



Developmental Disabilities Hospice & Palliative Care

E-Newsletter November 2008 Vol. 2(11)

November is National Hospice/Palliative Care Month!

This month is an excellent time for the Hospice and Palliative Care service community to reach out to underserved populations and raise awareness of the invaluable system of care that these services provide at end-of-life. One such underserved population is the developmentally disabled community, their families as well as those who work with and care for them. In an effort to increase awareness of how utilizing Hospice and Palliative Care can benefit them, hospice and palliative care organizations across the nation are working to reach out and develop new community partnerships both in the professional healthcare community and among the public.

◆The White House has issued a 2008 *National Hospice Month proclamation*. The proclamation is available to read on the [White House](#) web-site.

◆‘Caring Connections’ is offering a free community presentation outreach tool entitled “*Hospice Can Help You and Your Family*” that your organization can adapt and use for your outreach activities within the developmentally disabled community. The presentation is available in English, Spanish and Chinese and can be downloaded for free from Caring Connections. To access these materials as well as the outreach materials provided by NHPCO use this link: [Hospice Outreach](#)

◆The National Hospice and Palliative Care Organization (NHPCO) has released updated facts and figures about the utilization and benefits hospice care in America. For instance, NHPCO estimates that approximately 38.8% of all deaths in the United States were under the care of a hospice program, but what percentage of the developmentally disabled community utilizes hospice is unknown. To access this document follow this link: [Hospice Facts and Figures](#).

◆NHPCO has put together a compilation of outreach materials and encourage to take a look at the materials in the 2008-2009 Outreach Guide that include resources, materials and strategies that may help with outreach and awareness building efforts in November and all year long. To view and begin using these resources visit [NHPCO](#) website.

In the News

I/DD Hospice and Palliative Care Issues

► Palliative Care Center Releases State by State Report Card

Hospital palliative care programs make patients facing serious and chronic illness more comfortable by alleviating their pain and symptoms and counseling patients and their families. The Center to Advance Palliative Care released their report on state trends with regard to access to palliative care in our nation's hospitals. Key findings indicate that "America does a mediocre job caring for its sickest patients. The nation, as a whole, gets a C grade", the report says. Only Vermont, Montana and New Hampshire earned an A, according to America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals, a report based on a study in the October 2008 issue of the *Journal of Palliative Medicine*. Three states — Oklahoma, Alabama and Mississippi — received an "F". To find out how your state was graded and to read recommendations for education and policies to improve future grades, read the report in its entirety: [State by State Report Card](#).

► New Alzheimer's drug brings new hope

MSNBC has reported that this past July, at the International Conference on Alzheimer's Disease, a research team from the University of Aberdeen presented evidence that testing on a new drug called, 'Rember,' has been shown to slow the progression of Alzheimer's disease by up to 81 per cent. The drug is said to function by breaking up the protein tangles in the brain that leads to Alzheimer's. The team also reported that researchers hope to carry out a final trial on Rember by the end of 2009, and if that is successful the drug could be available by 2012. Read the entire article at the Times Online: [New drug advances Alzheimer's treatment](#).

► Developmental Disabilities Planning Council (DDPC) Hospice Project Cited in National Publication

The "Newsletter of the Network on Ethics and Intellectual Disability" (Vol. 11, No. 1, Winter 2008) includes an article on the ethical questions addressed by the DDPC funded Hospice and cross-systems training initiative that was conducted by the Hospice & Palliative Care Association of NYS and NYSARC, Inc. in 2007. The article, written by Lawrence R. Faulkner, former Deputy General Counsel for the NYS, OMRDD, highlights the importance of training and cross-systems collaboration in addressing the complex, legal and personally/professionally difficult ethical questions facing caregivers making end of life decisions. Read this very informative article on page 5 of the publication: [End-of-Life Healthcare for those with Developmental Disabilities](#).

► End-of-Life Decisions Focus of Senate Hearing

To identify barriers to end-of-life decision-making and to raise awareness about the need for solutions, the U.S. Senate Special Committee on Aging held a September hearing examining the difficult questions facing American families forced to decide how best to honor their loved one's end-of-life wishes. The committee has oversight authority rather than legislative authority; its members hold forums and hearings to call attention to issues of national concern. "Despite the fact that each one of us will eventually get sick and die, almost no federal support for research aimed at improving the quality of life during chronic

and serious illness has been available to develop the evidence base necessary to relieve suffering and reliably help patients and families in need,” Dr. Meier testified. Read the entire article published in the Senior Spectrum: [Senate Hearings on End-of-life Issues](#)

Public Policy & Advocacy Opportunities



We have been keeping you informed about the status of the **Medicare Hospice Protection Act** Hospice rate cuts planned for 2009. The National Hospice and Palliative Care Organization (NHPCO) has taken the extraordinary step of filing a lawsuit against the Centers for Medicare and Medicaid Services (CMS), seeking to block the elimination of the Budget Neutrality Adjustment Factor (BNAF) that is used to compute Medicare’s hospice reimbursement rates. This decision to move forward with this challenge to the rate cuts was based on countless feedback the staff has received from providers and other advocates regarding the potential impact of the rate cuts on patient/family care. NHPCO wants to make advocates aware that these rate cuts, if allowed to go into effect, are likely going to be permanent. ♦♦ NHPCO has provided an easy to read FAQ sheet to answer to any questions that may arise and provide talking points about the lawsuit. To access this information please use the following link: [NHPCO](#)

NYS Policies for End of life care for persons with Developmental Disabilities



All persons with intellectual and developmental disabilities have a right to access the full range of end-of-life care options that are available through hospice and palliative care services, but the truth is that this is often not the case. One of the biggest barriers to ensuring end-of-life care choices for people with intellectual and developmental disabilities are in the legal arena. Conflicting State laws and regulations concerning guardianship, informed consent, DNRs and related health care decisions can create barriers for individual choice. Following is information on recent I/DD & end of life NYS laws, and amendments.

♦♦ On July 7th, 2008 Governor Patterson signed into law **(A.10833/Chapter 262)**. This breakthrough legislation is the first of its kind in the nation, and was written to fill a gap in the 2002 ‘Health Care Decisions Act for Persons with Mental Retardation’ (HCDA) signed by then Governor Pataki. The HCDA was put in place to provide a mechanism through which difficult health care and end-of-life decisions could be made by involved, but non-guardians on behalf of family members who were never capable of expressing their wishes. However, there was no mechanism for those who had no family to advocate for them, this new legislation provides a compassionate solution to the suffering caused by that provision gap. **Chapter 262** authorizes *Surrogate Decision-making Committees* (SDMCs) to act as guardians and make end-of-life decisions for those persons with developmental disabilities who are not represented by an involved family member or guardian. The decision making authority includes the decision to prevent extreme suffering by withholding or withdrawing life-sustaining treatment.

NOTE: this law will not become effective until January 3, 2009

♦♦ **Chapter 210**, authorizing (on a demonstration basis) the use of a simplified advanced health care directive form, for exclusive use by persons with developmental disabilities, was

also signed by Governor Patterson on July 7th, 2008. The simplified forms will include pictures to illustrate the meaning of certain difficult to grasp concepts and the use of elementary school-level language so that individuals, who might otherwise be unable to make their wishes known, can understand the health care choices available to them and to choose a health care proxy themselves. While this law became effective upon the date of approval, the simplified advanced health care directive forms are not yet available.

~~ We will keep you informed as to the status of these forms in upcoming months ~~



The Down Syndrome Community Celebrates an Important Victory

After three years of advocacy, the U.S. Senate and the U.S. House of Representatives passed S. 1810, the '*Prenatal and Postnatal Diagnosis Conditions Awareness Act.*' Advocates state that the treatment options, functional development, opportunities and accomplishments of individuals with Down syndrome have improved dramatically over the years, yet decades old stereotypes still persist, and all too often information provided is out-dated and/or inaccurate. This bill ensures that pregnant women receiving a positive prenatal test result and parents receiving a postnatal diagnosis will be more likely to receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, Web sites, information clearinghouses, adoption registries, and parent support networks and programs specific to Down syndrome and other prenatally diagnosed conditions. To learn more about this bill follow the link to the [Down Syndrome Information Alliance](#) website.

Information and Resources

► Improving Quality of Life for People with Disabilities

The New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (NYS CQCAPD), in partnership with eighteen service and support organizations for people with disabilities, are working together to learn more about the diverse lives of people with disabilities. This information will help service providers and those who plan services and supports make them more responsive to people with disabilities. To help gather this information they are conducting two major activities:

Focus groups - Focus groups are going to be held across New York State to learn how people with disabilities and their family members define a good quality of life, what supports a good quality of life, the challenges faced and what would improve quality of life.

Quality of Life Stories – The partnership is reaching out to people with disabilities and their family members to volunteer to tell their story by sharing their thoughts about what quality of life means to them. To contact the commission, submit your story, or speak with someone about conducting a focus group follow this link: [Improving Quality of Life for People with Disabilities](#)

► End of life care for the developmentally disabled can be challenging

The Journal of the American Board of Family Medicine (JABFP) has reprinted an article addressing the clinical and ethical issues of prolonging life through medically advanced methods for a person with developmental disabilities and unknown end-of-life choices. This

article concludes that while the care of patients with mental incapacity can be clinically and ethically challenging, end-of-life preferences can be facilitated only when the patient's legal representative and the physician(s) actively advocate for the patient's best interests and communicate frequently and openly. To read the entire article, follow this link:

[End of life Care for a Man with Developmental Disabilities](#)

► **Advanced Certified Hospice and Palliative Care Social Worker Credential Announced**

NHPCO and the National Association of Social Workers were pleased to announce the creation of the Advanced Certified Hospice and Palliative Social Worker credential. The ACHP-SW credential was developed jointly by NHPCO and NASW, and was announced at NHPCO's recent Clinical Team Conference in Dallas. It is the first national credential to recognize the specialized knowledge, skills, and abilities of professional social workers in hospice and palliative care settings. To read more, visit: [Social Work Credentials](#)

Developmental Disabilities Hospice & Palliative Care Online Discussion Forum is

a collaborative initiative by NYSARC Inc., the Hospice and Palliative Care Association of New York State, and the Center for Excellence in Aging Services with funding provided by the NYS Developmental Disabilities Planning Council.



~~The goal of the forum is to improve end of life care for persons with developmental disabilities through greater utilization of hospice and palliative care services.

~~The forum was developed to provide a safe and accessible platform that would encourage a learning dialog to take place between the developmental disabilities and the hospice/palliative care service provider communities and advocates.

~~ The forum features a professionally facilitated discussion board where registered members are able to post questions and concerns and then receive answers from experts and/or their peers on a specific topic.

- There will be no discussion for the month of November ~ **Happy Thanksgiving** ~
- Our topic for December will be '**Alternative Therapies in Palliative Care**' please consider joining us for this fascinating discussion!

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Each of you have a wealth of experience and knowledge to share, together we can create a thriving community where knowledge, ideas and experiences are shared to improve end of life care for persons with developmental disabilities and all who are close to them.

Not yet a member?

**Joining is easy!** Simply visit the forum's registration page [Here](#) and register today!

## Upcoming Events ~~ Mark your Calendar

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| <p><b>November 18<sup>th</sup><br/>&amp;<br/>December 15<sup>th</sup><br/>6-8pm</b></p> <p>O.D. Heck<br/>Development<br/>Center – Bldg 5<br/>Balltown Rd,<br/>Schenectady, NY</p> | <p style="text-align: center;"><b>Fathers Network Meeting</b></p> <p>The Fathers Network was developed to support fathers who are facing the emotions and challenges of parenting a child with special needs. All dads are invited to join the group and network with other fathers who have ‘been there’.</p> <p style="text-align: center;">***The December 15<sup>th</sup> meeting will include a<br/><b>‘Special Care Planning Workshop’</b> by William Van Evers, CLU***<br/><i>Mothers and Fathers are welcome to attend this presentation</i></p> <p>To RSVP for this event or for more information please contact Jim Swart at:<br/>518 381-4350 or JMSwart1@verizon.net</p>                                                                                                                                                     |
| <p><b>November 24th,<br/>2008</b></p> <p>Desmond Hotel and<br/>Conference Center<br/>in Albany, NY</p>                                                                            | <p style="text-align: center;"><b>12<sup>th</sup> Annual Alzheimer’s Association Conference for Caregivers</b></p> <p>This annual conference is a wonderful opportunity to hear from leaders in the field of Alzheimer's disease and learn about the latest in research and treatment options. At the conference you can attend a variety of workshops, experience the Virtual Dementia Tour, and visit with the more than 30 exhibitors who will be there to showcase their products and answer your questions.</p> <p style="text-align: center;">For more information:<br/>Call Gretchen at: 438-2217 ext 208<br/>Email: <a href="mailto:gretchen.moore-simmons@alz.org">gretchen.moore-simmons@alz.org</a></p>                                                                                                                       |
| <p><b>April 21-22, 2009</b></p> <p>Omni Shoreham<br/>Hotel, Washington,<br/>DC</p>                                                                                                | <p style="text-align: center;"><b>24<sup>th</sup> Management and Leadership Conference and the 2009 National Hospice Foundation Gala</b></p> <p>Early-bird registration is now open for the premier end-of-life leadership conference, NHPCO's 24th Management and Leadership Conference</p> <ul style="list-style-type: none"> <li>• Participate in the development and implementation of advocacy strategies to promote hospice and palliative care</li> <li>• Discuss changes in the regulatory, public policy and healthcare landscapes that impact hospice and palliative care</li> <li>• Examine best practices in advanced operations that distinguish quality programs</li> </ul> <p style="text-align: center;">For more information visit the NHPCO website here:<br/><a href="#">Management and Leadership Conference</a></p> |
| <p><b>May 28-29, 2009</b></p> <p>Saratoga Hilton<br/>534 Broadway<br/>Saratoga Springs,<br/>NY</p>                                                                                | <p style="text-align: center;"><b>HPCANYS' 29th Annual Interdisciplinary Meeting and Seminar<br/>"Embracing Change...Transforming the Future"</b></p> <p>This annual event promises to be as amazing and deeply thought provoking as in years past. It is designed to provide opportunities for networking, education, and thoughtful discussion about end-of-life care.<br/>If you can make it, it's well worth the trip.</p> <p style="text-align: center;"><b>HPCANY is providing one free registration to this conference!</b></p> <p style="text-align: center;"><u>~~This opportunity is only for those forum members who have posted on at least one discussion board. The lucky recipient will be chosen in a random drawing raffle~~</u></p>                                                                                    |

## ***As Always - We want to hear from you!***

We welcome suggestions on content for our monthly newsletter! Would you like us to list your event? Do you have a story to tell? So you have a best practice to share? If any of our alert readers come across any news, advocacy opportunities or policy issues they would like to share, or if you have a specific topic that you would like addressed in the newsletter or in a forum discussion, click [here](#) to send it along to the newsletter editor.

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