follow-up, Communication, and Documentation of Meds

Why are these important?

Types of situations that require documentation, follow-up, communication

Critical components of face-to-face communication and written documentation

Correct MAR documentation

Recognizing/responding to potential abuse, neglect, and exploitation situations related to meds

#### 6. Using Medication References and Resources

Why check a med reference?

Med reference sources

Benefits/limitations of med reference sources

Demo ability to use med reference source

For more information: contact Bill Tapp at [bill@collegeofdirectsupport.com](mailto:bill@collegeofdirectsupport.com)

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### New Jersey Community Services Curriculum Medication Training 5th Edition (2006)

The Elizabeth M. Boggs Center on Developmental Disabilities and the Robert Wood Johnson Medical School

#### Table of Contents

- Medication and Related Issues
- Categories and Effects of Medications
- Obtaining Medications
- Documentation and Storage
- Administering Medications

For more information: contact Robin May MSN, ANP-C, CDDN at [Robin.May@dhs.state.nj.us](mailto:Robin.May@dhs.state.nj.us)

## Supporting the Aging Adult (continued from page 1)

examined the life expectancy of individuals with CP. “Hutton et al. evaluated the effect of motor and cognitive disabilities on survival of 768 people born in England between 1960 and 1990. Survival rates for women and men with CP until age 40 were 82.8% and 82.5% respectively. Nearly 98% without severe cognitive or motor impairments lived to age 35 and beyond. Survival, at age 35, decreased to 62.9% and 59.0% for those people with severe cognitive and motor disabilities, respectively.”<sup>2</sup> Independent ambulation and the ability to eat orally have been noted to be the strongest indicators for longevity.<sup>2</sup>

### Health Concerns of the Aging Adult with CP

For the person with CP, achieving and maintaining the highest possible level of function, health, and capacity for independence are ongoing goals through each stage of life. To accomplish this, much of the focus of daily care is on the prevention and management of secondary conditions, which may include seizures, gastrointestinal problems, visual/auditory impairments, intellectual impairment, learning disabilities, and communication disorders. Obesity may be seen in conjunction with overeating and inactivity; conversely, malnutrition may occur in conjunction with swallowing difficulties (contributing to prolonged and fatiguing mealtimes), dental problems, and potential risk of aspiration. Further, up to 15% of individuals with CP, particularly those with bilateral involvement, have neurogenic bladder contributing to the occurrence of urinary tract infections and incontinence.<sup>10</sup>

Table 1

Type	Occurrence	Area of brain injury	Manifestations
Spastic	70–80% of persons w/ CP	Cortical brain (the outermost layer of the cerebrum)	Too much muscle tone Stiff movements esp. in legs, arms and/or back; scissoring gait and toe-walking often seen
Athetoid (Dyskinetic)	10-20% of persons with CP	Basal ganglia	Slow, uncontrolled body movements varying between spastic and low muscle tone; can be exacerbated by stress and absent during sleep
Ataxic	5-10% of persons with CP	Cerebellum	Poor coordination, balance, and depth perception; may walk with a wide-based gait; possible intention tremors hindering fine motor functions

Through research studies, focused discussion groups and personal accounts of adults with cerebral palsy, musculoskeletal complaints, pain and fatigue have been identified as predominant health concerns.<sup>3,6,7,10</sup> Common musculoskeletal conditions experienced by individuals with CP include degenerative arthritis, joint stiffness, muscle contracture, and scoliosis. Individuals with CP may also be especially predisposed to early development of osteopenia and osteoporosis with increased risk for pathologic fractures due to low calcium intake, decreased exposure to sunlight, immobility, spasticity and the long-term effects of anticonvulsant medications. Further, individuals with CP may begin to notice increased fatigue and decreased endurance as early as their late thirties.<sup>7</sup> A Norwegian study of 406 individuals found that adults with CP had significantly more physical fatigue than the general population. This was noted to be associated with “increasing age, low physical function, no physical activity, general health problems, and low life satisfaction.”<sup>10</sup> Another study reported that individuals with CP consume three to five times more energy during ambulation than individuals without CP.<sup>10</sup>

Pain and fatigue change an individual’s level of activity. Loss of coordination and balance can precipitate more falls for the ambulant individual. The ability to speak takes more effort and the speech becomes more difficult to understand. This can contribute to social isolation and potentially to behavior problems due to frustrating attempts to communicate needs and wants. Therefore, ongoing assessment and management of an individual’s activity tolerance and pain should be an integral part of the plan of care for the adult with CP. In general, pain assessment tools for the typical population can be equally useful for the person with CP and the use of multiple tools may enhance the reliability of the assessment. For the individual with intellectual impairment, a sample of tools that have shown some evidence of reliability and validity include the PAINAD (Pain Assessment in Advanced Dementia),<sup>5</sup> the CNPI (Checklist of Nonverbal Pain Indicators), the NOPPAIN (Non-Communicative Patient’s Pain Assessment Instrument; a nurse assistant administered tool) and the PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate). Along with pain assessment, any mobility and/or transfer equipment should be assessed to assure adequate support for comfort and safety. If pain medication, exercise, or other therapeutic interventions are prescribed, it is also important to assess their effectiveness and assure that the medical treatment plan is reviewed accordingly.

### Promoting Health and Wellness in the Aging Adult with CP

Given the individualized effects of CP, the nursing care management of all individuals with CP must be particularly person-centered and unique. Encouraging active participation of the individual and any significant support person(s) in his/her life is essential to discovering personal needs and desired life outcomes. Teaming with the individual with CP and his/her family and other significant support persons, the I/DD nurse

## Supporting the Aging Adult (continued from page 6)

can serve a pivotal role in supporting effective care coordination with medical practitioners, pharmacists, physical and occupational therapists, speech pathologists, social service providers and others.

Since CP is diagnosed in childhood, pediatricians and pediatric specialists have been the leaders in advancing medical care for people with CP. Hence, many adult medical practitioners lack knowledge about CP and its related secondary conditions. The lack of accessible clinics, financial incentives, and physicians' willingness to accommodate individuals with spasticity or other movement disorders further add to the challenges of adults seeking basic medical care. Rapp and Torres<sup>8</sup> provide an excellent guide for a complete review of systems and physical examination of individuals with CP. Available reprints of this guide (see information in References) may be a useful teaching tool for I/DD nurse advocates when encountering knowledgeable adult medical or dental practitioners.

In a broad sense, preventive health and wellness needs of the aging adult with CP are not unlike those of the typical population. It is important to note, though, that in comparison with the typical population, persons with CP "have a higher mortality from ischemic heart disease, cerebrovascular disease and digestive disorders and appear to be at increased risk of breast and brain cancer. Preventable deaths from drowning (e.g., in swimming pools, hot tubs, and bathtubs) and from motor vehicle crashes involving pedestrians occur more often in persons with CP"<sup>4</sup> than in the typical population. Therefore, regular assessment of cholesterol, LDL, HDL, and triglyceride levels along with mammograms, colonoscopies, osteoporosis screenings, and safety education, should be considered within any preventive health planning with the aging individual with CP. Timely seasonal flu, pneumococcal and tetanus/pertussis

immunizations should also be considered due to the potential for respiratory complications.

People with CP "must maintain higher levels of physical fitness than the [typical] population to counteract declining function from the natural aging process (e.g., decreased endurance and strength) and from changes related to their underlying condition (e.g., decreased mobility, spasticity, pain, contractures)".<sup>10</sup> A regular physical activity plan or program can help to maintain or improve physical capabilities and potentially minimize or decrease the assistance needed for activities of daily living. Collaborating with the individual and his/her support persons, I/DD nurses can assist in arranging a regular physical activity program which may or may not be a part of structured therapy. Making it fun and providing opportunity for group interaction encourages participation. I/DD nurses can also advocate to break down barriers in the community, such as access to fitness centers or instructors who are not comfortable interacting with people with disabilities. There is still a need for more research about how much, how intense, and what type of exercise most benefits people with CP.

Nutrition, dental care and bowel/bladder management are also essential areas to address in promoting health and wellness. Reviewing dietary likes and dislikes and educating about good food options in the context of any gastrointestinal conditions (particularly vomiting due to delayed gastric emptying and constipation), swallowing difficulties, and risks for aspiration can support achieving adequate and healthy nutrition and hydration and bowel management. Promoting a relaxing mealtime environment may ease spasticity and minimize fatigue. If the person receives nutrition via a gastrostomy tube, providing him/her with the opportunity to choose, regardless of cognitive capacity, to participate with others during mealtime

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10. Zaffuto-Sforza, Celeste D. DO (2005) Aging and Cerebral Palsy *Physical Medicine and Rehabilitation Clinics of North America*, 16, 235-249

## Mary Gage Award

DDNA's Board of Directors is now accepting nominations for the Mary Gage Award, with the winner to be announced at the 2011 DDNA Annual Education Conference being held at the Marriott Hartford in Hartford, CT. This award is named in honor of Mary Gage, RN, who resides in New York State. It is through her leadership and perseverance with the support of a task force from the New York State MR/DD Nurses Association that the Developmental Disabilities Nurses Association evolved.

### Selection Criteria

The nominee:

- Has contributed significantly to the field of DD nursing.
- Has persevered in improving the quality of care for persons with I/DD.
- Has demonstrated notable commitment to the DDNA organization.
- Must be an active member of the Developmental Disabilities Nurses Association.

### Nomination Format

To submit a nomination for this prestigious DDNA award, send the nominee's name and mailing address, along with a statement describing how the candidate has satisfied the selection criteria. Please include your name, mailing address, contact telephone number, and your email address, if available.

The nomination may be mailed to: DDNA, PO Box 536489, Orlando, FL 32853-6489 or faxed to 407-426-7440. Nominations may also be emailed through the contact page. Please put "Mary Gage Award Nomination" in the subject line of the email. If you have any questions about the nomination, please call DDNA at 800-888-6733.

### Deadline

Please submit your nomination by March 15, 2011. Nominations received after this date will not be eligible for consideration for the 2011 award.

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## 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-

# News and Information

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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.

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

leave visible bruises on the skin, but they certainly do leave marks on the heart.

When you see someone else - another nurse, a support person, a physician, a family member, another client, a stranger, anyone - bully a person with DD, of course you step up to defend and protect the person. But, are you sometimes a bully? Ahhh . . . that's a harder question, because we all have our "moments" when we may not realize the effect we have on others. Do you roll your eyes when someone else says something? Do you ever mutter comments about someone under your breath? Do you talk negatively about co-workers and/or clients behind their backs? Do you become harsh when you are frustrated? Do you condescend instead of care? Or are you accepting and supportive of differences? Do you rejoice in other people's success? Do you strive to make every person you meet feel happier and most positive about themselves? Is it your goal to put a smile on peoples' faces? As nurses, we model caring to others -even on those tough days. We set the standard. My new year's resolution this year is be as kind as possible in all circumstances and to speak up when I see someone who needs to be protected from unkindness. It is preventative nursing care. If we can stop a bully, we can stop the wounding.

On that note . . . may your holiday season be filled with peace, love, hope and understanding. And may you continue to bring peace, love, hope and understanding to the world! May you receive all the gifts that really matter and may your heart be blessed with your giving.

Mary Alice Willis, MSN RN  
Executive Director

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.

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## *Supporting the Aging Adult* (continued from page 7)

supports social interaction. Promoting a diligent yet patient approach to daily oral hygiene, especially when significant spasticity is present, supports preventive oral health. This is particularly important given the challenge of access to regular dental care and the potential detrimental effects of anticonvulsant medications on the teeth and gums. A bladder management program and adequate physical assistance and/or supports for toileting help to promote continence and prevent urinary tract infections.

Finally, establishing and maintaining a therapeutic, "good listener" relationship with the individual with CP will encourage open and timely communication about any physical or mental health concerns or changes that occur. And....it could make the difference between life or death.

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Do you have comments, questions, best practices, or nursing research ideas to share on this topic? DDNA offers an online discussion forum for its members at [www.ddna.org](http://www.ddna.org); click on "Forums". You are invited to join in a discussion in the "Aging and Cerebral Palsy" forum. Reminder: DDNA members will need to log in with username and password.

Resources for more information:

1. American Association on Cerebral Palsy and Developmental Medicine (AACPDM); [www.aacpdm.org](http://www.aacpdm.org)
2. Cerebral Palsy International Research Foundation - the only Foundation in the US entirely devoted to research for the prevention and treatment of cerebral palsy; [www.cpirf.org](http://www.cpirf.org)
3. United Cerebral Palsy; [www.ucp.org](http://www.ucp.org)

*Grateful appreciation is expressed to Leah Ederer, MD, for reviewing this article. Dr. Ederer is a Family Practitioner who is an advocate and educator concerning the health care needs of people with intellectual and developmental disabilities. She also serves as the Medical Advisor for Special Olympics Wisconsin Health Promotion efforts.*

## Greetings DDNA Members

Now that winter is here. . . I hope you're someplace warm and comfortable as you peruse the newsletter...whether beside a cozy fireplace or at sunny poolside!

## Chapter Update

As 2010 draws to a close, you need to know that DDNA is vibrant and growing! I have received a number of requests for information about starting chapters and am excited that, at the moment, we will be inducting at least three chapters at the Hartford conference on Tuesday, May 17, 2011! If you are thinking about starting a chapter, please contact [admin@ddna.org](mailto:admin@ddna.org) and I'll be happy to connect with you. Remember that chapters can be local (facility or community), regional (part of a state), or statewide. Multiple chapters in one state are encouraged so driving distances are reasonable and members can stay regularly connected. Also, consider linking with chapters in adjacent states and host a conference together or request to become a planning partner with a state that already has regular conferences.

## DDNA Conference - Hartford 2011

May 2011 will be here before you know it! Are you getting ready?? The Board would really like to encourage lots of member involvement in this year's conference. Last time, I shared a few ways you and your chapter or network can do just that. Here's a reminder...

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! Go to [www.ddna.org](http://www.ddna.org), click on "Conference," then scroll down to "Poster Sessions for the 2011 Conference." Talk it over in your Chapter or Network and submit a Poster Presentation Registration form soon!

And then there's the Silent Auction, too! Gather your members who have a creative touch and plan to contribute a small (fits in a suitcase) item or two from your Chapter or Network. How about a small basket with a movie theme?? Or a tea and crackers theme??? Or a book lover's theme??? Single items are terrific too!

## Looking for a Couple of Nurse Leaders

We are seeking candidates to run for election to the DDNA Board of Directors as President Elect and Treasurer so be sure to check out all the elections information provided in this newsletter. It really is true that being a Board member does require

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

## Arizona Chapter

For information, visit the website at [www.ddna.org/chapters/arizona](http://www.ddna.org/chapters/arizona) or contact Sharon Atwood at (623)986-0120 or email: [sharonnurseatwood@yahoo.com](mailto:sharonnurseatwood@yahoo.com).

## Northern California DDNA Network

For NCDDNA 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 (916)552-9228 or email: [elaine.rawes@dhcs.ca.gov](mailto:elaine.rawes@dhcs.ca.gov).

## 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

If anyone has current contact information for this association, please contact [admin@ddna.org](mailto:admin@ddna.org).

## Connecticut DDNA

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

## District of Columbia Chapter

For information, contact Deborah King Harris, RN, MSN/MBA, at (202)527-4658 or email [dharris@projectredirect.org](mailto:dharris@projectredirect.org).

## The Mid-Florida Chapter

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)371-2949 or email [carolyn1621@yahoo.com](mailto:carolyn1621@yahoo.com).

## 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 Chapter

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

a substantial commitment of time and effort, but it is a great opportunity to have an active role in shaping the present and future of DDNA. I/DD nurses are facing some difficult realities, but with constructive ideas and optimism we can continue to build a great organization. We know there are many great I/DD nurse leaders in our Chapters and Networks. Please do think about running for office! Then make sure to get your election application materials in by March 31, 2011.

## Finally.....don't forget to send in your Annual Organizational Report for 2010

The due date is February 1, 2011. You'll be reporting on calendar year January - December 2010.

The new forms are available at [www.ddna.org](http://www.ddna.org), click on "Chapters" or "Networks", then scroll down to "Chapter/Network Annual Reports" and select the correct form (Chapter or Network) to complete.

In this season of giving, thank you for your gifts of time, dedication, and perseverance. Not everyone we serve can say "Thank you!" but a smile that comes from being loved and cared for can sure make it all worthwhile!

Warmest holiday wishes to you and those you love!

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

## Northern Illinois Chapter

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

### Recap of Goals for 2010:

Campaign to Grow Membership-

We want to provide all nurses practicing in the south-central region of Indiana an opportunity to become members. The SIDDNA has been in contact with nurses from many organizations throughout the year and will continue this effort into 2011.

SIDDNA Website Development-

The Southern Indiana Developmental Disabilities Nurses Association website is now up and running. Thank you to volunteer Kendra Martin who designed and set up the website for our organization. [SIDDNA.org](http://SIDDNA.org)

Officer Elections were held in August of this year: Susan Gray, Treasurer, Dave Hopkins, Secretary, Rachel Hodnett, Vice-President, and Kathy Auberry, President

### Meeting Dates for 2011:

February 17, May 19, and August 18, 2011  
All Meetings are held at Christole, Inc. 200 S Hawthorne, Nashville, IN from 10a.-12:30pm

For information contact Donella Miller, at (765)284-4166 or email: [dmiller@hillcroft.org](mailto:dmiller@hillcroft.org).

## Iowa DDNA

For information, contact Rose Magnussen, RN, CRRN at 712-324-5406 or email [rmagnussen@villagenorthwest.org](mailto:rmagnussen@villagenorthwest.org). Please visit the website at [www.iddna.org](http://www.iddna.org)

## Kansas Chapter

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

## Kentucky Network

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

## Louisiana Chapter

For network information, contact Mitzie Daniel, at (318)452-5904 or email: [mitzie.daniel@la.gov](mailto:mitzie.daniel@la.gov).

## Maine Developmental Disabilities Nurses Network

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

## Massachusetts Chapter

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

For more information contact Sherrie Hayter, RN, CDDN by phone at (508)265-6860 or email [Sherrill.Hayter@state.ma.us](mailto:Sherrill.Hayter@state.ma.us).

## 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).

## Minnesota Chapter

The Minnesota Chapter of DDNA started the 2010-2011 Kick-off in September with a dinner presentation from GSK Pharmacies on "Benign Prostatic Hypertrophy." We were all quite interested to learn more ways that we can help our aging male consumers. October brought another excellent presentation on "Dry Mouth" from GSK Pharmacies that allowed our nurses to really understand the propensity and treatment of this common disorder. Several nurses questioned whether a consumer really displayed liquid-seeking behaviors or could it truly be dry mouth syndrome. Many people living in sheltered environments may not be able to ask for liquids or access them freely. Yet another insightful presentation hosted by Geritom Medical.

November always brings a wonderful holiday potluck! Yum! We had over 25 nurses attend, with 2 new members, and need I mention: the food was fabulous! This was a general meeting where each nurse brings up topics of interest or concern. The group offers feedback from our wonderful "think-tank of nurses" and always support.

We are so fortunate to have such a cohesive group of nurses. I am certain 2011 will bring more education and more new faces to our meetings!

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@capstoneservices.net](mailto:wherbers@capstoneservices.net).

## Western Missouri Chapter

For information, email Janet Owings at [janet.owings@dmh.mo.gov](mailto:janet.owings@dmh.mo.gov) or phone (816)889-6298.

## Nebraska DDNA Nurse Network

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

# Chapter/Network News

## Developmental Disabilities Nurses of New Hampshire

For information about the DDNNH, please contact Jennifer Boisvert, RN, MS by email at [jboisvert@resources.com](mailto:jboisvert@resources.com); phone: (603)225-5870 x18; 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).

## Southern New Jersey Chapter

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.

## New Mexico Chapter

On November 12, 2010, New Mexico Developmental Disabilities Nurses Association (NMDDNA) held their annual conference "It's Not Just a Face 2010" at the Roadrunner Food Bank in Albuquerque. Approximately 50 nurses and CMAs attended the conference. The presenters were Vonnie Sachse, former ARCA Family Based Director; Boyad Lewis, ARCA QMRP; Habib Majid, pharmacist from Pharmicare; and Kathy Salazar and Dottie Dooley, foster parents from ARCA's Fam-

ily Based Services. It was a very successful conference. Plans are already underway for next year's conference. NMDDNA is in the process of developing a website and currently has a Facebook site! NMDDNA would like to give a heartfelt thanks to Sue Sterling in the ARCA Foundation Department for all of her help; ARCA for all of their wonderful support in assisting us with providing conference materials; ADDCP (Anna Otero Hatanaka) for the wonderful bagels and water; Continuum of Care for their continuing support of NMDDNA by awarding scholarships to the National DDNA conference; and lastly to the board of directors for NMDDNA for all of their hard work and dedication to ensure that the DD nurses in NM were able to attend a quality conference

For information, contact Lauren S. C. DeCarlo, RN, CDDN, at (505)332-6700 or email: [lstobie@arc-a.org](mailto:lstobie@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.

## Pennsylvania Developmental Disabilities Nurses' Network

For information, contact Kimberly Cahill at (717)835-2277. Email [kimc983@comcast.net](mailto:kimc983@comcast.net)

## Rhode Island DDNA

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

## 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)238-4802; email: [mhendon@orangegrove.org](mailto:mhendon@orangegrove.org)

## 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 (972)732-0188 or [gweiss@rescare.com](mailto:gweiss@rescare.com).

## Southwest Texas Chapter

For information, contact Marcia Bitting, RN, BSN, MPH, at (210)789-7217 or email: [bittingdnm@satx.rr.com](mailto:bittingdnm@satx.rr.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).

## Northern Virginia Chapter

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).

## Wisconsin Chapter

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).

# Save the Date!!



DDNA 19th Annual Education Conference  
Hartford, Connecticut - May 14-17, 2011

# Web Sightings

## Sexuality and People with I/DD and Other Disabilities

The publication “Impact: Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities” affirms and supports sexuality as a part of the lives of individuals with disabilities. Published by the Institute on Community Integration, University of Minnesota, its articles cover topics ranging from sexuality education in the home and school; to personal stories of dating, marriage and parenthood; to legal and ethical issues for staff and agencies providing services for people with disabilities. This Impact issue is available for free online at <http://ici.umn.edu/products/impact/232/232.pdf> or in a text-only version at <http://ici.umn.edu/products/impact/232>. In addition, a free print copy can be requested by calling 612-624-4512 or emailing [icipub@umn.edu](mailto:icipub@umn.edu) at the Institute on Community Integration University of Minnesota.

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## Gastrostomy Tube (G-Tube)

From Nemours: [http://kidshealth.org/parent/system/surgery/g\\_tube.html](http://kidshealth.org/parent/system/surgery/g_tube.html)

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## Cerebral Palsy

Journal of the American Medical Association’s Patient Page on Cerebral Palsy: <http://jama.ama-assn.org/cgi/reprint/304/9/1028>

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## End-of-Life Care

End-of-Life Care for Children With Terminal Illness, from Nemours: [http://kidshealth.org/parent/system/ill/bfs\\_hospice\\_care.html](http://kidshealth.org/parent/system/ill/bfs_hospice_care.html)

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## Life in Motion Spasticity Fact Sheet

[www.life-in-motion.org/downloads/factsheets/LIM\\_spasticity.pdf](http://www.life-in-motion.org/downloads/factsheets/LIM_spasticity.pdf)

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## Medicaid and Managed Care: Key Data, Trends, and Issues

[www.kff.org/medicaid/upload/8046.pdf](http://www.kff.org/medicaid/upload/8046.pdf)

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## What is nonsyndromic holoprosencephaly?

<http://ghr.nlm.nih.gov/condition/nonsyndromic-holoprosencephaly>

## CDC - Hearing Loss, Home - NCBDDD

CDC’s information about hearing loss in children, including facts, screening and diagnosis, types of hearing loss, treatment and intervention services, data and statistics, articles, research and tracking, recommendations and guidelines, free materials, and links to other website.

[www.cdc.gov/ncbddd/hearingloss/index.html](http://www.cdc.gov/ncbddd/hearingloss/index.html)

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## Asperger Syndrome and High Functioning Autism ToolKit

This pdf is an excellent list of resources for Asperger Syndrome. [www.autismspeaks.org/docs/family\\_services\\_docs/AS-HFA\\_Tool\\_Kit.pdf](http://www.autismspeaks.org/docs/family_services_docs/AS-HFA_Tool_Kit.pdf)

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## Brain Facts

Ever need a good definition of parts and function of the brain? This link connects to a glossary of brain facts from the Society for Neuroscience.

<http://web.sfn.org/skins/main/pdf/brainfacts/2008/glossary.pdf>

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## CDC Features

Information for Women with Disabilities About Breast Cancer.

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

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## Cordocentesis

From MayoClinic.com: [www.mayoclinic.com/health/percutaneous-umbilical-blood-sampling/MY00147/METHOD=print](http://www.mayoclinic.com/health/percutaneous-umbilical-blood-sampling/MY00147/METHOD=print)

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## Neural Tube Defects

From the March of Dimes: [www.marchofdimes.com/professionals/14332\\_66227.asp](http://www.marchofdimes.com/professionals/14332_66227.asp)

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## Learning About Cri du Chat

From Genome.gov: [www.genome.gov/19517558](http://www.genome.gov/19517558)

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## Genetic Testing

From Genome.gov: [www.genome.gov/10002335](http://www.genome.gov/10002335)

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Web Sightings continued on page 33

## Autistic Toddlers Prefer to Gaze at Geometric Patterns: Study

When given the choice to gaze at geometric patterns or children dancing and playing, toddlers with autism spent more time looking at the patterns while typically developing toddlers preferred to look at other kids, a new study finds.

The finding could be another clue to helping doctors and parents spot the disorder early, when treatment can be most effective, experts said.

In the study, researchers showed 110 toddlers ages 14 months to 3.5 years old two video screens, each of which was simultaneously playing a one-minute video. One video was of “screensavers” that featured moving geometric shapes and patterns; the other video was of children dancing, jumping, smiling and playing.

About 37 of the children had either been diagnosed with an autism spectrum disorder or were later diagnosed with an autism spectrum disorder; 22 of the children had another developmental delay, while 51 were developing in the usual way.

While children viewed the videos, researchers used an “eye tracker” -- a tiny infrared beam bounced off the lens of the toddlers’ eyes -- to measure where the children focused their gaze.

About 40 percent of children who had been diagnosed with autism or who were later diagnosed with autism spent more than half of the time staring at the geometric patterns, while only one (less than 2 percent) of the typically developing toddlers preferred the geometric patterns.

About 9 percent of children with developmental delays preferred the geometric patterns.

All of the children who showed the strongest preference for the geometric pattern -- that is, they gazed at it more than 69 percent of the time -- had autism, according to the study.

“Only autistic babies looked at the geometric patterns more than 69 percent of the time. No normal babies did at all,” said lead study author Karen Pierce, an assistant professor of neuroscience at University of California, San Diego, and clinical research director at the UCSD Autism Center of Excellence. “It’s pretty clear that showing heightened interest in geometric patterns and repetitive moving objects is a risk factor for autism.”

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

While many children are not diagnosed until after age 3, interest is growing in uncovering the early signs of the disorder so that children can receive treatment sooner, when it may be the most beneficial, said Rebecca Landa, director of the Center for Autism & Related Disorders at Kennedy Krieger Institute.

She said it would be valuable to follow the 60 percent of autistic children who did not show a preference for the geometric patterns at the time of the study, to determine if later on they did, or if they continued to prefer the more social images.

Another question is whether early intervention would cause the autistic children to become more social, she added.

“It’s a really neat study, and the findings make a lot of sense,” Landa said. “Autism is heterogenous. Some with autism are aloof. Others with autism are social, but they are socially unusual in their behavior. There is still a lot more digging that needs to be done to understand the children in the autism spectrum disorder group that didn’t prefer the geometric patterns.”

While there is no one sign that’s a clear indicator of autism, parents may want to pay attention if they notice their toddlers fixated on things like spinning fans for long periods of time, or spinning the wheels of a toy car, or flicking the eyelids of a baby doll, or other repetitive behaviors, Pierce said.

The study also found that autistic children had fewer saccades, or eye movements, while looking at the geometric patterns than the normally developing children did while looking at the social images. “It was as if the patterns had a hypnotic effect,” Pierce said.

On the other hand, when looking at the social images, the autistic kids had more saccades than the normally developing or developmentally delayed toddlers.

The UCSD finding comes on the heels of another study, released Friday by Landa’s team at Kennedy Krieger, that also looked at the early signs of autism. It found that infants at high risk of autism were less likely to spontaneously look at their parents than other infants.

In the study, Landa and her colleagues observed 25 six-month-old babies who had an autistic sibling and 25 infants with no family history of autism.

Infant siblings of children with autism are 25 times more likely to develop autism, according to the study in the September issue of the *Journal of Child Psychology and Psychiatry*.

Both sets of infants were equally likely to look at their parent when the parent tried to get their attention, Landa said.

But the babies at high risk of autism were less likely to look over at their parents when unprompted and spent more time fixated on toys or a joystick used in the experiment.

“This is about social initiation,” Landa said. “The baby siblings of children with autism looked less often and with less duration. It’s something parents should keep an eye on.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103003.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103003.html)

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## Infants May Display Subtle Autism Signs at 6 Months: Study

Scientists report that they may have detected signs of autism in 6-month-old babies, but it's too early to know if the findings could lead to earlier diagnosis of the condition.

Currently, doctors can only diagnose autism in the second year of life or later, Robert T. Schultz, director of the Center for Autism Research at Children's Hospital of Philadelphia, explained in an interview. Earlier diagnosis could make a difference for kids because "generally, the feeling in the field is that the earlier the intervention, the better the child's outcome," said Schultz, who was not involved in the study but is familiar with the findings of the new research.

The researchers studied 25 babies who had siblings with autism, putting them at higher risk for the disorder, and 25 other babies whose families didn't have a history of autism.

The investigators allowed the babies to figure out how to play with a toy while their caregivers sat nearby. The babies at higher risk of autism spent more time fixated on the toy than the other babies and less time looking at their caregivers when the caregivers weren't engaging them.

"This is about social initiation. The baby siblings of children with autism looked less often and with less duration. It's something parents should keep an eye on," said study co-author Rebecca Landa, director of Kennedy Krieger Institute's Center for Autism and Related Disorders.

But the differences between high-risk and lower-risk babies at this age may be too small for parents to notice, said Schultz. He suggested that parents should focus on looking for possible signs of autism in their children after the age of 1 year. Lack of eye contact is one red flag, he noted.

The study, published in the September issue of the *Journal of Child Psychology and Psychiatry*, saw no difference in cause-and-effect learning abilities between the two groups of children.

In another recent study, researchers at the New York State Institute for Basic Research in Developmental Disabilities reported seeing other subtle signs of autism in infants.

When they looked at babies who had spent time in the neonatal intensive care unit, they found that those later diagnosed with an autism spectrum disorder were more likely to have had differences in visual processing and abnormal muscle tone at 1 month of age than the other babies.

That research is published in the September issue of *Pediatrics*.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_102952.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_102952.html)

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## Many HIV-Infected Kids Could Use Cheaper Treatment Safely

For HIV-infected children in the developing world, treatment choices have been limited by concerns over the possible development of resistance to drugs they received as infants during failed attempts to prevent their infection in the first place.

But a new U.S. National Institutes of Health-funded study suggests there may be a way to administer one particularly cheap and practical HIV drug -- nevirapine -- safely and effectively to many of these children.

The finding was detailed by study co-author Louise Kuhn, a professor of epidemiology at the Mailman School of Public Health at Columbia University in New York City, and Dr. Lynne Mofenson, chief of the pediatric, adolescent and maternal AIDS branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, during a recent teleconference.

The study itself will be published in the Sept. 8 issue of the *Journal of the American Medical Association*.

Mofenson noted that globally 430,000 infants become infected with HIV. About 90 percent of these children live in sub-Saharan Africa.

To tackle this immense problem, public health officials often turn to nevirapine. A single dose of the drug given at birth to the newborn of an HIV-infected mother can reduce the risk of HIV transmission by as much as 50 percent, Mofenson explained.

However, those infants who go on to become infected run the risk of developing a nevirapine-resistant strain of virus. And resistance testing, though available, is far too expensive to be considered a practical screening tool in the developing world.

So, about three years ago the World Health Organization recommended that HIV-infected children who had first been given nevirapine not be given the effective and cost-effective treatment again in favor of a costly protease inhibitor cocktail that is difficult to store and transport.

In this latest study, the researchers focused on the treatment of 195 children infected with HIV who were cared for at one hospital in Johannesburg, South Africa, between 2005 and 2009.

For these children, nevirapine at birth had failed to prevent HIV infection.

As a result, each child was placed on a protease inhibitor regimen, which involved three drugs: ritonavir-boosted lopinavir, stavudine and lamivudine. All the children fared well on this cocktail, having maintained a desirably low viral load for a minimum of three months over the course of their first year of treatment.

At the launch of the study, about half the children were randomly switched to a nevirapine treatment: namely, replacing ritonavir with nevirapine in the drug cocktail.

The other children stayed with their standard protease inhibitor regimen. Blood samples were taken at 4, 12, 24, 36 and 52 weeks.

The authors found that children who had fared well (for an average of nine months) under a non-nevirapine protease-inhibitor drug regimen appeared to fare even better once they switched to a nevirapine treatment.

“Those children who changed to nevirapine were actually more likely to maintain the virus below 50 copies per milliliter (ml) in the blood, which is the lowest detectable limit that we use to measure the amount of virus in the blood,” explained Kuhn.

Among the nevirapine group, 66 percent of the children remained below this threshold. For the standard treatment group, just 42 percent achieved that goal.

However, they cautioned that about one in five of the children who switched to nevirapine did not fare well, with viral loads rising beyond 1,000 copies/ml.

Nevertheless, with a majority of children reacting well to the switch, Kuhn and her colleagues suggest the approach could cut costs and improve treatment, so long as viral loads are monitored.

“What this shows is that this is a unique and innovative, but also reasonable, alternative strategy, and it will allow us to treat many more children,” Mofenson said. “Because compared with the protease inhibitors we use now, nevirapine is much less expensive -- about \$55 a year per child compared to about \$280 a year for the PIs.”

“So this will allow us to treat five times as many children for the same price,” she noted. “Which is why this is so critical.”

Kuhn added that nevirapine offers other crucial pluses.

“Our group is very, very encouraged by these results, because the biggest factor in HIV treatment is adherence,” she explained. “The drugs don’t work if you don’t take them. And here the big problem is that it’s very, very difficult for parents to get their children to take what we currently offer them two times a day because they are really horrible, foul-tasting drugs.”

“So if we can move to something like nevirapine - which has a kind of a sweet taste that children don’t really mind so much -- it would be very helpful,” she said.

Dr. Geoffrey A. Weinberg, a pediatric infectious disease expert at Golisano Children’s Hospital at the University of Rochester Medical Center in New York, agreed that a nevirapine treatment option would be helpful.

“The important message is that many children will do better with anti-HIV therapy based on nevirapine,” he said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103037.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103037.html)

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## Brain Scans Could Spot Developmental Problems in Kids

A new study suggests that a quick MRI scan could tell doctors if a child’s brain is maturing properly, potentially providing an early warning sign that mental problems are developing.

Researchers say the strategy could turn an ordinary brain scan into a tool similar to the age-old growth charts that tell pediatricians if kids are growing at an appropriate rate.

“It’s a way to understand individual differences and make predictions about an individual’s neurologic and psychological health,” said study co-author Dr. Bradley L. Schlaggar. “The earlier you can intervene, the more likely it is that you’ll benefit a patient.”

Currently, brain scans don’t play a major role in the treatment of mental illness, said Schlaggar, an associate professor of developmental neurology at Washington University School of Medicine and St. Louis Children’s Hospital.

It’s possible to find a tumor or diagnose a stroke with the help of a brain scan, he said, but the technology almost always fails to reveal any problems in the brain of a person who has a disorder like autism, schizophrenia or epilepsy. “That’s vexing,” he said, “because you know that something is wrong with the brain, but the report is normal.”

In the new study, Schlaggar and colleagues report that they’ve found a way around this challenge. Using MRI technology that detects which areas of the brain are most active based on their usage of oxygen, they scanned 238 volunteers aged 7 to 30. They compiled the results and developed a baseline of what the brains of people should look like as they grow older.

The findings, which are published in the Sept. 10 issue of *Science*, could allow doctors to measure whether a patient’s brain has matured to the level it should have reached based on his or her age, Schlaggar said.

But if a child’s brain isn’t as developed as it should be, can doctors do anything about it? Possibly, said Dr. Paul R. Carney, chief of pediatric neurology at the University of Florida.

If a 7-year-old child has a frontal lobe that looks like that of a 5-year-old, for example, doctors could turn to learning therapies designed to boost that part of the brain, said Carney, who’s familiar with the findings.

“Right now, most learning techniques don’t speak to a specific brain network,” Carney said. “But here, you’d be able to design a therapy and measure the response.”

In other words, the brain scans could both diagnose a problem in the brain and help gauge whether a treatment is working.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103131.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103131.html)

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## More Evidence That Vaccines Don't Cause Autism

Infants exposed to the highest levels of thimerosal, a mercury-laden preservative that used to be found in many vaccines, were no more likely to develop autism than infants exposed to only a little thimerosal, new research finds.

The study offers more reassurance to parents who worry that vaccination raises their children's risk for autism, the researchers said.

"Prenatal and early life exposure to ethylmercury from thimerosal in vaccines or immunoglobulin products does not increase a child's risk of developing autism," concluded senior study author Dr. Frank DeStefano, director of the immunization safety office at the U.S. Centers for Disease Control and Prevention.

The study was released online Sept. 13 in advance of publication in the October print issue of Pediatrics.

Thimerosal has been used as a preservative in vaccines since the 1930s, according to background information in the article.

Concerns about the chemical began to crop up in 1999, when the U.S. Food and Drug Administration said that because of the increased number of thimerosal-containing vaccines added to the infant vaccination schedule, infants may be exposed to too much mercury. Thimerosal used to be found in hepatitis B, Hib (Haemophilus influenzae type B) and DTP (diphtheria, tetanus, pertussis) vaccines, among others.

During the ensuing years, the FDA worked with manufacturers to eliminate thimerosal from vaccines, according to the agency's Web site. Today, thimerosal has been removed or reduced to trace amounts in all vaccines routinely recommended for children 6 years of age and younger, with the exception of inactivated seasonal flu vaccine, according to the FDA. Parents who are concerned about thimerosal can ask for a preservative-free version, DeStefano said.

And thimerosal wasn't the only proposed autism-vaccine link. A 1998 paper in The Lancet suggested the MMR (measles-mumps-rubella) vaccine might trigger autism. The journal later retracted the paper, and numerous studies have refuted any link between the MMR vaccine and autism.

In February of 2009, a U.S. federal court ruled that there was no scientific evidence linking vaccines to autism.

In the new study, researchers examined medical records and conducted interviews with the mothers of 256 children with an autism spectrum disorder and 752 children matched by birth year who did not have autism. The children were all members of three health care management organizations in California and Massachusetts.

Researchers also gathered information about the manufacture and lot number of the vaccines that the children received, to determine how much thimerosal they were likely exposed to.

Children in the highest 10 percent of thimerosal exposure, either prenatally or between infancy and 20 months, were no more likely to have autism, an autism spectrum disorder or autism spectrum disorder with regression than children in the lowest 10 percent of exposure.

"This study adds to a large body of evidence indicating that early thimerosal exposure through vaccination does not cause autism," said Geraldine Dawson, chief science officer for a leading advocacy group, Autism Speaks. Dawson was not involved with the research.

She urged parents to have their children vaccinated.

"We encourage parents to have their children vaccinated and to establish a trusting relationship with their child's pediatrician so they can discuss any concerns they have," Dawson said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103233.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103233.html)

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## Research Sheds Light on Why Autism Is More Prevalent in Boys

A new study is helping unravel an enduring mystery surrounding autism: Why boys are much more likely to be affected by the disorder than girls.

An international team led by Dr. John Vincent, of the Centre for Addiction and Mental Health in Toronto, examined specific genes in almost 3,000 people with an autism spectrum disorder (ASD) and 246 others with intellectual disability. They then compared that data to genes from more than 10,000 control individuals.

Reporting in the Sept. 15 issue of Science Translational Medicine, the team found that mutations in the PTCHD1 ("patched") gene are linked to inherited forms of autism and intellectual disability in about 1 percent of affected people in the study. It was not found in any of the controls, however.

"Our data indicate that mutations at the PTCHD1 locus are ... strongly associated with ASD," the researchers concluded.

They also noted that this gene is typically located on the single X-chromosome in males.

The study "provides further clues as to why ASD affects four times more males than females," said Andy Shih, vice president for scientific affairs at Autism Speaks. "PTCHD1 is part of a neurobiological pathway that determines the development of human embryos. It is one of several genes recently implicated in both ASD and intellectual disabilities."

The finding adds a little more clarity to the murky origins of autism, Shih said.

While each new genetic discovery "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,” he said. “Identification of a male-linked genetic mutation begins to address the previously unknown basis for often reported skewed male-to-female ratio in autism.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103340.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103340.html)

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## Autistic Children Don't Seem to Yawn 'Contagiously'

Children with an autism spectrum disorder tend not to yawn “contagiously” -- that is, yawn in response to seeing others yawn, a new study suggests.

Yawning is a type of “emotional contagion,” an unconscious response that reflects a recognition of how others are feeling. And unconsciously mimicking the behavior of parents and others is an important step in a child’s social and emotional development, said study lead author Molly Helt, a doctoral candidate at the University of Connecticut.

Autistic children’s lack of imitation puts them at a disadvantage when it comes to learning empathy and other social skills, Helt said. For example, prior research has shown that when people see others smile, they subtly smile as well. The movement of the facial muscles kicks a feedback mechanism into gear, lifting mood.

“‘Emotional contagion’ means I get to experience a little bit of the emotion you experience,” Helt said. “That gives rise to intuition, empathy and good social skills. The fact that autistic children are not yawning is a signal those basic social bonds that are forming in infants and children are not forming in children with autism.”

The study is published in the September/October issue of the journal *Child Development*.

In one experiment, researchers observed 120 typically developing children ages 1 to 6 years while they listened to a 12-minute story read aloud. The storyteller yawned four times during the reading.

Children began “contagious yawning,” or yawning within 90 seconds of seeing the storyteller yawn, at about age 4. About 35 percent of 4-year-olds and 40 percent of 5- and 6-year-olds yawned in response to seeing the storyteller yawn; none of the 1-year-olds, 5 percent of 2-year-olds and 10 percent of 3-year-olds yawned.

In a second experiment, the researchers observed 28 children ages 6 to 15 with an autism spectrum disorder and 63 children without autism who were matched for age or mental development. Again, the storyteller yawned four times.

Only about 11 percent of children with an autism spectrum disorder yawned after the storyteller yawned, compared to 43

percent of typically developing children.

Among children with autistic disorder, a more severe form of the syndrome, none yawned contagiously, while about 23 percent of kids with pervasive developmental disorder -- a milder form of autism -- yawned.

“Typical infants seem to be growing more emotionally attuned with others as they age, with the age of 4 being critical for that,” Helt said. “Kids with autism don’t seem to be becoming more and more emotionally attuned with others as they age.”

The study doesn’t prove that a lack of “contagious yawning” is a sure sign of a developmental problem.

Helt also noted that it’s possible that the autistic children weren’t paying attention to others around them, or they noticed the yawns and other facial expressions but didn’t know how to interpret them.

Geraldine Dawson is chief science officer for Autism Speaks, an advocacy group dedicated to funding research into the causes, prevention, treatment and a cure for autism. She said: “It is well known that children with autism are less likely to imitate other people. This study suggests that this difficulty in imitation extends to very basic behaviors, such as yawning.”

Intervention programs that target “imitation skills” can be very effective in helping children with autism in their social development, she added.

In a second study in the same issue of the journal, researchers from the Institute of Education in London found that thinking and perception skills of children with autism spectrum disorders can vary substantially among individual children and can improve over time.

The researchers assessed the abilities of 37 children with autism spectrum disorder and 31 typically developing children at ages 5 to 6 years and again three years later. The study found that not all children had the same level of weakness in each area, and after three years, many showed marked improvement.

Most children were better able to understand others’ thoughts and feelings, and had an improved ability to regulate and control their behavior.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103339.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103339.html)

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## Abnormalities in Brain Histamine may be Key Factor in Tourette Syndrome

Since the first case description in the 19th century, the causes of Tourette syndrome have been a mystery. Now researchers have identified a rare gene mutation responsible for the disorder in one family. The gene is needed for producing histamine, a small molecule with many roles in the body, including signaling in the brain.

“This finding gives us an important glimpse at the molecular pathways that could be involved in Tourette syndrome generally,” said Laura Mamounas, Ph.D., a program director at NIH’s National Institute of Neurological Disorders and Stroke (NINDS), which contributed major funding for the work. Other funding for the study came from the National Institute of Mental Health (NIMH) and several private foundations.

The study was published in the *New England Journal of Medicine* and led by Matthew State, M.D., Ph.D., an associate professor in the Child Study Center and in the departments of psychiatry and genetics at Yale University in New Haven, Conn. and co-director of the Yale Program on Neurogenetics.

Tourette syndrome is characterized by tics, which are involuntary movements (such as shoulder shrugs or head jerks) and vocalizations (such as throat-clearing, grunting, or outbursts of profanity) that happen in rapid succession. More than 50 percent of people with Tourette syndrome also have attention deficit hyperactivity disorder (ADHD) or obsessive compulsive disorder (OCD). Meanwhile, Tourette syndrome and other tic disorders are sometimes observed in children with autism.

Tourette syndrome clearly has a strong genetic component, but in most families, the inheritance patterns tend to be complicated, which has made it difficult to link specific genes to the disorder, said Dr. State.

The new study focuses on a family referred to Dr. State by the Tourette Syndrome Association. The father has Tourette and OCD, all eight children have Tourette, and two also have OCD. Dr. State and his team found that all of the affected family members share a mutation in the HDC gene, which encodes an enzyme needed to produce histamine. The mutation reduces the activity of the enzyme.

In the general population, mutations in this gene are very rare and probably contribute to very few cases of Tourette syndrome. The researchers did not find the family’s mutation in DNA from more than 700 other individuals with Tourette syndrome, or in DNA from nearly 2000 individuals free of any known neurological disorders. The team also failed to find any copy number variants (CNVs) - meaning deletions or duplications - of the HDC gene in 840 individuals with Tourette syndrome or 10,000 other individuals.

The true value of the gene discovery lies in its potential to reveal how brain function is altered in Tourette syndrome, said Dr. Mamounas. She likened it to the discovery that mutations in the alpha-synuclein gene can cause Parkinson’s disease. Such mutations are very rare, but they have helped researchers understand how nerve cells die in Parkinson’s.

Although histamine helps promote immune responses, Dr. State theorizes that Tourette syndrome is tied to histamine’s function in the brain. Mice that lack the HDC gene are prone to repetitive behaviors that resemble tics, but the mice improve when they are given drugs that act on histamine receptors

found only in the brain. There are also interactions between histamine and dopamine, a common target of drugs that are used to reduce tics in Tourette patients.

“The deeper you go into the literature, the more it seems that we should have been thinking of histamine as a potential player in Tourette syndrome all along,” Dr. State said.

The family continues to be involved in research to explore histamine’s role in Tourette. The father, mother and adult children are undergoing brain imaging tests to determine if they have detectable changes in histamine or dopamine neurotransmission. Dr. State is also recreating the family’s HDC mutation in mice to see if that leads to an improved mouse model of Tourette syndrome.

Meanwhile, genetic research on Tourette is moving ahead on other fronts. Dr. State reported several years ago that mutations in the SLITRK1 gene are associated with Tourette syndrome in a small fraction of cases. He is continuing to investigate how strong that association is, and how the gene fits into the disorder. A recent NIH-funded study in *Nature Medicine* shows that in mice, deletion of a related gene called SLITRK5 leads to OCD-like behaviors.

Finally, in a study published in *Neurology*, researchers at Wayne State University in Detroit conducted a genome-wide search for CNVs in 111 Tourette patients and 73 unaffected individuals. This analysis revealed five genomic regions of interest, including a gene previously associated with autism. The results were not statistically significant, but they raise “thought-provoking questions about the relationship between Tourette syndrome and other neurodevelopmental conditions,” according to an editorial in *Neurology*. The study was funded by an NIH Clinical and Translational Science Award (CTSA), and utilized DNA samples from the NINDS Human Genetics DNA and Cell Line Repository.

Source: [www.ninds.nih.gov/news\\_and\\_events/news\\_articles/Abnormalities%20in%20Brain%20Histamine%20may%20be%20Key%20Factor%20in%20Tourette%20Syndrome.htm](http://www.ninds.nih.gov/news_and_events/news_articles/Abnormalities%20in%20Brain%20Histamine%20may%20be%20Key%20Factor%20in%20Tourette%20Syndrome.htm)

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## Scientists Find Possible Molecular Triggers for Sudden Unexplained Death in Epilepsy

In the brains and hearts of animal models, neuroscientists have uncovered new clues about molecular triggers for sudden unexplained death in epilepsy, or SUDEP. Evidence from two studies linked SUDEP to faulty ion channels, protein gateways essential for transmitting electrical signals. The discoveries could help medical researchers predict or find ways to reduce the risk of death in epilepsy, according to Jeffrey L. Noebels, M.D., Ph.D., the senior investigator on both studies. Dr. Noebels is professor of neurology, neuroscience, and molecular and human genetics at Baylor College of Medicine in Houston, Texas, where the research took place.

Most people with epilepsy have a normal lifespan, but for poorly understood reasons the seizure disorder is associated with a higher incidence of unexplained death, classified as SUDEP. Studies indicate that SUDEP accounts for between 2 to 18 percent of deaths in individuals with idiopathic epilepsy (epilepsy with an unknown cause) and that it appears to occur more frequently in younger patients with treatment-resistant forms of the disorder. Although researchers have long suspected a connection between SUDEP and underlying cardiac or respiratory problems, the recent research is among the first to pinpoint several key biological mechanisms.

In a study published in April 2010, Baylor investigators led by Edward Glasscock, Ph.D., examined mice bred to lack a gene for Kv1.1 ion channels. Previous research showed that such mice have severe epilepsy and often die very young.

Dr. Glasscock and colleagues recorded electrical signals in the brains and hearts of the mutant mice. They observed that when the mice had epileptic seizures their heartbeats became erratic. In some cases this led to death by cardiac arrest. The investigators determined that defective ion channels were present in the vagus nerve, which runs from the brainstem to the heart and regulates cardiac rhythms.

“In mice without Kv1.1 channels, we think the vagus nerve loses control and sends extra nerve impulses to the heart, telling it to slow down – and even stop beating – when it shouldn’t,” Dr. Glasscock said.

This was the second gene that scientists in Dr. Noebel’s laboratory have implicated in SUDEP. In a study published in October 2009, investigators led by Baylor’s Alica M. Goldman, M.D., Ph.D., examined a gene mutation associated with Long QT syndrome (LQTS). According to Dr. Goldman, this syndrome is marked by irregular heartbeats (cardiac arrhythmias), frequent fainting spells and a higher risk of sudden death. Some research suggests that the fainting spells are actually epileptic seizures. Mutations in the gene for the KvLQT1 ion channel are the most common cause of LQTS.

Dr. Goldman’s team observed that mice bred with this genetic mutation had both life-threatening heart rhythm irregularities and frequent epileptic seizures. Previously it was thought that the gene affected only heart cells; however, this study showed for the first time that the flawed KvLQT1 ion channels were also present in neurons. According to Dr. Noebel’s study demonstrated the long-sought molecular link between heart and brain in epilepsy.

Dr. Goldman said this important evidence suggests that one way to reduce the risk of SUDEP in people with idiopathic epilepsy is to check for heart rhythm irregularities. This can be done through a test called an electrocardiogram (ECG, or EKG). Until very recently, she explained, people with seizure disorders did not routinely receive ECG tests because there was no firm evidence of a relationship between LQTS and epilepsy. Dr. Goldman is now screening epilepsy patients to determine whether they have the same

gene mutations associated with seizures and sudden death as those seen in the mice in the study.

Both teams of investigators at Baylor were supported in part by grants from the National Institute of Neurological Disorders and Stroke (NINDS).

“The identification of these genetic and molecular triggers associated with SUDEP represents a major step forward,” said Brandy Fureman, Ph.D., an NINDS neuroscientist and a program director for epilepsy research. “Future studies can build on these insights to broaden our understanding of other genes and risk factors involved, and guide efforts to translate research into therapeutic interventions to safeguard patients who are at risk,” she said.

Source: [www.ninds.nih.gov/news\\_and\\_events/news\\_articles/Epilepsy\\_Genes\\_and\\_SUDEP.htm](http://www.ninds.nih.gov/news_and_events/news_articles/Epilepsy_Genes_and_SUDEP.htm)

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## C-section, induced labor more common with epilepsy

Pregnant women with epilepsy, particularly those on anti-seizure medications, may have higher rates of cesarean section and heavy bleeding after delivery than other women, a new study finds.

The increased odds are small, researchers stress, and in general, women with epilepsy have a low rate of complications during labor and delivery. Nor should pregnant women on anti-epilepsy drugs interpret the findings as an indication they should stop their medication.

But the findings, reported in the obstetrics journal BJOG, add to evidence that women with epilepsy tend to have more pregnancy-related problems than women without the disorder.

It’s estimated that more than 90 percent of pregnant women with epilepsy deliver a healthy baby, according to the Epilepsy Foundation of America.

However, these women do generally have higher risks of certain pregnancy complications, like vaginal bleeding, anemia, preterm birth and preeclampsia -- a disorder marked by high blood pressure and protein buildup in the urine, due to stress on the kidneys.

Studies have come to conflicting conclusions as to whether women with epilepsy have higher risks of complications related to labor and delivery -- such as a greater need for labor induction, instrument-assisted delivery or C-section, or a higher risk of heavy bleeding.

But many of those studies have been relatively small and hospital-based (rather than using data from women in the general population).

So for the new study, researchers used Norway’s national birth registry to analyze information on more than 365,000 women who gave birth between 1999 and 2005. A total of 2,805 of those women, or 0.8 percent, had epilepsy or a history of it.

Overall, the data showed that “the majority of women with epilepsy have a low risk of complications during labor and delivery, and can deliver vaginally,” lead researcher Dr. Ingrid Borthen, of the University of Bergen in Norway, told Reuters Health in an email.

Still, they did have increased risks of C-section, particularly planned ones. And women on anti-epilepsy drugs had higher rates of requiring labor induction and heavy bleeding after giving birth.

Among women without epilepsy, 13 percent had their labor induced, versus 19.5 percent of women on anti-epilepsy drugs. The rate among women not on an anti-epilepsy drug was 14 percent -- which was not statistically different from women without epilepsy.

When it came to C-section, 14 percent of women without epilepsy had the procedure -- either planned or unplanned -- versus 18 percent of women with epilepsy who were not on anti-epilepsy drugs, and 21 percent of those who were on the drugs.

Epilepsy was particularly linked to a higher risk of planned C-section, compared with women without the disorder. The odds were 50 percent greater for women not on anti-epilepsy drugs, and 90 percent greater for women on the drugs when other factors -- like the woman’s age and childbirth history -- were taken into account.

Heavy bleeding after birth, meanwhile, was also more common among women on anti-epilepsy drugs -- affecting 19 percent, compared with just under 14 percent of women without epilepsy.

In the case of such postpartum bleeding, the epilepsy medications may be a cause, according to the researchers.

Anti-epilepsy drugs, they note, are associated with vaginal bleeding during pregnancy, possibly related to their propensity for causing folate deficiency or their effects on vitamin K, which is involved in blood clotting.

It is not clear, though, why women on anti-epilepsy drugs had particularly elevated rates of labor induction and C-section, according to Borthen. It could be related to the fact that women who stayed on anti-epilepsy drugs during pregnancy likely had more-severe epilepsy than women who were not on the medications.

Epilepsy itself is not an indication for labor induction, Borthen said, and the increased rate was not explained by relatively higher rates of pregnancy complications among women with epilepsy. Similarly, such complications did not explain the increased C-section rates among both women on anti-epilepsy drugs and those not on the drugs.

It’s possible, according to Borthen, that women with poorer seizure control during pregnancy were more likely to have a labor induction or C-section. But the researchers lacked the information to study that question.

The findings build on recent evidence that women with epilepsy may, in fact, have somewhat higher risks of C-section and labor induction, according to Dr. Page B. Pennell of Brigham & Women’s Hospital and Harvard Medical School in Boston, who was not involved in the study.

Now the question for researchers is why, said Pennell, who is also chair of the professional advisory board for the Epilepsy Foundation.

One possibility, she told Reuters Health in an interview, is that obstetricians are more likely to plan an induction or C-section for a woman with epilepsy, particularly a woman with more-severe epilepsy. They might, for example, worry that these women will have seizures during spontaneous labor and delivery -- even though, research suggests, this happens to less than 2 percent of women.

The bottom line for women with epilepsy, according to Pennell, is that the excess risks of labor induction, C-section and heavy bleeding after birth appear relatively small.

And for women on anti-epilepsy drugs, she said, “this should in no way be taken to mean that they should stop taking their medication.”

It is not clear how well the current findings can be extrapolated to countries other than Norway, as obstetric practices can vary widely from nation to nation.

Norway, Borthen noted, has a fairly low C-section rate, as exemplified by the 14 percent rate among women without epilepsy. In the U.S., by contrast, about one-third of all deliveries are done C-section.

The generally low rate in Norway, according to Borthen, made it easier for this study to demonstrate a difference associated with epilepsy.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103626.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103626.html)

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## Injections May Relieve Drooling in Nerve-Damaged Kids

Botulinum toxin injections may temporarily relieve drooling in children with certain neurological conditions, a new European study has found.

Depending on its severity, drooling can lead to stigmatization and social neglect, numerous daily clothing changes, skin irritation around the mouth, aspiration pneumonia and dehydration, Dr. Arthur Scheffer of Radboud University Medical Center in Nijmegen, the Netherlands, and colleagues noted in a news release about their study.

In the study, Scheffer’s team gave botulinum toxin injections to 131 children, average age 10.9 years, with cerebral palsy or other non-progressive neurological conditions, as well as moderate to severe drooling. The injections were confined

to the submandibular glands, which are responsible for 70 percent of saliva production while a person is resting.

Two months after the injections, the average drooling quotient had fallen to 15.5 (on a scale of zero to 100) from 28.8 at the start of the study. And, the study authors noted, 61 patients achieved a 50 percent reduction in drooling.

At the eight-month follow-up, the average drooling quotient was 18.7, according to the report in the September issue of the journal *Archives of Otolaryngology -- Head & Neck Surgery*.

The findings “indicate that most patients who initially respond well to injection can expect an effect to last between 19 and 33 weeks. Although the 46.6 percent success rate might appear low, its safety and efficacy make botulinum toxin a useful first-line invasive treatment if conservative measures have failed,” the researchers concluded in the news release from the journal’s publisher.

Botulinum toxin injections have been used safely for years, according to the American Academy of Pediatrics. Side effects can include rash, whole-body muscle soreness, difficulty swallowing and weakness in the injected muscles, but they usually go away quickly, the AAP notes.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103601.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103601.html)

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## Gene Disorder Linked to ADHD

Many who suffer from attention-deficit hyperactivity disorder (ADHD) appear to have a genetic abnormality that may predispose them to the condition, British researchers report.

Their finding bolsters the belief that ADHD is not solely a social problem but can have origins in an individual’s biology. ADHD affects 3 percent to 5 percent of children in the United States, according to the U.S. National Institute of Mental Health.

“ADHD is a complex disorder, and we have known for quite some time that it has a strong genetic composition,” said lead researcher Nigel Williams, a senior lecturer in the department of psychological medicine and neurology at the Cardiff University School of Medicine in England.

“This is directly supported by our results, which provide direct evidence that ADHD is a neurodevelopmental disorder,” he said.

The report is published online Sept. 30 in *The Lancet*.

For the study, Williams’ team analyzed DNA from 366 children with ADHD, comparing it with the DNA from 1,047 children without the condition.

Children with ADHD were more likely to have missing or duplicated segments of DNA -- called copy number variations (CNVs) -- than were children without ADHD, the researchers found. This type of genetic variation is more common in those with brain disorders, they noted.

In addition, they reported finding significant overlap between these CNVs and CNVs associated with autism and schizophrenia. Though they are separate conditions, there’s some overlap between ADHD and autism in terms of symptoms and learning problems, so the two conditions might share a biological basis, the researchers suggested.

The most striking overlap, they said, was found on a region of chromosome 16 that has been linked to schizophrenia and other major psychiatric disorders and includes a gene that plays a role in the development of the brain.

Children with ADHD tend to be restless, impulsive and easily distracted, often leading to serious problems at home and at school. Some have blamed the condition on such things as bad parenting and high-sugar diets.

However, others have cited evidence that ADHD may be partly genetic. Children of someone with ADHD have been shown to be more likely to have the condition. Other research has reported that, with identical twins, if one twin has ADHD, the other has a 75 percent chance of having the condition.

Though no cure exists for ADHD, symptoms usually can be managed with medications and behavioral interventions, according to Williams’ team.

Michael L. Cuccaro, an associate professor in the department of human genetics at the Hussman Institute for Human Genomics at the University of Miami Miller School of Medicine, said he was not surprised by the finding. “We are moving in a direction where CNVs are playing a role in a number of different neurobehavioral conditions,” Cuccaro said.

CNVs are important in disrupting pathways that could cause mental problems, he explained. “A CNV in the same location could give rise to any number of different conditions,” he said.

Cuccaro said he doesn’t think a given CNV is specific to ADHD but rather that the effects of a CNV are more likely to result in ADHD plus intellectual disability. “A lot of things can go wrong when you have a CNV,” he said.

And, he said, knowing the genetic landscape that can predispose someone to ADHD or another developmental condition could eventually become useful in diagnosing the conditions.

Knowing the genetics involved in ADHD also might lead to new treatments, as well as making current treatments more effective, Cuccaro said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_103859.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_103859.html)

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## Danish Study Suggests Jaundice-Autism Link

Newborn babies who have jaundice may be at higher risk of developing autism later on, new research suggests, but other experts said far more research needs to be done before a cause-and-effect relationship is proven.

Researchers in Denmark analyzed information from national registries that included all Danish children born between 1994 and 2004, nearly 734,000 children.

Babies who developed serious jaundice in the days after birth were 67 percent more likely to be diagnosed with autism later on. Babies with jaundice were also more likely to develop other types of “psychological development” delays, according to the study.

When the statistics were broken down further, the researchers found the heightened autism risk only among jaundiced children born in the fall and winter (between October and March) or whose mothers had given birth before. Those children had a two to three times greater chance of developing autism.

“It’s an interesting finding that should be followed up with more mechanistic studies,” said Alycia Halladay, director of research for environmental sciences at Autism Speaks. Halladay was not involved with the study.

There was no apparent association between jaundice and autism in first-born children or those born in the spring and summer (between April and September), according to the study, which was published online Oct. 11 in *Pediatrics* and will appear in the November print issue of the journal.

The study authors said they compensated for factors such as birth weight that could affect jaundice risk. Preterm infants are at higher risk of jaundice.

Jaundice is the most common condition in newborns requiring medical attention or readmission to the hospital, according to background information in the study.

It occurs when bilirubin, a byproduct of the breakdown of red blood cells, builds up, giving the skin and whites of the eyes a yellowish tinge. Bilirubin is typically taken care of by the liver and excreted as bile through the intestines.

But in many babies, the bilirubin can’t be broken down fast enough, often because their livers are still maturing.

Previous research about a link between jaundice and autism has been inconclusive, Halladay said. A 2005 study involving California children found no evidence of a connection between jaundice and autism. But, more recent studies in Sweden and Denmark did find an association -- but no proof of cause-and-effect -- between jaundice and autism spectrum disorders.

Autism is a developmental disorder that causes problems with social and communication skills and can lead to repetitive or restrictive behaviors. Because the condition has a wide range of symptoms and degrees of severity, autism is now called autism spectrum disorders. About one in 110 children in the United States has the disorder, according to the U.S. Centers for Disease Control and Prevention.

Experts stress that there is likely no one single cause of autism, but multiple genetic and environmental factors may contribute to the disorder.

No one knows exactly why jaundice might have a role in

autism, said Dr. Gary Goldstein, a professor of pediatrics and neurology at Johns Hopkins University and president and CEO of the Kennedy Krieger Institute in Baltimore.

“Bilirubin is a neurotoxin that can impact the speech, language and hearing pathways of the brain,” he said. “So you can imagine why, if someone was genetically prone to autism, it could be a trigger.”

While the new study is “intriguing,” it has limitations, Goldstein said. The study authors did not confirm that the children had autism either by looking at their medical charts or doing actual exams. Nor did the researchers have measurements of bilirubin levels in the blood, so there’s no way of knowing if the more severe the jaundice, the greater the chances of autism. In addition, it’s unknown how and if the infants were treated for jaundice or how that might affect autism risk, he said.

If your baby appears to be jaundiced, notify your pediatrician. Sunlight helps in the breakdown of bilirubin, Halladay said, so doctors may prescribe light therapy for mild to moderate jaundice. And though most jaundice clears up fairly easily, there can be more serious causes and consequences of severe jaundice, she said.

In related news, a study in the November issue of *The American Journal of Psychiatry* suggests that the brothers and sisters of children with autism may be more prone to subtle neurological delays or other problems than had been previously suspected.

The research, based on data from almost 3,000 children tracked by the Interactive Autism Network, found that about one in five siblings who were thought to be unaffected by autism-type characteristics actually experience language delays or speech problems early in life. The study also suggests that the preponderance of autism traits in boys rather than girls may not be as pronounced as experts have believed.

“Many siblings of children on the spectrum have significant, subclinical traits of autism but, for whatever reason, they never actually develop the disorder,” study author Dr. John N. Constantino, of Washington University School of Medicine in St. Louis, said in a university news release.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_104242.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_104242.html)

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## Low Vitality Score at Birth Associated with Cerebral Palsy Risk

A low vitality score at birth is strongly associated with a later diagnosis of cerebral palsy, a disorder involving muscle impairment and body movement that appears during the first few years of life, a new study indicates.

The Apgar score (zero to 10) is based on five vitality-related criteria -- complexion, pulse rate, reaction when stimulated, muscle tone, and breathing. An Apgar score of 3 or less is

regarded as critically low, 4 to 6 is fairly low, and 7 to 10 is generally normal.

For this study, researchers examined data from 543,064 Norwegian children born between 1986 and 1995. Of those children, 988 (1.8 in 1,000) were diagnosed with cerebral palsy before they were 5 years old. (In Western countries, cerebral palsy generally affects two to three children out of every 1,000 born.)

The researchers found that children with an Apgar score of less than 3 at birth had a 100-fold higher incidence of cerebral palsy than those with a score of 10. The association between a low Apgar score and cerebral palsy was high in children with normal birth weight and modest in children with low birth weight.

“Despite the strong association of low Apgar score with cerebral palsy, it is encouraging that almost 90 percent of children with an Apgar score of less than 4 did not develop cerebral palsy,” the researchers wrote.

They said their findings suggest that the causes of cerebral palsy are closely associated with factors that reduce infant vitality, they concluded. They suggested that a low Apgar score may sometimes indicate brain impairment that occurred during pregnancy or delivery.

In an accompanying editorial, professor Nigel Paneth of Michigan State University said that although most babies with a low Apgar score recover and do well, infants with a low score “should be watched closely for the persistence or development of brain damage, especially in the light of robust evidence that babies with brain injury may benefit from head or body cooling.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_104193.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_104193.html)

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## Siblings of Autistic Children May Also Have Subtle Traits

As many as one in five siblings of children with autism may have subtler problems with language and speech, according to new research involving nearly 3,000 children.

What isn't yet clear is if these problems indicate a milder form of an autism spectrum disorder, or exactly what type of intervention, if any, might be needed to help these youngsters.

“Smaller studies have reported that in families with children with autism, many children who don't have an autism diagnosis have had a language delay,” said the study's lead author, Dr. John Constantino, professor of psychiatry and pediatrics at the Washington University School of Medicine in St. Louis, Mo. “When we looked at this huge sample, we saw the same thing -- about 20 percent of children presumed to be non-autistic had language delays and autistic qualities in their speech. In

the general population, the prevalence of these traits is only about 7 percent,” he said.

Results of the study were published in the November issue of the *American Journal of Psychiatry*.

Although many siblings of children with autism are completely unaffected by the disorder, the disorder is far more likely to strike the brother or sister of someone with autism than someone without an affected sibling. In fact, the risk of a sibling of someone with autism having the disorder is 22-fold higher, according to background information in the article.

What the current study sought to further tease out was whether or not certain autistic traits -- conditions that might not trigger a diagnosis of autism, but nonetheless could still cause problems -- might be more prevalent in siblings of children with an autism diagnosis.

The researchers used data from an American, Internet-based family register compiled by the Interactive Autism Network, which includes more than 35,000 participants. In addition to providing information about the children in their families who had been diagnosed with autism, some parents also completed a Social Responsiveness Scale questionnaire on each of the children living in their home between the ages of 4 and 18 years old.

A total of 1,235 families, including almost 3,000 children, provided all of the information necessary for the current study.

The study found that 10.9 percent of families had more than one child with an autism diagnosis, and an additional 20 percent had children who weren't diagnosed with autism, but who had language delays. Half of the group with language delays also had autistic qualities in their speech patterns.

The study also found that girls were more likely to have these subtle traits of potential autism spectrum disorder. They suggest that if these were taken into account, the current notion that there is a wide preponderance of boys versus girls diagnosed with an autism spectrum disorder might narrow to as low as three boys for every two girls affected.

This study's findings also provide further evidence that autism spectrum disorders have, at least in part, a genetic basis, according to Constantino.

Scott Hunter, director of pediatric neuropsychology at the University of Chicago Medical Center, agreed that this study adds to the evidence suggesting that genes are one likely cause of autism spectrum disorders.

Because parents completed the questionnaires, this study wasn't able to determine if the siblings were experiencing a mild form of autism, or if these were isolated language delays.

Both experts thought that it would be a good idea for families with one autistic child to have their other children screened, and Hunter said that you should definitely seek a thorough evaluation if you notice any trouble in language acquisition in children who don't have autism.

“If you are a parent of a child with autism, it’s probably important to talk to your pediatrician about your other child’s development,” said Hunter.

“The likelihood of other children in the family potentially being affected by a language or social impairment is relatively high, so keep an appropriate level of vigilance. These less-severe symptoms may nevertheless be substantially impairing in school and friendships,” explained Constantino.

Both experts agreed that if intervention is necessary, treatment that’s started sooner generally leads to better outcomes. But, noted Hunter, “It’s never too late to intervene.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_104305.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_104305.html)

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## Loss of Nutrients Following Gastric Bypass Surgery in Adolescent Girls Increases Risk for Neural Tube Defects

An increasing number of obese adolescents, particularly females, are undergoing gastric bypass surgery. Yet a case study presented Sunday, Oct. 3, at the American Academy of Pediatrics (AAP) National Conference and Exhibition in San Francisco, highlights the possible link between gastric bypass surgery in adolescent girls and an increased risk for neural tube defects, which can lead to varying degrees of disability such as paralysis and mental retardation due to damage to the nervous system, in their future children.

Neural tube defects in the brain and spinal cord can be due to nutritional deficiencies. The report, “Neural Tube Defects: An Unforeseen Consequence of Gastric Bypass Surgery in Young Female Patients?” reviewed the case of a young patient who had undergone gastric bypass surgery prior to becoming pregnant. She presented to the Fetal Treatment Center at UCSF Benioff Children’s Hospital to discuss the possibility of fetal surgery as her fetus had spina bifida. A literature review found six additional documented cases of children born with neural tube defects thought to be due to maternal nutritional deficiencies, particularly malabsorption (when the body cannot absorb nutrients), following bypass surgery.

It is well documented that gastric bypass surgery leads to malabsorption causing multiple nutritional deficiencies, including folate (folic acid), which is a key element in the prevention of neural tube defects. Although daily folate replacement can reverse this deficiency, adolescents often don’t comply with medication regimens.

This situation is especially critical because adolescents who have undergone gastric bypass surgery are at an increased risk of unintended pregnancies.

“We postulate that the malabsorption of folate, poor compliance with nutritional supplements and a higher risk of

unintended pregnancies places young women at an increased risk for pregnancies complicated with neural tube defects,” said senior study author Diana L. Farmer, MD.

“Although obesity is epidemic in this country, we believe non-reversible gastric bypass surgery should be avoided in adolescent women given the potential increased risk of fetal neural tube defects,” Farmer said. “If gastric bypass is performed on an adolescent female, great efforts must be made to minimize the risks of both unintended pregnancies and nutritional deficiencies. This should include extensive pre-surgery counseling and frequent post-operative follow-up, as well as consideration of highly efficacious contraceptives such as an intra-uterine device.”

Source: [www.healthychildren.org/English/news/Pages/Loss-of-Nutrients-Following-Gastric-Bypass-Surgery-in-Adolescent-Girls-Increases-Risk-for-Neural-Tube-Defects.aspx](http://www.healthychildren.org/English/news/Pages/Loss-of-Nutrients-Following-Gastric-Bypass-Surgery-in-Adolescent-Girls-Increases-Risk-for-Neural-Tube-Defects.aspx)

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## Preference for Moving Shapes vs. People Linked to Autism in Babies

A 1-minute video showing computer screensavers next to videos of dancing children may prove to be a simple, inexpensive screening tool for autism spectrum disorders (ASD) in toddlers. According to an NIMH-funded study, infants as young as 14 months old who had autism spent more time looking at the moving shapes than social images, in contrast to typically developing children and those who had delays but not autism. The study was published online, September 6, 2010, in the *Archives of General Psychiatry*.

### Background

Among the hallmark signs of ASD are repetitive behaviors, which may include persistent and intense preoccupation with objects. For example, a child with ASD may fixate on moving objects or parts of objects, like the moving blade of a fan or spinning tires on a car. Whether this behavior could predict or identify ASD in very young children had not previously been studied.

### About the study

To study this phenomenon, Karen Pierce, Ph.D., at the University of California San Diego School of Medicine, and colleagues enrolled 110 toddlers, ages 14-42 months. Of this group, 37 had ASD, 22 were developmentally delayed (DD) but did not have ASD, and 51 had typical development (TD).

The toddlers viewed a 1-minute video showing geometric patterns on one side—basically a computer screensaver—and children exercising, dancing, or otherwise in action on the other side. Using eye tracking technology, the researchers measured how long the toddlers looked at each type of movement and how many times they switched from looking at one type or part of an image to another.

## Results

In this study, 40 percent of toddlers with ASD spent significantly more time fixating on moving geometric patterns compared with 9.9 percent in the DD group and 1.9 percent of TD children. The other 60 percent of toddlers with ASD performed similarly to their DD and TD peers, showing a preference for social movement. If a toddler spent more than 69 percent of the time fixating on geometric patterns, ASD could be predicted 100 percent of the time.

While viewing the video, DD and TD children tended to let their eyes wander, changing their focus from one part of an image to another. Among toddlers with ASD, however, those who preferred geometric patterns showed significantly less eye movement when viewing geometric patterns, gazing at only a few parts of an image for extended periods of time. These children also showed significantly more frequent eye movement than DD or TD toddlers when viewing social movement.

A subsample of 41 toddlers were re-tested an average of 8 months later. The researchers found that the toddlers' preferences generally stayed the same between the original study and the follow-up.

## Significance

The results suggest that assessing infants' visual preference for geometric vs. social movement, including the amount of time they spend staring at moving geometric patterns, is an inexpensive and easy-to-conduct screening method for ASD.

"What an infant prefers to look at when given a choice between two images may turn out to be a more clearly observable indicator of autism risk than how he or she looks at a single image," Pierce said.

That most of the toddlers with ASD in this study responded in the same way as DD and TD children came as a surprise to the researchers. They suggest that differing patterns of brain activity may underlie toddlers' preference for geometric or social movement. Brain imaging studies would help to confirm whether subgroups of ASD can be distinguished by brain activity patterns.

## What's Next

According to the researchers, this screening tool may also be useful in identifying babies who would benefit from further developmental evaluation or even early treatment. The findings also provide new lines of inquiry regarding the role of various brain regions involved in processing social cues and shifting attention in the development of ASD.

Source: [www.nimh.nih.gov/science-news/2010/preference-for-moving-shapes-vs-people-linked-to-autism-in-babies.shtml](http://www.nimh.nih.gov/science-news/2010/preference-for-moving-shapes-vs-people-linked-to-autism-in-babies.shtml)

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## FDA approves new indication for Afinitor

The U.S. Food and Drug Administration approved the cancer drug Afinitor (everolimus) on Friday to treat patients with subependymal giant cell astrocytoma (SEGA) associated with tuberous sclerosis (TS), a rare genetic disorder. This approval was for treatments of SEGA that can not be treated with surgery.

TS causes benign (non-cancerous) tumors to grow in the brain and in other parts of the body including the eyes, lungs, liver, heart, skin and kidneys. TS occurs as a result of genetic mutations that lead to the development of tumors and results in a variety of possible symptoms including learning and developmental disabilities, skin abnormalities, seizures, and lung and kidney disease.

SEGAs are considered a major diagnostic feature of TS and are slow growing tumors, seen in 6 percent to 9 percent of patients. The disease can be fatal for patients who develop complications with tumor growth on the brain. Surgery is used to remove the tumor growths in some patients.

"Patients with this disease currently have limited treatment options beyond surgical intervention," said Richard Pazdur, M.D., director of the Office of Oncology Drug Products in the FDA's Center for Drug Evaluation and Research "It is important for research to continue in rare diseases where patients have few or no existing drug treatment options."

The drug was approved under the FDA's accelerated approval program. The program allows the FDA to approve a drug to treat serious diseases with an unmet medical need based on an endpoint thought to reasonably predict clinical benefit. The company is required to collect additional long term efficacy and safety data confirming the drug's benefit. This program provides earlier patient access to promising new or existing drugs while the confirmatory clinical trials are being conducted.

Afinitor was first approved in March 2009 to treat kidney cancer after patients fail treatment with Sutent (sunitinib) or Nexavar (sorafenib).

A single study of 28 patients was used to evaluate the safety and effectiveness of Afinitor to treat SEGA. At six months into the study, nine patients (32 percent) had a greater than 50 percent reduction in space the tumor occupied (tumor volume) of their largest SEGA tumor lesion. The length of time from when a patient's tumor visibly shrank and then remained stable (duration of response) for these nine patients ranged from about three months to two and one-half years with a median of 266 days. Seven of these patients retained the greater than 50 percent reduction in space the tumor occupied at time of last follow up.

Patients participating in the study did not develop any new tumors. However, no tumor resolved completely. Four of the patients on this study had previous surgery, but their tumor grew back. After receiving Afinitor, three of these patients

experienced greater than 50 percent reduction in tumor volume.

In patients treated with Afinitor for SEGA, the most commonly reported side effects included upper respiratory tract infections, sinus and ear infections, mouth sores, and fever. Common laboratory test abnormalities included liver enzyme elevations, high blood cholesterol and triglycerides (hyperlipidemia), high blood sugar, and decreases in white blood cells, red blood cells (anemia), and platelets. In patients with kidney cancer (renal cell carcinoma), lung inflammation (pneumonitis) and decreases in kidney (renal) function also have been reported.

Everolimus is also approved under an alternative trade name, Zortress, for prophylaxis of organ rejection in adult patients at low-moderate immunologic risk receiving a kidney transplant. Zortress has a different safety profile in these patients. Please refer to the Zortress prescribing information.

Source: [www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm231793.htm](http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm231793.htm)

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## Gene Associated With Autism May Alter How Brain Functions

People with a common genetic variant that's associated with autism have a "disconnect" between their frontal lobe and other areas of the brain important for language, brain scans show.

The disconnect may help explain some of the language and communication difficulties that are characteristic of autism, researchers report in the Nov. 3 issue of *Science Translational Medicine*.

About one-third of all people carry the variant of the CNTNAP2 gene that is associated with a heightened risk of autism, as well as attention-deficit/hyperactivity disorder, Tourette syndrome, schizophrenia and other language difficulties.

In the study, researchers performed functional MRI brain scans -- which measure blood flow in the brain -- on 32 children who had the gene variant. Half had an autism spectrum disorder, while half were developing normally.

Regardless of whether the kids had autism or not, children with the CNTNAP2 "risk" gene showed more activity in the frontal lobe of the brain (specifically, inside the prefrontal cortex) during a "language learning" task than those without the risk gene.

In those without the risk gene, activity in the prefrontal cortex decreased during the task. Instead, there was more connectivity between the frontal lobe and other areas of the brain, including the left side of the brain, which is involved with language.

In children with the risk gene variant, brain scans showed that

the frontal lobe was "over-connected" to itself rather than connected in a normal fashion with the rest of the brain.

"In the kids who carry the risk version, instead of having nice clean connections between frontal lobe and the left side of the brain where you process language, you see more of a broad connection throughout the frontal lobe, almost as if it's talking to itself," said lead study author Ashley Scott-Van Zeeland, a postdoctoral research fellow at Scripps Translational Science Institute in San Diego.

"Instead of having a highly efficient connection to the left side of the brain, they are sampling all over the frontal lobe," the researcher said. "That could help explain some of the language difficulties in autism."

Scott-Van Zeeland did the research as a doctoral candidate at University of California, Los Angeles.

The CNTNAP2 gene helps "wire" the brain: It is known to be active in utero when the structure of the brain is forming, Scott-Van Zeeland said. Unlocking its role in brain function could help in the development of new early interventions or treatments for autism.

Experts point out, however, that the gene variant is part of the spectrum of normal gene variation, and those who have it will not necessarily develop any intellectual disorder.

With some one-third of the population possessing the gene variant, not everyone who has the variant has autism, of course. Conversely, there are plenty of people with autism who don't have the variant, said Dr. Gary Goldstein, president and CEO of the Kennedy Krieger Institute in Baltimore, which serves children and teens with autism and other developmental disorders. Goldstein was not involved with the study.

So it's important to keep in mind that while people who have the CNTNAP2 variant may be more susceptible to autism, there are other genetic or environmental triggers involved, he explained.

But this study does "break new ground," he said, in correlating a known risk gene for autism with alterations in brain activity, as seen in functional MRI imaging.

Previous studies have linked certain genes with autism, while others have shown an association between brain imaging and a child's behavior. But this is among the first to show how a gene associated with autism might alter how the brain functions, Goldstein said.

Think of the brain like an orchestra, he suggested. When the piano starts to play, the rest of the orchestra turns down the volume in order to hear the piano. In autism, perhaps the volume isn't being "turned down" inside the frontal lobe, making it difficult to shift attention to other things, he said.

"What they are really showing is when you have this risk gene, this part of the brain doesn't tune down in the same way it does in people who don't have it," Goldstein said. "That's consistent with what's seen in kids with autism."

They have these very focused interests. They may very good at what they are doing, but they're not engaging others or the rest of their brain."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105131.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105131.html)

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## Health Tip: NSAIDs Induce Ulcers in Some

Peptic ulcers are sores that form inside the stomach or intestines. Taking nonsteroidal anti-inflammatory drugs (NSAIDs) for chronic pain can contribute to NSAID-induced ulcers in some people, the American Gastroenterological Association says.

The association mentions these risk factors for NSAID-induced ulcers:

- Being age 60 or older.
- Having a history of internal bleeding or ulcers.
- Taking steroids such as prednisone, or blood thinners such as warfarin.
- Regularly using tobacco or alcohol.
- Having side effects from NSAIDs, such as heartburn or upset stomach.
- Using NSAIDs in greater doses than recommended, or using them long term.
- Taking multiple medications that contain NSAIDs.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105219.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105219.html)

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## Genetic Deletion Linked to Raised Risk of Autism, Schizophrenia

An international consortium of researchers has linked a regional abnormality found in a specific chromosome to a significantly increased risk for both autism spectrum disorders (ASD) and schizophrenia.

Although previous work has indicated that genetic mutations play an important role in the risk of both disorders, this latest finding is the first to hone in on this specific abnormality, which takes the form of a wholesale absence of a certain sequence of genetic material.

Individuals missing the chromosome 17 sequence are about 14 times more likely to develop autism and schizophrenia, the research team estimated.

"We have uncovered a [genetic] variation that confers a very high risk for ASD, schizophrenia and neurodevelopmental disorders," study author Dr. Daniel Moreno-De-Luca, a post-doctoral fellow in the department of human genetics at Emory

University in Atlanta, said in a university news release.

Moreno-De-Luca further explained the significance of the finding by noting that this particular region, comprised of 15 genes, "is among the 10 most frequent pathogenic recurrent genomic deletions identified in children with unexplained neurodevelopment impairments. We believe it also may increase risk for other psychiatric conditions such as bipolar disorder."

He and his colleagues report their findings in the Nov. 4 online edition of the American Journal of Human Genetics.

Identification of this new genetic marker for autism and schizophrenia stemmed from work with about 23,000 patients diagnosed with autism, developmental delay, intellectual disability or schizophrenia, 24 of whom had the chromosome 17 deletion.

By contrast, among a pool of nearly 52,500 healthy patients, none were found to be missing the genetic material, the investigators reported.

The authors noted that prior research had established that a mutation in one of the 15 missing genes in the newly identified sequence is a cause of both renal cysts and diabetes syndrome.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105233.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105233.html)

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## Brain Organizes Itself for Introspection as Children Age: Study

As children mature, increased synchronization between specific areas of the brain alter how they view themselves and others, a new study suggests.

This includes an increasing aptitude for introspection, researchers say.

Georgetown University Medical Center researchers used functional MRI to examine the activity of the five scattered brain regions that comprise what's known as the default-mode network (DMN).

It's believed that the DMN -- which is only active when the mind is at rest and allowed to wander or daydream -- plays an important role in a person's introspective understanding of themselves and others, and in the formation of beliefs, intentions and desires through autobiographical memory, the study authors explained.

The researchers found that the DMN regions don't yet work together in children ages 6 to 9. These areas light up in an fMRI scan (which tracks brain activity in real time), but they do not do so simultaneously. However, by ages 10 to 12, the regions begin to function together and at ages 13 to 19 they're fully coordinated.

"These results suggest that children develop introspection over time as their brains develop," first author and neurosci-

entist Stuart Washington said in a GUMC news release. “Before then they are somewhat egocentric, which is not to mean that they are negatively self-centered, but they think that everyone views the world in the same way they do. They lack perspective in that way.”

The study was to be presented Sunday at the annual meeting of the Society for Neuroscience, in San Diego.

The team also pointed out that previous research has suggested that the DMN is not well synchronized in many people with autism.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105546.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105546.html)

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## For Teens With Autism, Handwriting Problems May Persist

Poor handwriting among children with autism tends to persist well into the teen years, a new study finds.

Unlike with younger children, the reason for the poor handwriting among teens seems to have less to do with motor skills issues than with problems in “perceptual reasoning,” or the ability to reason through problems with nonverbal material.

The study, by researchers at the Kennedy Krieger Institute in Baltimore, is published in the Nov. 16 issue of *Neurology*.

In the study, 24 girls and boys aged 12 to 16, half of whom had an autism spectrum disorder, were asked to write a scrambled sentence (“the brown jumped lazy fox quick dogs over”) as neatly as they could.

IQ tests showed all of the teens, both with autism and typically developing, scored within the normal range of perceptual reasoning. Researchers also tested teens’ motor skills, including balance and timed movements.

The handwriting sample was scored on five measures, including legibility, form, alignment, size and spacing.

On average, kids with autism had poorer handwriting than kids without autism. The average score for autistic kids was 167 out of 204 possible points, and normally developing teens scored an average of 183.

While teens with autism were also more likely to have motor skill impairments, problems in that area were not associated with sloppier handwriting.

Yet scoring worse on the test of perceptual reasoning was associated with worse handwriting among children with autism.

“The importance of this research was not ‘if’ children and adolescents with autism struggle with handwriting, which many individuals can already attest to, but rather to document the extent of the challenge and determine if we could reveal

anything about ‘why’ it is the case,” senior study author Amy Bastian, director of the Motion Analysis Laboratory at the Kennedy Krieger Institute, said in an institute news release.

Handwriting problems may offer clues about how the brains of kids with autism function and what types of interventions could help overcome such difficulties, the study authors explained.

Handwriting is important for success in school, in social life and on the job, said Geraldine Dawson, chief science officer at Autism Speaks. Being able to write clearly is even more important for people who have difficulty communicating verbally, as many with autism do.

“Almost every subject taught in school requires handwriting skills, so if a child or adolescent has writing difficulties, this can be very frustrating,” Dawson said. “Kids with autism may need more time to complete their tests and homework.”

An occupational therapist can determine why a child or adolescent is having difficulty writing and offer help, Dawson said.

“Handwriting requires many skills, including visual skills, hand strength, memory, and good posture,” Dawson said. “Different kids have different problems, so it is important to individualize the methods used to improve handwriting.”

Therapies that may work include using special pencil grippers, lined paper and exercises to improve posture, coordination and strength. Some kids find that using a computer or other keyboard is much easier than writing.

“Using an alternative form of communication, such as a keyboard, can make a world of difference for some kids,” Dawson said.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105573.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105573.html)

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## Viral counts necessary for gauging health of children with HIV

For children being treated for HIV in less developed countries, monitoring to predict the occurrence of serious HIV-related illnesses is most accurate if it includes a measure of HIV levels in the blood, according to a National Institutes of Health study conducted throughout Latin America.

Termed viral load, the quantity of human immunodeficiency virus (HIV) genetic material in the blood is a barometer of the effectiveness of HIV treatment. High viral loads indicate potential treatment failure, which can then lead to a weakened immune system and increased risk of infections.

Monitoring children’s viral load is standard in the United States. However, the technology to perform viral load testing is difficult and expensive to maintain and, for these reasons, is often unavailable in less developed settings. Instead, in these

settings, clinical symptoms or immune cell number are used to monitor the effectiveness of therapy. The current study is the first to assess the value of adding viral load to monitoring of symptoms and tests of immune function in children receiving anti-HIV treatment in a less developed setting.

The study authors noted that, in resource poor settings, shipping blood samples to a central facility where viral load levels could be measured might provide a cost effective alternative to performing viral load measurements at each clinical care site.

The researchers found that a viral load of 5,000 copies per milliliter of blood predicts a higher risk of serious illness in children on HIV treatment, providing clinical evidence for new World Health Organization recommendation (<http://www.who.int/hiv/pub/paediatric/infants2010/en/index.html>) on when to change HIV medications when it appears that a child's HIV treatment is failing.

“Our study showed that adding viral load monitoring would significantly improve the monitoring regimen used to safeguard the health of children being treated for HIV.” said George K. Siberry, M.D., M.P.H., senior author of the study. Dr. Siberry is a medical officer in the Pediatric, Adolescent and Maternal AIDS Branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the NIH institute that funded the research.

The authors noted that using dried blood spots for viral load testing might provide a cost effective alternative to routine viral load testing methods. Although they did not evaluate this alternative in their study, the authors cited earlier research, of blood spots collected on filter paper. The authors noted that blood spots could be readily used to detect viral load at the level that predicted clinical illness in the current study. Filter paper, such as that used for newborn screening programs in the United States, could be used to collect blood samples in remote or poor areas, which could then be shipped to a central facility where they could be processed reliably and economically.

The study was led by first author Ricardo Oliveira, of the Federal University of Rio de Janeiro. He collaborated with colleagues at the University of Sao Paulo, University of Caxias do Sul, Federal University of Sao Paulo and the Emilio Ribas Institute of Infectious Diseases, all in Brazil, as well as researchers at Westat and the NICHD. The study was undertaken as part of the NICHD International Site Development Initiative (NISDI).

“The NISDI pediatric protocol follows HIV-infected children in Latin America as a way to learn more about the impact of the infection and its treatment on children while also helping to build clinical research infrastructure,” explained NISDI principal investigator Dr. Rohan Hazra. The findings were published online in the journal *Clinical Infectious Diseases*.

To conduct the study, the researchers analyzed the medical records of 600 children with HIV who were receiving treatment at hospitals in Brazil, Mexico and Peru. The children were under age 15 and had been on anti-HIV medication for at least six months.

The children's viral load levels were monitored every six months, along with counts of CD4 white blood cells (to measure immune strength) and oxygen-carrying molecules (hemoglobin) in red blood cells. The children's growth and development were also followed.

The researchers sought to determine whether the most recent measurements of viral load could predict serious HIV-related illnesses, classified by the World Health Organization as stage 3 and 4 events (<http://www.womenchildrenhiv.org/wchiv?page=charts-00-02>). Stage 3 and 4 events are the most serious of the HIV-related illnesses that affect people whose immune systems have been weakened by the virus. The research team evaluated the predictive value of two viral load levels: 400 copies of viral genetic material per milliliter of blood and 5,000 copies per milliliter. The team also analyzed the added risk of incremental increases in viral load.

The research team found that the measure of a child's most recent viral load was the most effective for predicting illness, especially when the level was above 5,000 copies per milliliter. Above this threshold, a child had nearly twice the risk of developing a WHO stage 3 or 4 event. The researchers found that this prediction was independent of CD4 cell and hemoglobin levels in the blood as well as the child's body mass index. A combination of all three measurements most accurately predicted impending illness.

Source: [www.nih.gov/news/health/nov2010/nichd-18.htm](http://www.nih.gov/news/health/nov2010/nichd-18.htm)

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## For Autistic Kids, IQ May Not Predict School Achievement

IQ is typically a good predictor of academic performance, but not necessarily in autistic children, a new study shows.

Researchers tested the IQs and reading, spelling and math abilities of 30, “high-functioning” 9-year-old autistic children. Researchers also assessed the children's social functioning through parental and teacher reports at ages 6 and 9.

In 90 percent of the children, their academic achievement diverged substantially from predictions based on their intelligence-test scores.

So did the autistic kids do better or worse than expected?

The answer: both. Some did more poorly on academic tests than their IQs would indicate, while some did better than their IQs would suggest.

The breakdown was about half and half. Eighteen children did better on at least one academic test, particularly spelling and word recognition, than their IQs would predict, while 18 did worse on each test, suggesting a possible learning disability in that specific area.

“Ninety percent of the kids had a discrepancy. We didn’t expect it to be such a common occurrence,” said study author Annette Estes, a research assistant professor at the University of Washington Autism Center in Seattle. “In most typically developing kids, these discrepancies are very, very rare.”

The study was published online in the *Journal of Autism and Developmental Disorders*.

IQ, or intelligence quotient, is assessed using standardized tests. An average score is 100, and normal is anything 15 points above or below 100. Prior research has shown that in the general population, IQ scores are a good predictor of academic performance.

Early diagnosis and early behavioral interventions are helping kids with an autism spectrum disorder make rapid strides that decades ago would have been unlikely, Estes said.

Up to 70 percent of autistic children are considered high-functioning, which in this study was defined as an IQ of 70 or above, although most had an IQ in the average or above-average range.

Researchers found no association between problem behavior and academic achievement.

But social skills did seem to matter in how well kids did at school. Children who had higher social skills at age 6, including such skills as introducing themselves to others and understanding compromise and cooperation, had better word reading skills at age 9.

The next step for researchers is to determine how the children actually do in the classroom, Estes said.

Questions she’d like to answer are whether teachers and others recognize the children with the higher IQs and academic abilities, or if social and communication difficulties hold them back, and, conversely, do they identify kids who have a learning disability in one particular area?

“Some may be really excellent at math, but because of attention problems that might not be recognized,” Estes said. “Or, if the child seems to be doing pretty well, maybe people aren’t aware that they are struggling in certain areas.”

Future studies are also needed to determine if low achievement is connected to specific learning disabilities and to better understand high achievement in children with autism spectrum disorder, the researchers said.

Amy Keefer, a clinical psychologist at the Kennedy Krieger

Institute’s Center for Autism and Related Disorders in Baltimore, said she often sees such divergences between intelligence scores and certain academic skills in her patients with an autism spectrum disorder.

“Anecdotally, I see it happening a lot,” Keefer said. “It highlights how complex the neurocognitive profile is for high-functioning kids with ASD and that complexity is what leads to these unusual patterns in academic achievement.”

Reading comprehension is a common area of struggle for some kids with autism, Keefer said. Though some may be excellent readers as far as recognizing words, they often have more difficulty understanding what they’re reading.

In addition, while some kids with autism are very good at math, they excel in doing calculations but can get thrown off when the same math problem is presented not in numbers but as a “verbal problem.”

Figuring out how kids with autism learn best is critical, Estes said.

“Children with autism, later in development are thought to be at higher risk of anxiety or depression,” Estes said. “Academics is a potential source of mastery and self-esteem that, if enhanced, could buffer them from one of those challenges. And [academic success] has implications for being able to be successful later on in higher education and jobs.”

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105902.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105902.html)

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## Children Born ‘Late Pre-Term’ More Prone to Low IQ

Being born just a few weeks early might have a long-term impact on a child’s IQ and ability to pay attention, new research suggests.

In a study that compared babies born at term (40 weeks) to those born between 34 to 36 weeks (called “late pre-term”), researchers found that the children born early had more than twice the risk of having an IQ score below 85 and about double the risk of having socioemotional difficulties, such as attention problems, at age 6.

“There’s a subgroup of children born late pre-term that have an increased risk of developing problems by age 6,” concluded study author Nicole Talge, a postdoctoral research associate in the department of epidemiology at Michigan State University in East Lansing, Mich.

“What this study tells us is that late prematurity is not a benign situation. Not every kid will have a problem, but there’s a higher chance for some to have interaction problems, attention problems and lower IQ,” added one expert, neonatal psychologist Cheryl Milford of Magee-Women’s Hospital at the

University of Pittsburgh Medical Center.

Milford said the reason for the risk is that the brain simply isn't developed enough at 34 to 36 weeks. "A lot of the development of higher-order functioning in the brain is occurring in the 34-to-36-week range," she explained, adding that "there's a reason that humans gestate for 40 weeks."

The current study included 168 pairs of babies -- one born at term and one born between 34 and 36 weeks. The babies were born during 1983 and 1985. At age 6, they had their IQ scores measured and their teachers reported on classroom behaviors.

The Michigan team found that late pre-term birth more than doubled the risk of having an IQ score of less than 85. Furthermore, the odds of having emotional difficulties, such as attention problems, were about twice as high for those born a little bit early compared to the children born at full-term.

Results of the study appear in the December issue of *Pediatrics*.

Talge said it's important to note that not every child born at 34 to 36 weeks had problems. In fact, most didn't. "Only about 20 percent fell below that IQ threshold, and that means 80 percent were above that. And, about 20 to 30 percent had internalizing or attention problems," she said.

"We now have a greater understanding that each week matters," said Dr. Michael Msall, chief of developmental and behavioral pediatrics at the University of Chicago Medical Center. However, he said that "the good news from this study is that at age 6, even in a different era of neonatology [the 1980s], these kids did quite well. Yes, on a population basis, there may have been some problems, but I think that it may be like being five pounds overweight on a population basis, and most of these differences may be subtle."

However, he said that if parents see that their child is struggling with schoolwork, or is having a hard time paying attention in school, they shouldn't hesitate to ask for help. "Talk to your child's pediatrician or their teacher; let them know you want to make sure your child stays on track. Recognize the problems and develop a strategy to manage them," said Msall.

Milford agreed. "Babies who are born late pre-term look like small, full-term babies, and for a long time the perception was that they were just a little early, but that they were mostly developed," she said. "The reality is, if you had a late pre-term infant, you should be looking to see if they're on track. Do they have any behavioral issues? If so, you need to find out what resources are available to you in the community and at school."

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_105895.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_105895.html)

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## Cell Dysfunction May Play Part in Autism

Autistic children are much more likely to have defects in a cellular structure called the mitochondria, which is responsible for producing the energy used by brain cells, preliminary research finds.

These defects may help to explain the onset or the severity of autism in some children, according to the study in the Dec. 1 issue of the *Journal of the American Medical Association*.

"In this report, children with full syndrome autism were more likely to have mitochondrial dysfunction than healthy, age-matched control children," said study author Cecilia Giulivi, a professor of biochemistry at the University of California, Davis. "But we don't know if mitochondrial dysfunction is a cause of autism or a consequence of autism."

Mitochondria, sometimes called cellular "powerhouses," produce energy that's used to fuel a cell's activity -- an especially important function in the brain, Giulivi said.

When mitochondria don't function properly, the results can be devastating. Mitochondrial dysfunction has been implicated in neurological conditions ranging from Parkinson's and Alzheimer's disease to schizophrenia and bipolar disorder.

Mitochondrial disease can lead to symptoms including muscle weakness, exercise intolerance (pain and muscle cramps during exercise), gastrointestinal disorders, seizures, liver disease, vision and hearing problems, developmental delays and increased susceptibility to infection.

While previous small studies have suggested some children with autism may also have mitochondrial dysfunction, measuring the function of mitochondria isn't easy because brain biopsies are out of the question, Giulivi said.

Another area of the body in which mitochondria are active is in the muscles, but biopsying muscle tissue is also invasive, she added.

In the new study, Giulivi analyzed the mitochondria in lymphocyte cells, an immune system component found in the blood, of 10 children aged 2 to 5 with "full syndrome" autism and 10 normally developing children.

They found children with autism were far more likely to have mitochondrial dysfunction, including defects in mitochondrial DNA and abnormalities in the levels of various enzymes produced by the mitochondria.

"There has been evidence before that some children with autism have a mitochondrial disorder, but we haven't been able to do routine screening because a muscle biopsy is quite invasive," said Geraldine Dawson, chief science officer for Autism Speaks, which helped fund the research. "This study suggests we might be able to do a blood sample, which would allow us to do routine screening."

Still the findings come with caveats. While the study suggests mitochondrial dysfunction plays a role in at least some cases of autism, the researchers stressed that the results are preliminary and more studies in larger numbers of children are needed.

And there are many unknowns, including how mitochondrial dysfunction in brain cells might alter brain function in a way that leads to some of the symptoms of autism, including communication and social difficulties.

The researchers also don't know when the mitochondrial dysfunction starts -- in the womb, in infancy or later, and how that might impact the onset of autism or what other environmental or genetic factors may also contribute.

Parents should also keep in mind that autism is a "heterogeneous" disorder, Dawson said. In the new study, only one child met the clinical threshold for a mitochondrial disorder, while others showed varying degrees of mitochondrial abnormalities.

"The fact that so many were showing some evidence of a mitochondrial dysfunction is remarkable because that has never been shown before," Dawson said. "This could be a subtype of autism, or could be a contributing factor to many types. It could be a cause or a consequence. We really don't know at

this point, but the important thing is there really is something different about the way the mitochondria are functioning in some children with autism."

The 10 children with autism in the study all had "full syndrome" autism. Children on the less severe end of the autism spectrum were not included in the study.

Among the various mitochondrial defects, researchers found that mitochondria from children with autism consumed less oxygen than mitochondria from the children without autism, suggesting less mitochondrial activity.

The cells of children with autism also produced twice as much hydrogen peroxide, which can lead to oxidative stress, which can damage DNA.

Giulivi urged pediatricians to be on the lookout for symptoms that might indicate mitochondrial dysfunction in autistic children, including vision or hearing problems, seizures or exercise intolerance such as muscle cramps during intensive physical activity.

Source: [www.nlm.nih.gov/medlineplus/news/fullstory\\_106118.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_106118.html)

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*Web Sightings* (continued from page 13)

## **About Face: How the Brain Recognizes and Processes Faces**

[http://sfn.org/index.aspx?pagename=brainBriefings\\_10\\_aboutface](http://sfn.org/index.aspx?pagename=brainBriefings_10_aboutface)

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## **Interactive Autism Network**

The increasing number of children diagnosed with autism—an estimated one in 110 in the United States—creates a need for faster researcher about autism. The Kennedy Krieger Institute of Baltimore has developed the Interactive Autism Network (IAN), the nation's largest online autism research study. It connects people affected by autism with researchers who need study participants. For more information, go to: [www.ianproject.org/](http://www.ianproject.org/)

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## **The Public Health Dimensions of the Epilepsies - Institute of Medicine**

The Institute of Medicine is undertaking a new study that will consider the public health dimensions of the epilepsies in the United States—including health care and human services, health literacy, and education. The IOM will recommend

priorities in these areas in order to better understand the public health impact of the epilepsies and to meet the needs of people with epilepsy and their caregivers.

Visit [www.iom.edu/Activities/Disease/Epilepsy.aspx](http://www.iom.edu/Activities/Disease/Epilepsy.aspx)

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## **Avoiding Bullying**

Children, teenagers, and adults with I/DD are often prime targets for bullying. Here is some useful information from the American Academy of Pediatrics about bullying, how to avoid it, and what to do to put an end to it.

[www.healthychildren.org/English/safety-prevention/at-play/Pages/Avoiding-Bullying.aspx](http://www.healthychildren.org/English/safety-prevention/at-play/Pages/Avoiding-Bullying.aspx)

[www.healthychildren.org/English/safety-prevention/at-play/Pages/Bullying-Its-Not-Ok.aspx](http://www.healthychildren.org/English/safety-prevention/at-play/Pages/Bullying-Its-Not-Ok.aspx)

[www.healthychildren.org/English/safety-prevention/at-play/Pages/Teen-Safety-Putting-An-End-To-Bullying.aspx](http://www.healthychildren.org/English/safety-prevention/at-play/Pages/Teen-Safety-Putting-An-End-To-Bullying.aspx)

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## **Managing Epilepsy Well Network**

[www.sph.emory.edu/ManagingEpilepsyWell](http://www.sph.emory.edu/ManagingEpilepsyWell)