



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

June 2010 Vol. 4(6)

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Reporting on I/DD Hospice and Palliative Care Issues

In the News

► **The NY Times** June 23rd, article [‘Promise Seen for Detection of Alzheimer’s’](#) is the most recent in a series examining the worldwide struggle to find answers about Alzheimer’s disease entitled, *A Vanishing Mind*. This new article details the collaboration of Hospice patients with researchers who were determining the efficacy of a new diagnostic scan that would for the first time provide the medical field with a reliable way to diagnose the presence of Alzheimer’s in patients with memory problems.

Dr. Skovronsky decided to approach Hospice and ask if terminal patients would like to participate in the study by having brain scans now and then brain autopsies once death occurred to see if the scans showed just what the test indicated. Although some Hospice and family doctors had misgivings, they found most patients and their families agreed and said they were grateful to have been asked. The researchers then enlisted some hospice patients with a dementia diagnosis and others who did not for the study. Although this may seem controversial to some, the results were very hopeful and researchers are certain that this study will have a tremendous effect on the detection and treatment of Alzheimer’s in the future. Access the article [here](#).

► **A June 7th US News & World Report** article entitled, [‘Talk about End of Life Wishes Now’](#) discusses the importance of making clear and informed choices about treatment decisions in the event of life-threatening illnesses or accidents and making sure that they are heard and understood.

PACE uses a program called Five Wishes to help its palliative care team work with PACE participants. Five Wishes, developed by Aging with Dignity in Tallahassee, Fla., uses a five-point form to explain end-of-life options. Most states will now accept a completed and signed [Five Wishes](#) form as a legally enforceable living will. To check on your state, or to learn more about Five Wishes follow this [link](#).

► **Americans are Treated and Over-treated to Death:** this article from the Associated Press was published on June 28th in a number of news publications nationwide. The article tells the story of Rosaria Vandenberg, a young woman who died of an incurable brain tumor in 2004 and underwent aggressive treatment up until the day before she died. Rosaria Vandenberg’s sister-in-law, Alexandra Drane states that Rosario’s *‘precious time at home could have come sooner if the family had known how to talk about alternatives to aggressive treatment. We might*

have just taken her home and stuck her in a beautiful chair outside under the sun and let her gorgeous little daughter play around her — not just torture her" in the hospital. Rosaria's struggle and the outcome are all too familiar for many families ~ reporting statistics from the Dartmouth Atlas Project which tracks health care trends, the article states that *'more than 80 percent of patients say they want to avoid hospitalization and intensive care when they are dying.'* Yet the numbers show that's not what is happening ~ The National Hospice & Palliative Care Organization (NHPCO) states that, *'the average time spent in hospice and palliative care, which stresses comfort and quality of life once an illness is incurable, is falling because people are starting it too late. In 2008, one-third of people who received hospice care had it for a week or less.'* The article again brings the up controversial subject of end-of-life counseling and this article points out that it is again worth thinking about. To read the article in full, use this [link](#).

Public Policy News / Advocacy Opportunities

► **Disability Data Modernization Act** introduced to the Senate in 2009 would require that, in the questionnaires used in the taking of any decennial census of population or American Community Survey, standard functional ability questions be included to provide a reliable indicator of need for long-term care. If you are interested in reading the bill or if you would like to either express support or opposition, you can use this [link](#).

► **Ari Ne'eman appointed to serve on the National Council on Disability** Last December President Obama nominated eight new members to the National Council on Disability, which makes recommendations to the president and Congress on disability issues; one of those recommended was Ari Ne'eman, the 22-year-old founder of the Autistic Self-Advocacy Network. Early this year however, all of the nominations were confirmed except that of Ne'eman because a hold was placed on Ne'eman's nomination anonymously by one or more members of the body. Nevertheless, after months of delay the hold was withdrawn and the Senate unanimously confirmed Ari Ne'eman on Tuesday to become the first person with autism to serve on the National Council on Disability. Ne'eman has been opposed by parts of the Autism advocacy community because of his controversial position of accepting autism rather than focusing on a cure; the exclusive focus on a cure, he contends, amounts to medically engineering people like him out of existence and that the advocacy community should be *"spending at least as much money on improving our quality of life instead of trying to get rid of us."* Ne'eman made his name with such strong opinions as these, and has at times publicly butted heads with Autism Speaks, the nation's largest autism advocacy organization. A recent [NY Times article](#) points out that *"Mr. Ne'eman is at the forefront of a growing movement that describes autism as a form of 'neurodiversity' that should be embraced and accommodated, just as physical disabilities have led to the construction of ramps and stalls in public restrooms for people with disabilities. Autism, he and others say, is a part of their identity."* But for many parents whose kids are severely affected by the disorder, they want autism to go away for good, or at the very least they want their children to improve; Ne'eman, they charge, can't possibly understand this and he shouldn't be appointed a representative for the entire spectrum. Read the article using the following link: [Nominee to Disability Council Is Lightning Rod for Dispute on Views of Autism](#)

► **The Arc Joins With Other Advocates to Protect Patients/Keep Health Law Intact** Last week, the [ARC](#) filed an amicus brief (a brief offered by a person or organization who are

not a party to a case, volunteering to offer information to assist a court in deciding a matter before it) in the US District Court for the Eastern District of Virginia in response to a lawsuit filed there by Virginia's attorney general that challenges the constitutionality of the 'Patient Protection and Affordable Care Act' ([Virginia v. Sebelius](#)). Advocacy groups say that this lawsuit would weaken health reform's protection against discrimination based on pre-existing medical conditions, which would have direct implications for persons with a developmental or intellectual disability. The ARC brief urges the courts to protect Americans from frivolous lawsuits that would have the effect of undermining protections provided by the nation's new health care reform legislation.

Information and Resources

► **The Hastings Center reports** on an MRI scan helping with end of life decisions for people who have no capacity to speak or communicate their wishes. This is a fascinating article that details a study conducted by researchers from the University of Cambridge that was recently published in the New England Journal of Medicine. The article describes how functional magnetic resonance imaging or *'MRI may someday be used as a communication tool for patients with disordered conscious, in the vegetative and minimally conscious states.'*

Use the following link to read this article ~ *please note* that you may have to register on the Hastings Center site to access the article: [In the Blink of an Eye](#)

► **Experiences Of Self-Advocates Captured In Time.** A new collection of videotaped oral histories is putting the spotlight on leaders of the disability self-advocacy movement. While self-advocacy has become increasingly relevant in the last several decades, organizers of the oral history collection say there is little documentation of it, and few works have explored the rich history, culture, and significance of the movement; this life history project was undertaken to help fill this void.

The online compilation of personal stories from 13 individuals with intellectual and developmental disabilities influential in shaping the self-advocacy movement is part of a larger collection of materials on disability rights at the University of California, Berkeley library. *"The collection is perhaps the most in-depth exploration of the transformative impact and cultural meaning of the self-advocacy movement,"* said Tamar Heller, president of the Association of University Centers on Disabilities. *"Spanning over six decades, the life stories of self-advocates document how far we have come as a society while reminding us how much further we still must go."*

Self-advocates from across the country were interviewed for inclusion in the project, transcripts and excerpts of the video interviews are now available online at the Bancroft/Berkley UC Library: [Oral History of Leaders with Developmental Disabilities in the Self-Advocacy Movement](#)

► **Medical Orders for Life-Sustaining Treatment (MOLST) Update**

One June 1st the Family Health Care Decisions Act (FHCDA) became law allowing a patient's family member, including a domestic partner, to make health care decisions when the patient is not able to do so. As a result, the New York State Department of Health (NYSDOH) updated the MOLST form to make it more user-friendly and to align the MOLST form with the new law.

The NYSDOH is also developing checklists setting forth the legal requirements for issuing orders with respect to life sustaining treatment using the MOLST form, which should be

available by July 1, 2010...we will keep you informed. To access the new form posted on the NYSDOH public website, use the following link, and remember MOLST forms should be printed on bright pink paper: [DOH-5033 MOLST](#). Additional information and hard copies can be obtained from [Compassion and Support](#) - End-of-Life and Palliative Care Planning, MOLST of New York State.

PLEASE NOTE that under the FHCDA, the rules concerning medical orders issued based on the consent of surrogates have changed, it will be important to confer with legal counsel or to be sure that the appropriate official(s) in your health care facility **are consulted prior to** using the MOLST form to record orders issued based on the consent of a surrogate. *This form has NOT yet been approved by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities* for use as a non-hospital DNR/DNI form for persons with mental retardation or developmental disabilities, or for persons with mental illness who are incapable of making their own health care decisions, or for those who have a guardian appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act.

► **The NYC Office of the Self-Advocacy Association of NYS** (SANY) is engaged in an educational marketing campaign fighting to end the *“much loathed, absolutely dreaded, simply outdated & never acceptable ‘R-word!’* SANY is a grassroots, not-for-profit organization that is run for and primarily by, people with developmental disabilities. They are dedicated to debunking myths and stereotypes about disability, creating a system that is more person-centered, and teaching people with developmental disabilities how to speak out and stand up for their rights. The NYC Office has recently completed their “R-word” Public Service Announcement (PSA) created by self-advocates and consists of a series of street interviews conducted by Self-Advocates in New York City revealing the public's feelings on the "R-word". They would like for the video to be widely distributed and discussed, you can view the video using the following link and provide comments or feedback to SANY once you take a look at it: NYC Self Advocacy Office [Video on ‘R’ word](#)

SANY's next step is to engage in a poster campaign to End the ‘R-word!’ Self-advocate designed posters will be distributed on college campuses, cafes, & community centers throughout the city, letting people know that the “R-word” has to go! If you or your agency would like to be involved please contact your local office and they will email out posters for your distribution ~ to find your local office use this [link](#).

► **The Bus Stop club** is a non-profit organization that provides a wonderful opportunity for siblings of children with chronic illness or special needs to go under the care and supervision of healthcare workers and to get the support they need to help overcome the everyday battles they are faced with. *Any child, age 7-15, living in the Capital Region area of Upstate New York, who has a sibling suffering from a chronic illness or disability, is eligible to participate.* Many times, siblings face problems at home and at school that go unnoticed because their brother or sister has been diagnosed with a physical or mental disability, requiring much of the parents' attention.

The Bus Stop Club provides sessions that allow siblings to share experiences in a safe fun environment, to ask questions and to learn about the disease process that their brother or sister is experiencing. The program is **FREE OF CHARGE** but registration is required prior to attending. For more information and registration forms use the following link:

[Bus Stop Club ~ Hop Aboard](#)

► On Saturday, September 25th, the NYC Chapter of the National Down Syndrome Society (NDSS) kicks off Down Syndrome Awareness Month with a Buddy Walk in the heart of Times Square with a video presentation on the Times Square Billboard with over 200 individuals with

Down Syndrome from around the world. They are still looking for photos ~ the cut-off date to send them is July 14 and winners will be contacted the week of August 1st. Please pass this information onto anyone you know who may want to submit a photo. Click [here](#) to learn more about the buddy walk and video presentation or to submit a photo.

Professional Development and Education

► **Book Review:** [A Life Worth Living: A Doctors Reflections on Illness in a High-Tech Era.](#) Written by Dr. Robert Martensen, a professor, physician, historian, and bioethicist; Martensen recently joined the National Institutes of Health as director of its Office of History and Museum and is a 2002 recipient of a Guggenheim Fellowship. **A Life Worth Living** is a book for people facing difficult decisions when faced with serious chronic conditions or a terminal illness. Dr. Martensen draws on decades of experience with patients and friends to explore the life cycle of serious illness and demonstrates how we and our loved ones can maintain dignity and resilience as we grapple with serious and often confusing choices about how best to manage our care. Using poignant case studies, he connects personal stories with reflections on mortality, human agency, and the value of cutting-edge technology in caring for the critically ill. Timely questions emerge: To what extent should efforts to extend human life be made? What is the value of nontraditional medical treatment? How has the American healthcare system affected treatment of the critically ill? And finally, what are our doctors' responsibilities to us as patients, and where do those responsibilities end? Read an excerpt as well as editorial and customer reviews here: [A Life Worth Living](#)

► **The difference between Hospice & Palliative Care:** A topic that continues to be a source of confusion with patients and professionals alike, **Medscape** published an expert interview conducted with Gabriella Kaplan about the differences between palliative and hospice care and the ways clinicians can help patients make more use of those services. Ms. Kaplan is an oncology clinical nurse specializing in end-of-life care at Trinitas Regional Medical Center in Elizabeth, NJ. Kaplan also writes and talks frequently on this issue and presented an abstract recently at the Oncology Nursing Society 35th Annual Congress.

Addressing how clinicians can be encouraged to offer and utilize palliative care for appropriate patients, Kaplan states her personal belief that the key to opening is access to educate the patient. *"We must educate the consumer. If we educate the public, then they tell the doctors what they want. If we start teaching the public that it's OK to tell your doctor that you don't want to be in pain, or remind them that you live in a 2-floor walkup so they won't prescribe a drug that exacerbates your shortness of breath or put you on oxygen — How are you going to get up and down the stairs with an oxygen tank? If we teach consumers to speak up, I think that would be better. But it will take time; there are no quick fixes."* There is much more to this interview, you can read the entire interview [here](#).

► **Medscape** offers a study from the May edition of the *Critical Care Medicine Journal* entitled, "It's Not Just What the Doctor Tells Me: Factors that Influence Surrogate Decision-makers' Perceptions of Prognosis." Because physicians and surrogate decision-makers for seriously ill patients often have different views of patients' prognoses, the researchers undertook this study to seek understanding as to what sources of knowledge surrogates rely on when estimating a patient's prognosis to weigh care options. The study examines the diverse types of knowledge that are relied on as well as how the relationship and opinion of the

physician might influence that knowledge. Understanding these sources of knowledge may help physicians better understand and address conflicts that may emerge over patients' prognosis. For example, *“Understanding that a family member believes the patient is mentally or physically stronger than the “average” patient may help shift the physicians away from a belief that “the family just doesn't get it” and toward an appreciation of the different sources of knowledge the family is incorporating into their considerations of prognosis.”*

The entire study can be accessed on Medscape with this [link](#).

► **“Fears, Misconceptions Keeping Children from Best End-of-Life Care,”** a study published in the current issue of the *Oncology Times*, examines several issues which prevent children from receiving the best palliative care possible at the end of their lives.

The study's senior author, Dr. Joanne Wolfe, director of pediatric palliative care at Dana-Farber Cancer Institute and Children's Hospital in Boston, states that, *“Despite the best intentions of oncology teams, they don't have the time to deliver comprehensive care to children facing the end of life.”* Wolfe established a Pediatric Advanced Care Team which is considered a model for palliative care. According to the article, *“Managing disease is a small part of the teams' services. Much of their time is spent counseling parents and even patients' siblings. They also help with such practical concerns as planning home care after a hospital discharge.”* But only about half the children who die at Children's and at Dana-Farber receive the team's services. Wolfe says that parents may avoid palliative care because they mistakenly think it means they will have to give up curative treatment. However, David Browning, MSW a noted pediatric palliative care expert and Director of the Initiative for Pediatric Palliative Care in Newton, MA states *“Oncologists have some power over how families prepare for a child's death. If oncologists have a good relationship with the parents, they will listen...when physicians provide end-of-life care, children suffer less.”* An article well worth reading, access it here: [Fears, Misconceptions Keeping Children from Best End-of-Life Care](#)

**Proposals are still being accepted for the 2010
Developmental Disabilities Hospice and Palliative Care Forum
Topics!**

The Developmental Disability Hospice & Palliative Care Forum is moving to a new platform and will resume again in 2010. We are happy to announce that we are accepting proposals from professionals in the community who would like to host a forum discussion.



If you are interested in:

- ✓ Educating forum members on cutting-edge topics and ideas related to end-of-life care
- ✓ Highlighting your programs on a statewide platform
- ✓ Presenting important research outcomes

- ✓ Networking with over 350 end-of-life health care professionals
 - ✓ Gaining recognition in the hospice and palliative care field
- Then please follow this link to [complete the application](#) and submit to HPCANYS, or email me at kconnell@hpcanys.org

Upcoming Events ~ ~ Mark your Calendar

<p>July 13-July 14, 2010 9:00am-4:00pm 421 W. Columbia St, Cohoes, NY</p>	<p style="text-align: center;">Program in Aging and Developmental Disabilities</p> <p style="text-align: center;">Presented by the Rochester School of Medicine and Dentistry's Strong Center <i>Hosted by the Eddy Alzheimer's Services</i></p> <p>Medical practitioners and relatives of people with Alzheimer's can learn how to use RESPA checklists, a new method for working with patients. The event, "(RESPA) Checklists: Train-the-Trainer," will go on July 13th & 14th at the Eddy Alzheimer's Services in Cohoes NY</p> <p>Participants should expect to master the checklist technique and be able to train others in its use. Tickets cost \$200 for individuals and \$300 for two people coming together.</p> <p style="text-align: center;">Click here for more information or to register.</p>
<p>July 14-15, 2010 Beth Israel Hospital 307 1st Ave New York, NY 10001</p>	<p style="text-align: center;">Pediatric ELNEC Training</p> <p style="text-align: center;">Presented by the Hospice & Palliative Care Association of NYS Hosted by Metro Jewish Hospice, NYC</p> <p>NYS hospices and certified home care agencies are now able to provide pediatric palliative care services under the Care at Home I&II Medicaid waiver.</p> <p>Register now for this two day intensive session that the New York State Department of Health has deemed as suitable for fulfilling the staff training requirement for participation as a provider in the Care at Home I & II Waiver program.</p> <p style="text-align: center;">Click here to register online.</p> <p><i>This continuing nursing education activity was approved for 8.5 contact hours by the New York State Nurses Association's Council on Continuing Education, which is accredited as an approver of continuing education in nursing by the American Nurses Credential Center's Commission on Accreditation under approval #7RUJV8-09</i></p>

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