

Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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Editor: *Kimberly Connell*

Reporting on I/DD Hospice and Palliative Care Issues

In the News

Although Health Care Reform legislation appears to be on hold in the current political climate, it is a topic that continues to spark discussion and debate and it generates news, particularly with regard to end-of-life care for vulnerable populations. Following are just a couple of news stories and articles that have been published in the past month concerning providing care to those persons.

► Dr. Bernadine Healy, health editor of *US News & World Report* and former head of the National Institute of Health, shares her views on what the Medicare program will look like if current health care reform legislation is enacted in an article entitled, [Medicare after Health Reform: Not Your Parents Plan](#). Healy's understanding is that the outcome of healthcare reform may be that, "The government, unbeknownst to many seniors, will rein in their health expenditures ever further by imposing cost-benefit hurdles." She anticipates that the elderly will be penalized the most if the new reliance on comparative effectiveness research results in denying needed care, that hospital care will be restricted while hospice and palliative care will be expanded. She recommends being "informed as never before," taking advantage of free end-of-life counseling, having a living will, and lining up "family members plus a good doctor who will support your wishes." You can access the article using the title link above.

► **Roundtable Discussion Highlights Vital Role for Palliative Care in Health Care Reform.** A number of leaders in the field of palliative medicine recently met to discuss and explore the "*unparalleled opportunities*" that now exist for the palliative care community to help define evolving health care reform policy. The discussion, moderated by Dr. Diane Meier, explored the successful approach to end-of-life care in the Veteran's Administration health care system and how it could serve as a model for the nation. The participants urged the palliative care community to "*be more proactive in promoting education and awareness, initiating a public conversation and countering misinformation, and demonstrating to politicians and stakeholders how palliative medicine has an important role in policies aimed at improving outcomes and linking evidence-based quality measures to reimbursement.*" Last month the *Journal of Palliative Medicine* published the roundtable discussion in an article titled, [Palliative Medicine: Politics and Policy](#), which you can read in its entirety with this link.

► The **New York Times article** published January 21st 2010 entitled, '[Offering Care for the Caregiver](#)' reports on a recently published position paper by the **American College of Physicians (ACP)**, titled, '[Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships](#).' The paper, endorsed by almost a dozen other professional medical organizations, and published in '*The Journal of General Internal Medicine*', highlights the challenges that can arise from the complex interaction among patient, doctor and caregiver and offers guidelines for providing the best care. Guidelines which center on validating the role that caregivers play in the health care plan of a person with a disability, life-limiting or chronic illness and recognize that the caregiver is an important part of the health care team, too.

In the article, Dr. Arthur Kleinman, a professor at Harvard Medical School who has recently become a caregiver himself, states that the medical profession has "*had outstanding diagnoses and very careful attention to defining the problem. But once the problem is defined and the limited pharmacological interventions prescribed, there has been neither interest nor knowledge about the rest of the aftercare, even in the most simple parts like finding a home health aide or getting a needs assessment by a social worker.*" It is his hope that the recent position paper on working with caregivers, by the American College of Physicians may spur changes in the profession.

The [NY Times article](#) gives a good synopsis of the paper, but if you would like to read it yourself you can access it using the ACP title link above.

► Earlier this month, the online **Wall Street Journal Medical Blog, KevinMD.com** published an article by Dr. Kevin Sho that sounds a warning to the medical community about diagnosis and treatments of dementias when treating patients with intellectual or developmental disabilities. The blog, entitled, "[Don't fall into the dementia trap when treating a developmental disability](#)," recounts Dr. Sho's observations over the years, that many patients with an intellectual or developmental disability who are admitted to the hospital for medical or surgical problems, are often treated as if they were in the end stages of dementia. Sho states that this occurs because often persons with a severe developmental disability can be severely cognitively and functionally impaired and may, on the surface, resemble those with advanced dementia. Dr. Sho states that, "when this mistake occurs, DD patients may have necessary diagnostic and therapeutic interventions withheld even though their physicians may be very competent and believe that they are doing the right thing by not treating these "obviously declining" patients too aggressively." Use the link above to read the entire post and the accompanying comments.

► Last month the **Developmental Disability Alliance of Western New York (DDAWNY)** held a press conference on how Paterson's proposed budget will negatively affect children with developmental disabilities. More than 100 parents and support staff coping with \$152 million in cuts for their kids in western New York attended the press conference, many of whom shared their own personal stories and concerns for the future with the proposed cuts for disability services in community group homes.

*If you would like to take a look at part of this press conference use the following link which will take you to a video about 11 minutes long. [DDAWNY Press Conference](#)

Public Policy News / Advocacy Opportunities

► **The National Hospice and Palliative Care Organization (NHPCO)**, in collaboration with its lobbying affiliate, the **Alliance for Care at the End of Life**, announces Capitol Hill Day 2010 which will offer an expanded opportunity for Hospice Advocates to sharpen their skills and tell the hospice story, plus more time to cover critical ground on Capitol Hill. [NHPCO's Capitol Hill Day 2010](#) offers the opportunity to learn the ins and outs of advocacy and participate in the political process and NHPCO will help make all of the appointments for Congressional meetings and provide the necessary materials for successful interactions with your federal officials; and respite rooms will be provided where attendees will be able to network and recap during many events along the way. Follow the link above for more information and registration.

Use the following link if you would like to take a look at a short video prepared by NHPCO to encourage all Hospice professionals and advocates to join them at Capitol Hill Day: [Hospice Action Network Channel](#)

► **The Arc of the United States**, United Cerebral Palsy (**UCP**), American Association on Intellectual and Developmental Disabilities (**AAIDD**), the Association of University Centers on Disabilities (**AUCD**), National Association of Councils on Developmental Disabilities (**NACDD**), and Self Advocates Becoming Empowered (**SABE**) invite you to join them as part of a grassroots network to advocate in a bipartisan manner for national public policies promoting the full inclusion of people with disabilities in our society.

The [Disability Policy Seminar](#) program will provide you with overviews from Washington's top policy experts about issues vital to the disability community and will arm you with the tools you need to champion the issues you care about most, and then you will have the opportunity to make your case before your Members of Congress and/or their staff, who want to hear from you about the issues affecting persons with intellectual and developmental disabilities and their families. The seminar will take place April 12th – 14th 2010 in Washington, DC. For more information about this important opportunity use the following link:

[Disability Policy Seminar, Working Together for a Future that Works](#)

► **The Center for Studying Disability Policy (CSDP)** hosts a series of lunchtime webinar/seminar series providing decision makers and others with an opportunity to hear about the latest disability policy research findings and discuss implications for disability policy. Experts from the center present recently released findings and lead discussions about their policy implications. You may attend forums in person if you are in the Maryland area, or you can attend via webinar, either way you must register to participate, since space for both in-person and webinar participants are limited. Registration will be closed once capacity has been reached. To view a list of upcoming webinars, use the following link: [Disability Policy Research Forums](#). You may also view a list of previous webinars and download the accompanying Power Point presentations from this same link.

For more information on the forums, email [Disability Forums](#) or contact [Natalia Rojas](#), by email or phone: (202) 250-3539.

► **The New York State Coalition for the Aging (NYSCA)** is sponsoring a Legislative Forum on New York's response to addressing the concerns and issues confronting its aging and disabled population. The event is designed in a manner to support the work of NYSCA and their member organizations, the Statewide Caregiving & Respite Coalition of NY and the Council of Senior Centers & Services of New York (**CSCS**) as well as the myriad of providers who work to ensure that individuals of all ages and levels of ability receive programs and services in the least restrictive environment. The current NYS budget is once again forcing

providers and families to confront the realities of shrinking resources at all levels of government. NYSCA believes that it is now more than ever that we have a strong statewide advocacy voice that speaks on behalf of community-based services and that this forum will provide a platform for that voice. Morning sessions will include a state budget briefing with Senator Ruben Diaz; the afternoon session will be devoted to bringing your voices to our State represents. NYSCA will prepare you for visits to your legislative representatives and after your visits we will reconvene to get your feedback. The forum will take place on March 10th, 2010 from 9:00am to 3:30pm at the Empire State Plaza, Meeting Room 4 & 5. If you or your organization is interested in attending, contact Joanne Macklin by phone at (518) 465-0641, or email her at info@coalitionforaging.org.

Information and Resources

▶ **New York ACTS (NYACTS.org)** is a website designed to provide current information on New York State services and supports for individuals with autism. The site was developed by a partnership of 11 State agencies that form the New York State Interagency Task Force on Autism. The site was developed as a way to bring reliable, current information to the public about autism and to assist New York's families to easily find State services for their loved ones with Autism Spectrum Disorder (ASD). Because individuals with ASD may need services from different State systems – education, health, mental health and developmental disabilities services – [NYACTS](http://NYACTS.org) offers a dedicated site from which people can get the information they need without any prior knowledge of New York's service agencies.

▶ **[The Legal Guide for the Seriously ill'](#)** is a project commissioned by National Hospice and Palliative Care Organization (NHPCO), and created by the **American Bar Association Commission on Law and Aging**. The guide was designed for both the critically ill and their caregivers to help get legal affairs in order. It addresses a number of issues that have gained prominent media attention in recent years, such as paying for health care, managing health and personal decisions, and patient rights. In addition, the Legal Guide for the Seriously Ill sheds light on recent legislative and regulatory changes, such as the recently enacted American Recovery and Reinvestment Act of 2009, which provides a 35 percent subsidy of the COBRA premium for up to nine months." Follow this [link](#) to access the guide.

▶ **The Journal of American Medical Association Article (JAMA)** published an article last month detailing the journey of an 86 year old woman diagnosed with multiple chronic conditions as she contemplates the end of her life. The article points out the fact that most deaths today result from long-standing chronic disease that are managed over long periods of time with the patients' concerns about of quality of life and the fear of becoming a burden on loved ones are aspects of the disease trajectory that are often only addressed within a multidisciplinary model of care such as hospice. The article provides an excellent review of hospice care as well as an excellent justification for extending this model of service to provide benefit earlier in the disease trajectory. If you would like to read the article, use the following link: [An 86 Year-old Woman with Cardiac Cachexia Contemplating the End of Her Life: Review of Hospice Care.](#)

▶ Last month **Medpage Today** published an article summarizing the results of a recent study reprinted in the *Clinical Journal of the American Society of Nephrology*, entitled, [“End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease.”](#) The article reports the results of a survey of 584 patients conducted by Dr. Sarah Dawson of the University of Alberta. The survey questions covered five main areas: self-reported

knowledge, importance of certain issues relating to advance care planning, patients' preferences for end-of-life care, and the status of current plans. Of those surveyed, only 8% of patients reported talking about end-of-life issues with family physicians, but 39% indicated that they wanted such discussions. Nearly half of patients with advanced chronic disease said they would like to make advance care plans with their physicians, but only 10% had actually discussed it. Commenting on the study, Dr. Daniel Cukor of Downstate Medical Center in Brooklyn, N.Y. stated that, *"It is not sufficient for the treatment team to be working only toward preserving life, but as patients become more ill, it is appropriate to help support patients' contemplation and facilitation of their end-of-life wishes."* This is a position shared by Dr. Dawson, who states that although the study showed that professionals as well as patients lack knowledge of end-of-life issues her recommendation going forward is that *"end-of-life care policies and resources be directed toward ensuring that patients die in their location of choice, which includes not only home but within-institutional settings, such as inpatient hospice."* To read the entire article, use the following link:

[Kidney Patients Fault Advance Care Planning](#)

Professional Development and Education

► **Book Review:** '[Sick to Death and Not Going to Take It Anymore!](#)' although this book was written several years ago by Dr. Joanne Lynn, it remains very relevant to the current national focus on health care reform. Dr. Lynn points out that our current health care system, like our concepts of health and disease, were developed at a time when life was mostly short, serious illnesses and disabilities were common at every age, and dying was quick. The book maintains that health care and community services are not equipped to meet the needs of people who face a prolonged period of progressive illness and disability before death. Lynn offers what she calls "an owner's manual for the health care system," which lays out facts, concepts, strategies, and action plans for genuine reform and gives the reader new ways to interpret information creatively, imagine innovative possibilities, and take steps to implement them. While you can purchase a copy of this book, you can follow the link above where you will find the complete book online on the Palliative Care Policy Center website.

Also, if you are interested, use the following link and listen to a [podcast](#) of Jackie Judd, a vice president of the Kaiser Family Foundation, talking with author Dr. Lynn about the importance of creating different care systems for persons (and their caregivers) suffering from chronic illness or disabilities. This is really worth a listen.

► **The Hospice Foundation of America (HFA)** September 2009 Webinar, [Supporting People with Intellectual Disabilities through Illness, Grief and Loss](#)' has been archived and will be available through September 2010. The webinar features Dr. Claire Lavin and Dr. Kenneth Doka, who discuss the differences, and the similarities, in how persons with intellectual disabilities may respond to the illness and death of a loved one. And as societal and medical changes have occurred, persons with intellectual disabilities are living longer and therefore facing their own illness and dying. Dr. Lavin will share her experience about some of the challenges that all caregivers face, and the need for more education and partnership to better serve this population. To view this archived webinar or to preview those presented in 2010, follow this [link](#).

► **The Advocate Institute is offering their Deluxe Webinar Collection CD: 32 Ways to Become a Better Advocate.** The CD contains 32 of the 90-minute Advocate Academy Webinars conducted between the Fall of 2006 and the Spring of 2009 plus all related

materials. This offers you or your organization over 48 hours of information presented by the nation's leading experts on an array of topics critical to special education advocacy. You can view all webinar titles by following this [link](#). If interested use the following link to purchase the collection for only \$49. [Advocate Academy Deluxe Webinar Collection CD](#)

► **People Planning Ahead: Communicating Health Care and End of Life Wishes**

Helping someone make healthcare and end-of-life decisions is one of the most profound services any of us can provide. [People Planning Ahead](#) is a new hands-on manual that provides a thorough approach to helping people through this challenging process in a way that is respectful and person-centered. The manual is an excellent resource for professionals and for family members and is useful for use with individuals of any capacity.

- Provides a structured way for planners to gather and organize information on a person's values, goals, and life and turn it into a detailed life plan
- Contains guidelines on planning stages of lives of an illness
- Includes plain language definitions of such terms as living wills, advance directives, competency, and capacity as well as other insights into end-of-life issues.
- Electronic questionnaires on accompanying CD-ROM make it easy to store and archive essential information
- Assists a person no matter where they may be on the wellness continuum, from healthy adults to those diagnosed with terminal illnesses.
- Comes with customized training workshops on end-of-life and person-centered planning

Click [here](#) to learn more about the manual, read a synopsis or preview the book.

► **The American Association on Intellectual and Developmental Disabilities**

(AAIDD) offers customized one day, two day and more comprehensive training programs to organizations providing end-of-life care services on implementing the person-centered planning practices contained in the [People Planning Ahead](#) manual as discussed above. For more information, please send an email to books@aaidd.org or call 800-424-3688.

► **The American Association on Intellectual and Developmental Disabilities**

(AAIDD) [Aging and End of Life Series](#) announces a new Webinar Series Scheduled for 2010. A new webinar will be presented on the 3rd Wednesday of every month.

Follow the link above to take a look at the 2010 schedule.

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If you missed January's AAIDD webinar presentation, '**Dementia among Adults with Down Syndrome,**' you can still register on the AAIDD site to listen to the archived webinar and download the accompanying materials by following this [link](#). This presentation will provide an overview of the information currently available on progression of dementia among adults with Down syndrome. General background material will be presented regarding the connection between Down syndrome and Alzheimer's disease, and findings from a large ongoing research program will be presented with an emphasis on individual differences in age of onset of dementia (i.e., risk) and rate of symptom progression. Additional findings regarding the effectiveness of "cognitive enhancing" medications will also be discussed, as will evidence supporting possible strategies for delaying declines in cognitive and functional abilities in vulnerable individuals.

► **The American Medical Student Association and Vitas Innovative Hospice Care (AMSA-VITAS)** announces an **End of Life Education Fellowship Program**. This is a six-week summer program designed to introduce medical students to end-of-life (EOL) issues.

This program offers an exciting and aggressive curriculum where students will be a part of a multidisciplinary team with the following objectives:

- Develop and practice basic interviewing and communication skills essential to EOL care
- Understand the psychological, sociological, cultural and spiritual aspects of death and dying
- Understand the pathophysiology and management of common symptoms at the end of life
- Recognize and respond to cultural, linguistic, and spiritual diversity
- Design and develop a plan for integrating EOL education into the curricula of the students' medical schools and residency programs.

\*\* Applications are now being accepted through March 22<sup>nd</sup>, 2010. The program will be held in Fort Lauderdale, Florida from June 21<sup>st</sup> – July 30<sup>th</sup>, 2010...there is no charge for the program and a 'Fellows Stipend' will be provided to help cover expenses. Use the following link for more information and registration.

[\*\*AMSA-VITAS End of Life Education Fellowship Program\*\*](#)

► **The Center to Advance Palliative Care (CAPC)** announces an important upcoming Audio Conference:

[\*\*Incorporating Palliative Care Services into Long Term Care Facilities\*\*](#)  
Thursday, March 25<sup>th</sup> 2010 from 1:30pm – 2:30 (Eastern Standard Time)

This presentation will discuss several models for increasing access to palliative care within long term care settings and speaks to some of the barriers that currently exist and will address the following objectives:

- Describe the demographic imperative and need for palliative care in long term care settings;
- Discuss current models of practice;
- How hospital palliative care programs impact hospital mortality data; and
- Discuss bedside care expectations for palliative care in long term care settings.

\*\* If you would like to register for this conference, take a look at the other educational opportunities currently being offered, or learn about the Continuing Education Credits available, simply follow this link: [\*\*CAPC Audio Conferences\*\*](#)

### **Announcement**

**Proposals are now 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 the Spring of 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 RFP](#) and submit to HPCANYS, or email me at [kconnell@hpcanys.org](mailto:kconnell@hpcanys.org)

**Upcoming Events ~~ Mark your Calendar**

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| <p><b>June 9<sup>th</sup> – June 11<sup>th</sup> 2010</b><br/>Providence, Rhode Island</p>                                           | <p><b>134<sup>th</sup> Annual Meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD)</b><br/><i>Imagining the Future, Celebrating the Past</i></p> <p><b>Patrick J. Kennedy</b>, who represents Rhode Island’s First Congressional District in the United States House of Representatives and the late Senator Kennedy’s son, will speak about his father’s vision and his family’s impact on the lives of people with intellectual and developmental disabilities and our field’s and association’s work.</p> <p>Click <a href="#">Here</a> for more information and registration.</p> |
| <p><b>Live Teleconference</b><br/><i>broadcast via-webcast and satellite on Wednesday, March 21<sup>st</sup>, 2010</i></p>           | <p>Hospice Foundation of America (<b>HFA</b>) Announces the <b>2010 National Bereavement Teleconference - Living with Grief: Cancer and End-of Life Care</b></p> <p>The teleconference will address care options related to cancer diagnoses as well as loss and grief reactions for patients, families and professional caregivers and will examine psychosocial aspects of cancer, pain management, and ethical issues related to the disease.</p> <p>To participate:<br/><a href="#">Register online now</a> or <a href="#">mail/fax your registration form.</a></p>                                                     |
| <p><b>April 12-14, 2010</b></p> <p>Hyatt Regency Washington<br/>on Capitol Hill<br/>400 NW New Jersey Avenue,<br/>Washington, DC</p> | <p><b>AAIDD Disability Policy Seminar</b></p> <p>The Seminar program will provide you with <b>overviews from Washington’s top policy experts</b> about issues vital to the disability community and will arm you with the tools you need to champion the issues you care about most.</p> <p>For more information and registration,<br/>please visit the Disability Website:<br/><a href="http://www.disabilitypolicyseminar.org/">http://www.disabilitypolicyseminar.org/</a></p>                                                                                                                                           |

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| <p><b>April 16<sup>th</sup>, 2010</b></p>                                                                                           | <p align="center"><b>2<sup>nd</sup> Annual National Health Care Decisions Day (NHDD)</b></p> <p>The <b>(NHDD)</b> initiative is a collaborative effort of national, state and community organizations committed to ensuring that all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions.</p> <p>If you or your organization is interested in learning more, or to download the application or participation form please visit: <a href="http://www.nationalhealthcaredecisionsday.org/">http://www.nationalhealthcaredecisionsday.org/</a>.</p>                  |
| <p><b>April 17<sup>th</sup>, 2010</b><br/>Bulmer Communications Center,<br/>Hudson Valley Community<br/>College, Troy, New York</p> | <p align="center"><b>The Capital Region Caregiver Coalition announces the 2010 Educational Day for Caregivers:</b></p> <p align="center"><b>Tools for Caregivers: Resources you can use when a senior relies on you</b></p> <p align="center">Workshops, Continental Breakfast, Keynote Address,<br/>Caregiver Connection Corner and Resource Fair!</p> <p align="center"><b><i>If you think you can't attend because you're caring for someone, Free Respite care available at an Eddy Daybreak Adult Day Care site nearby!</i></b></p> <p align="center">Advance registration is required, so please call 382-8481 ext.1238 for more details!</p>                 |
| <p><b>April 22 - 24, 2010</b><br/>Omni Shoreham Hotel<br/>Washington, DC</p>                                                        | <p align="center"><b>NHPCO's 25th Management and Leadership Conference:</b><br/><b>'Securing Our Roots, Expanding Our Reach'</b></p> <p>Each year NHPCO designs new educational programming for the Management and Leadership conference, reflecting the latest trends and innovations in hospice and palliative care and addressing all aspects of management and leadership. NHPCO invites leaders in end-of-life care to attend this conference.</p> <p align="center"><b>To learn more or to register use the following link:</b><br/><a href="http://www.nhpc.org/i4a/pages/index.cfm?pageID=5998">http://www.nhpc.org/i4a/pages/index.cfm?pageID=5998</a></p> |
| <p><b>May 13<sup>th</sup> &amp; 14<sup>th</sup>, 2010</b><br/>Marriot Hotel<br/>189 Wolf Road, Albany, NY</p>                       | <p align="center"><b>HPCANYS 30th Annual Interdisciplinary Seminar and Conference</b><br/><b>Mission – Vision – Reality ... Celebrating 30 Years!</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.</p> <p align="center">This year HPCANYS is celebrating its 30th year of service!!!<br/>If you can make it, it's well worth the trip.</p> <p align="center">For more information visit: <a href="http://hpcanys.org/index.asp">http://hpcanys.org/index.asp</a></p>                     |
| <p><b>May 20 &amp; 21, 2010</b><br/>Holiday Inn<br/>232 Broadway Saratoga<br/>Springs, NY</p>                                       | <p align="center"><b>SAVE THE DATE!</b><br/><b>19th Annual Third Age Conference</b><br/><b>Sponsored by the New York State Third Age Committee</b></p> <p>The Third Age Committee is dedicated to focusing on issues for aging persons with developmental disabilities, they sponsor this annual conference, provide a network of experienced trainers, as well as guidance and feedback to New York State's Office of Mental Retardation and Developmental Disabilities Aging Services.</p> <p>More information about this event will follow, but to learn more visit the <a href="#">Program in Aging and Developmental Disabilities</a> website.</p>             |

**May 27<sup>th</sup>, 2010**  
Buffalo Convention Center

### **Developmental Disability Awareness Day 2010**

Western New York Developmental Disabilities Awareness Day will be held this year on Thursday May 27, 2010 at the Buffalo Convention Center. Nominations are being accepted until March 9th for the Annual Appreciation Awards.

[Read more...](#)

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