

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.”¹ 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)

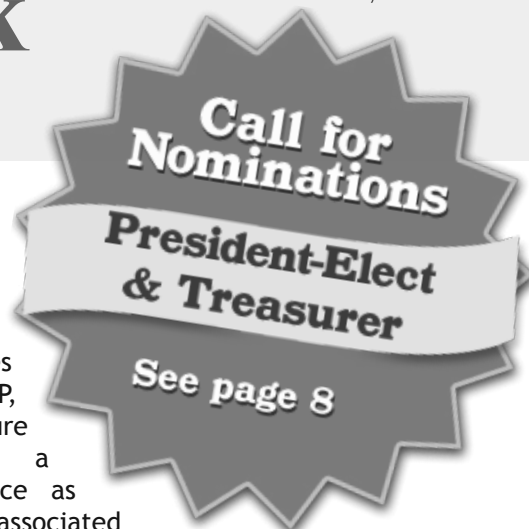
According to the National Dissemination Center for Children with Disabilities, CP occurs in approximately 2 per 1000 births. Coinciding with improved survival rates for low (<2500 grams; < 5lb, 8oz) and very low (<1500 grams; < 3 lbs, 5oz) birth weight babies, 1 in 20 infants with extreme prematurity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

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.”⁴

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.⁸ 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.

Directory of Contacts

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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.

If you have events you would like to see listed on this calendar, please contact the DDNA office at 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.

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) 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

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

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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

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.

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College of Direct Support - web-based learning system

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

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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

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- Medication and Related Issues
- Categories and Effects of Medications
- Obtaining Medications
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For more information: contact Robin May MSN, ANP-C, CDDN at 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.”² Independent ambulation and the ability to eat orally have been noted to be the strongest indicators for longevity.²

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.¹⁰

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.^{3,6,7,10} 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.⁷ 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.”¹⁰ Another study reported that individuals with CP consume three to five times more energy during ambulation than individuals without CP.¹⁰

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),⁵ 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

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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 Torres⁸ 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"⁴ 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)".¹⁰ 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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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.

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.

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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

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.

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, or call DDNA 9-5 ET at 800-888-6733.

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; 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
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
3. United Cerebral Palsy; 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 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, 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 or contact Sharon Atwood at (623)986-0120 or email: 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.

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.

Colorado Association of Nurses for the Developmentally Disabled

If anyone has current contact information for this association, please contact admin@ddna.org.

Connecticut DDNA

For information, contact Patricia Vibert, RN, CDDN, at (860)675-5215; email: 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.

The Mid-Florida Chapter

For information regarding the Mid-Florida Network of DDNA, contact Jan Schlaier at 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.

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.

Central Illinois Chapter

For information, contact Debra Davis, RN, BSN at (309)224-0797 or email: 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, 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.

Central Indiana DDNA

For information please contact Georgia Swank, RN, at (502)645-1226 or email: 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

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.

Iowa DDNA

For information, contact Rose Magnussen, RN, CRRN at 712-324-5406 or email rmagnussen@villagenorthwest.org. Please visit the website at 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.

Kentucky Network

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

Louisiana Chapter

For network information, contact Mitzie Daniel, at (318)452-5904 or email: 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.

Massachusetts Chapter

For more information about the Massachusetts chapter, visit 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.

DDNA of SE Michigan

For information please contact Lillian Durecki, RN, at (734)407-2500 ext. 315 or email: 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 and for more information, contact Wendy Herbers, RN, QMRP, at (952)401-4841 or email: wherbers@capstoneservices.net.

Western Missouri Chapter

For information, email Janet Owings at 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 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; phone: (603)225-5870 x18; or visit the website at: 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.

Southern New Jersey Chapter

For the latest news and information, contact Ann Yusko, RN, BSN, CDDN at 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.

NYS ID/DD Nurses Association Network

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

North Dakota DDNA

For information, contact Bernadette Vetter, RN, CDDN, at (170)663-0379 or email: 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. 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

Rhode Island DDNA

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

East Tennessee DDNA

For information, visit our website at www.etddna.com or contact Melinda Hendon RN, BSN, CDDN. Phone: (423)238-4802; email: 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.

DDNA of North Texas

For more information, please contact: Gwen Weiss, RN, CDDN at (972)732-0188 or gweiss@rescare.com.

Southwest Texas Chapter

For information, contact Marcia Bitting, RN, BSN, MPH, at (210)789-7217 or email: 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.

Northern Virginia Chapter

For information, contact Deborah Tatum-Johnson at (703)323-4097 or email: 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.

Save the Date!!



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