



# Long Term Care

As Unique as a Fingerprint



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## As Unique as a Fingerprint



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Our national partner, LeadingAge, is an association of 6,000 not-for-profit organizations dedicated to expanding the world of possibilities for aging. Together, we advance policies, promote practices and conduct research that supports, enables and empowers people to live fully as they age.

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Founded in 1961, LeadingAge New York represents more than 500 not-for-profit, public and mission-driven senior care providers, including nursing homes, senior housing, adult care facilities, continuing care retirement communities, assisted living, home care and community services providers which serve approximately 500,000 people across New York each year.

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## A Unique Fingerprint

A baby unable to breathe independently due to prematurity. A teen with terminal cancer. An adult in need of specialized bariatric care. A 50-year old woman in need of specialized memory care. A person with developmental disabilities whose parents are no longer able to provide care due to age. A returning veteran with special needs.

They all are part of the continuum of long term care but they often don't fit within mainstream models or payment structures.

For many LeadingAge New York members, serving a non-aging-specific or special needs population within long term care is their everyday business and sometimes the focus of their mission. In this issue of *LeadingAge New York Adviser*, a series of articles and interviews illustrates the themes, challenges and success of providing for people's needs that fall outside of the traditional definition of long term care.

Three providers of long term care services to children – Elizabeth Seton Pediatric Center, St. Mary's Healthcare System for Children and St. Margaret's

Center – explore how mission keeps pace with the changing landscape of healthcare, the challenges of a changing and uncertain payment structure, and highlight the purpose of their missions through amazing success stories.

Several other members talk about their forays into specialty populations including People, Inc., Cobble Hill Health Center and Livingston County Center

for Nursing and Rehabilitation. Finally, a series of articles contributed by the Hospice and Palliative Care Association of New York State explores the many different populations that are served by hospice and palliative care.

In the Spotlight feature you are introduced to Dylan Wrixon, LeadingAge New York's new government relations analyst. You can also find member achievements and happenings in the Noteworthy section.

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Sincerely,

A handwritten signature in black ink, appearing to read 'James W. Clyne Jr.'.

James W. Clyne Jr.  
President and CEO

*For many LeadingAge New York members, serving a non-aging-specific or special needs population within long term care is their everyday business and sometimes the focus of their mission.*



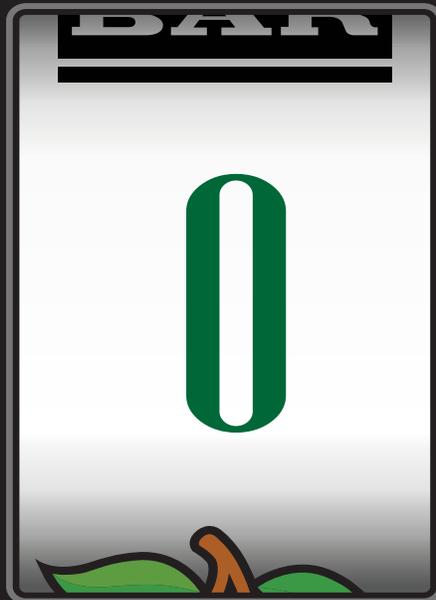
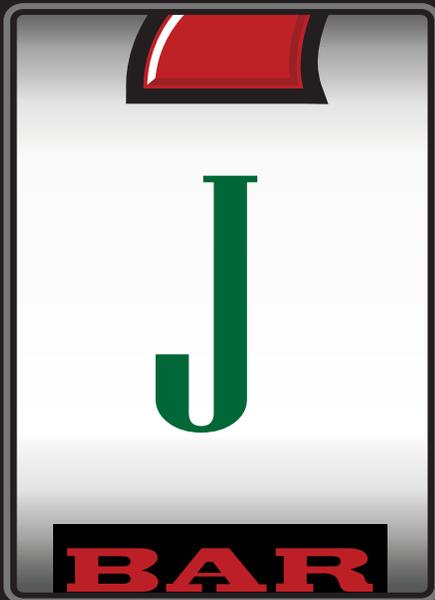
“ (We) contracted with ProCare to analyze our quality measures and care. Within just a few hours, (the consultant) ‘hit the nail on the head’ and gave us excellent advice. Our New York State Quality Score went from the 5<sup>th</sup> quintile to the 2<sup>nd</sup>!”

– Genesee County Nursing Home

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## Welcome Dylan Wrixon

*Meet Dylan Wrixon, government relations analyst*

*Dylan is the newest addition to LeadingAge New York's advocacy and public policy team.*

### **What attracted you to bring your talents to LeadingAge New York?**

LeadingAge NY has been proven to be one of the top places to work in New York State and offers many opportunities for me to showcase and use my skills from my past work experience.

### **Tell us about your past experiences and strengths that will lend themselves to this new role.**

The combined experience I have with the law firm Wilson Elser and the New York State Assembly allows me to approach issues from all angles. I have been involved in budget negotiations and a wide variety of issues. In the New York State Assembly I was responsible for the Government Employees Committee, the Woman's Task Force and Child Care workgroup. Tracking a wide variety of legislation has led me to this great opportunity at LeadingAge NY.

### **What are your career goals and how do you hope to grow through this role?**

I hope to be able to further understand the complex issues that relate to seniors in New York State and make a positive impact. I plan to grow extensively by learning these issues and contributing as a member of the team to the great work done by LeadingAge NY.

### **Did you have a mentor in your life and how did that relationship help build the person you are today?**

My mentors included many of the lobbyists at Wilson Elser. They help me to build knowledge, understand issues and ultimately understand the process of New York State legislation. After leaving Wilson Elser, my coworkers in the New York State Assembly broadened my view with a variety of issues that assisted me in learning how to understand constituent issues and to further understand the legislative process.

### **What keeps you up at night?**

What keeps me up at night is a loaded question. If it isn't my eight month old son, my dog or issues with my home, it is legislative issues that are out of my hands. I do everything in my power to keep everyone informed about legislative issues, but when it comes to breaking bad news, such as a bill we advocated for that doesn't go our way, it's never easy.

### **Do you have any special interests that help you maintain work/life balance? Tell us something surprising about Dylan Wrixon.**

Work/life balance for me is simply taking care of my family to the best of my ability. What are we without family? I wake up every day and ask myself how I can make things easier for my wife to better take care of and help our son develop.

### **What did we ask that we should have asked to know the real Dylan?**

One question that no one would know to ask given my role at LeadingAge NY is my unique collection of degrees. I originally received my Bachelor's degree in Mathematics and my Master's in Educational Psychology. The degrees I possess combined with my experience make me a very well rounded individual that is ready to take on any complex issue. 🌱



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## Find Out if Your Group Purchasing Pricing Is REALLY the Lowest?

Understanding the value of your current vendor relationships is critical. Given the uncertainty in the reimbursement system for senior living providers, organizations must be sure they are accessing competitive prices for quality goods and services. Even if you are currently purchasing through a Group Purchasing Organization, you may be able to save additional money. Value First can help you find savings through free cost studies in major spend categories including outsourced dining and rehabilitation services, food products, office supplies, medical supplies and janitorial and sanitation supplies.

Finding your savings is really easy. First, let us know that you want to participate in a free cost study and for what spend category. We will send you information detailing what specific data you will need to provide. Gather the data from recent invoices or directly from your distributor and submit it electronically to LeadingAge New York.

You're probably thinking this is going to be hours and hours of work and that you just don't have the time, right? Well, it's actually not that complicated or time consuming. Here are a few examples, of how you can save money on your bottom line.

*Remember that Value First can often beat any price you can negotiate directly with the vendor.*

Value First is the long term care division of MedAssets representing over 9,000 vendor contracts that can help you save significant money. When purchasing products your final cost includes the amount charged by the manufacturer in addition to the mark-up from the distributor and any applicable rebates. So, if the cost from the manufacturer is \$100 for a case of product and the distributor markup is 20 percent, you're paying \$120. Purchasing 500 cases annually would cost you \$60,000. Locating the cost savings involves examining and negotiating prices with both the distributor AND the manufacturers and negotiating both the actual unit cost and the mark-up.

First, let's look at the middle man, because it's always the middle man right? If you negotiate the markup at 15 percent per case, then your total cost will be \$115 and at 500 cases annually you will pay \$57,500. Your total savings will be \$2,500 or 4.2 percent.

If we negotiate with the manufacturer to bring the cost down to \$80 per case PLUS the lower 15 percent markup then your total cost per case is \$92 for a total annual cost of \$46,000 and a negotiated savings of \$14,000 or 23.3 percent.

So, how do you access manufacturer discounts? If you are a small provider or a very large multi-site provider you can attempt to negotiate directly with manufacturers. However, the process is labor intensive and leverage is limited to your annual spend in that specific

(See *Find Out* on page 10)





*Value First can help you find savings through free cost studies in major spend categories including outsourced dining and rehabilitation services, food products, office supplies, medical supplies, and janitorial and sanitation supplies.*

## Find Out ... (Continued from page 9)

category. Instead, you can access manufacturers through a GPO, leverage the spending of thousands of providers and off-load the negotiations to the GPO.

Remember that Value First can often beat any price you can negotiate directly with the vendor. Even if you belong to another GPO, unless it is an exclusive arrangement, give Value First a chance to save you money. Even if it is an exclusive arrangement, it never hurts to have information as leverage to use in your current arrangement.

Okay, you've got the facts, you know the results and, what is needed to get started. So, what are you waiting for? Start your savings today! 📄

*For more information contact: Sarah Daly at 518-867-8383 ext. 160 or by email at [sdaly@leadingagency.org](mailto:sdaly@leadingagency.org).*





## Bad People Want Your Patients' Data!

Cybercrime in the healthcare industry has become a complex social and political issue, with data security breaches making news every day. Both the private and public sectors are having data security challenges. Nobody is immune. There have been highly visible private attacks, like University of California, Los Angeles (UCLA) Health Systems, Accenture, and Blue Cross and Blue Shield. The government is just as susceptible. Remember the Department of Defense hack and Healthcare.gov breaches? The financial costs and damages to reputations are massive to the government, healthcare organizations, and patients. More importantly, individuals are affected financially and emotionally from this loss of privacy.

### Here are some numbers to put things in perspective:

- Over the next five years, data breaches will cost U.S. health systems \$305 billion in cumulative lifetime revenue.
- According to the U.S. Department of Health and Human Services, nearly 1.6 million people had their medical information stolen from health care providers last year.
- According to Accenture, it is estimated that one in 13 patients, approximately 25 million people, will have personal information stolen over the next five years.

While data security breaches used to be what happened in other industries, hackers are now selling stolen health information for several times the amount of stolen credit cards. As the health care industry becomes more reliant on

Information Technology (IT), a single data security breach can cripple a facility.

Appropriately, healthcare is held to a very high standard for information systems and data security. The challenge to protect and secure data is overwhelming for organizations to resolve. In order to compete in a very competitive marketplace, healthcare organizations must expand their abilities to exchange and use data, and embrace the new technologies that enable telehealth and telemedicine.

However, they must protect sensitive patient data while maintaining an aggressive cyber posture against threats. Not an easy task.

Skimping when it comes to security never has a positive impact on the bottom line. You get what you pay for. No company has ever regretted paying for the security and peace-of-mind a carefully planned security strategy delivers. The “bad guys” will always try to be a step ahead, but, as long as you place an emphasis on keeping the most up-to-date precautions in place, and encourage best practices and employee involvement in the ongoing protection of company assets, you can take the mystery out of data security and maintain the upper hand. 🌱

*Dennis O'Connell, director of healthcare solutions, Custom Computer Specialists can be reached at [www.customtech.com](http://www.customtech.com).*

*No company has ever regretted paying for the security and peace-of-mind a carefully planned security strategy delivers.*

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# Long Term Care

## AS UNIQUE AS A FINGERPRINT

Often when thinking about long term care thoughts go to some type of congregate setting that is designed to meet the needs of an aging population by delivering quality care and services. For many LeadingAge New York members this is a good analysis of their missions. However, for some the long term care needs are geared in whole, or in part, to a much younger or specialized population.

Realizing the long term care is indeed as unique as a fingerprint, LeadingAge New York Adviser reached out talk to some members serving special populations within long term care to explore some key questions including: how mission changes as needs change, how has managed care affected their services, what issues keep them up at night, the definition of success and future plans. Also in this section, a series of articles about hospice and palliative care, itself a niche within long term care, illustrate special populations and issues that require unique approaches and offerings.

## ST. MARGARET'S CENTER

By Beth Barends, executive director

As a Pediatric Skilled Nursing Facility in Albany, St. Margaret's Center, is committed to supporting the clinical and social needs of its residents to create and afford opportunities for them to reach their greatest potential. St. Margaret's has a long and rich history beginning in 1883 as a small home for abandoned babies. It had ties to the Episcopal Church and was named after the patron saint of orphans. St. Margaret's flourished and grew and moved to new locations over time. Today's location has been its home since 1936.

Today St. Margaret's is home for 92 children and young adults. It is part of a larger continuum of programs and services for people with disabilities that are offered by our parent corporation, the Center for Disability Services.

St. Margaret's is the only skilled nursing facility in New York State with a single, dedicated campus for both children and young adults. Admissions are accepted for children from birth to age 21 and for young adults ages 21 to 40. Our 20-bed Young Adult living unit was created in 1999 in response to our children living fuller, richer and healthier lives. This addition allows our children to continue living in this home into adulthood where their medical and clinical needs are addressed

with an abundance of specialized therapies and approaches for people with chronic developmental and physical disabilities. In 2010 we further expanded the facility to include pediatric ventilator and respite care.

St. Margaret's is committed to providing the same vibrant, fun, and enriched life experiences that all children and young adults should have regardless of whether they live with significant medical and physical diagnoses. Toward this goal we bring many talents into the facility to entertain as well as hosting field trips into the community. Our residents have recently enjoyed pumpkin picking, holiday parties, movies and the New York State museum in our local community.

St. Margaret's has been in a place of aggressive growth and transition during the past five years. Historically, most of our residents have lived at St. Margaret's for the long-term. Today, many of our children transition to their parents' homes once clinically stable and their families are well prepared for providing their child's care. We celebrate these many achievements and are proud to have successfully weaned one-third of our children from their ventilators, allowing for most of these children to transition back to their

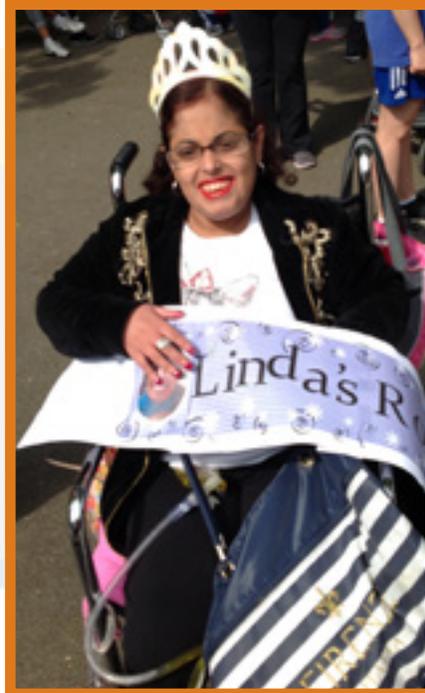
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family's homes despite significant medical needs. The therapy team delivers fabulous gains for our residents otherwise thought unlikely to progress, including therapies that have assisted residents with traumatic brain injuries to learn to walk and speak again.

As St. Margaret's moves into the future, we will collectively learn and grow with our residents, their families and our community. Many opportunities lay ahead as we adjust for increasing acuity of our residents and the associated cost of this care, advancing technology, diminishing community resources and complex reimbursement models. Our compassionate team is always focused on the individual residents and how to help each resident get better at life while advancing our facility's skills and systems for delivering highest quality of care. 🌈



# BARIATRIC CARE LIVINGSTON COUNTY CENTER FOR NURSING AND REHABILITATION

Interview with Franklin Bassett, director of long term care

## **What is your mission?**

Our mission is simple; we are dedicated to meeting the diverse healthcare needs of the community in a warm and caring environment where individuals are treated with compassion and respect. We support those facing life's challenges that come to us for care.

We are not a traditional nursing home operator per se as we market multiple nursing center service lines, which include: transitional care, memory care, respite, hospice, bariatric care, chronic care, medical model adult day health care and outpatient rehabilitative services.

## **Has the mission changed significantly over the life of the organization?**

The mission has changed significantly. The Livingston County Center for Nursing and Rehabilitation traces its origins to June 10, 1829, when the Livingston County Alms House and Farm was established on one hundred and thirty-six acres of land in the village of Geneseo, to serve "lunatics, paupers, deaf and dumb, blind and idiots." How times have changed!

In 2005 Livingston County closed two freestanding nursing homes, constructed in 1934 and 1964 with 314 beds, and consolidated services in a newly constructed

266-bed facility designed in the Neighborhood model. The new facility abandoned the traditional double load corridor construction design in favor of 12-bed Family Units; four Family Units comprise a Neighborhood. The Family Unit format has enabled service to discreet populations, among them a Bariatric Care program to serve morbidly obese individuals weighing up to 650 pounds.

## **What challenges do you feel are unique to serving this niche?**

There have been, and continue to be, numerous challenges. After ten years of service to bariatric individuals we have had to adjust expectations. While we had envisioned the program to be restorative in focus we have realized primarily chronic care outcomes. Social Work, Dietary and Nursing are challenged by the dual impacts of addiction and depression and the persistence of behaviors preventing rehabilitation despite programming for physical exercise and nutritional and psychological counseling. Staff sensitivity training is ongoing in effort to balance clinical management plans with resident rights of self-determination, principally issues related to meal portion sizes, fluid intakes and physical activity.

*(continued on page 18)*

*(continued from page 17)*

The bariatric population requires an environment designed and engineered around their unique needs. Specifically, split panel entry doors to resident rooms, tracked panel privacy curtains on bathrooms in lieu of doors, ceiling-based Transactive lifting equipment above beds, tubs, toilets and showers, 48-inch wide beds, bariatric bedside chairs, toilet supports and bariatric capacity scales. Transport vehicles must have lift gate widths and load capacities to enable transport to off-site medical appointments. A bariatric gurney for transferring and transporting residents is essential. The facility's emergency management plan must include a means for manual resident transfer via lift chair in the event stairwell evacuation is needed. A fall to the floor requires a specific Fall Team plan for enabling safe resident positioning onto a sling and mechanical lift transfer to chair or bed.

### **What keeps you up at night?**

Knowing that the fight against obesity in the general population is being lost and that referrals for admission are increasingly in need of some degree of bariatric services. As an organization we are replacing standard 36-inch beds with 42-inch widths as part of our capital improvement plan in an effort to reduce fall risks, improve safety with bed mobility and to expand the organization's ability to serve this population outside of the dedicated 12-bed Bariatric Care Program. The safety of staff and the individuals served is the gravest concern.

### **What does the future look like for the next 5-10 years for your mission?**

On December 3, 2005 the Center opened its doors and forever changed how the Livingston County community would experience nursing



home care. The occasion of our recent 10th anniversary has prompted reflecting on the recent past with pride as we understand the role our organization serves in the local health care community and the regional economy. As to the future, we will continue to explore, develop and implement niche services to meet community need. I anticipate services in our setting will grow increasingly subacute and hospital-like in focus as payer pressures and reimbursement methodology reforms compel a shift away from traditional “bed and breakfast” patient types; home- and community-based services will serve many of these patient types. Organization sustainability, particularly as a public provider, will hinge on expanding clinical competencies, expanding acute care collaborations and growing referral volumes by being the provider that delivers services meeting community needs. The future is exciting! I have always strived to provide aspirational leadership and the next several years will require a team that shares ownership and sustains its motivation as we seek to reinvent ourselves, yet again.

### **Tell us a success story that speaks to your mission.**

An inspiring case is that of “Mary,” a 68-year-old female admitted to the Bariatric

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Care Program at a weight of approximately 325 pounds. She had extensive abdominal hernias and due to her weight and discomfort was unable to drive her car, was homebound, socially isolated and unable to walk; a fall in her home led to hospitalization. On admission to our program Mary met with the care team and learned about the weight loss assistance services available to her. After evaluating her options Mary elected not to have gastric bypass or a lap band procedure, she chose to lose the weight on her own. Mary engaged the Registered Dietician for nutritional counseling, rehabilitative services for an exercise plan and psychological services for counseling. Mary embraced portion control and educated herself to make better food choices, she attended Physical Therapy to regain her mobility and actively participated in an exercise program, she also participated in on-going meetings with a counselor, and twelve months later, with support from her family and care team, Mary had lost 125 pounds. Because of the weight loss Mary was finally a surgical candidate for repair of the hernias that had plagued her for years. The surgeon was so impressed with Mary's weight loss success he agreed to perform a panniculectomy to remove excess skin at her abdominal fold at no cost to Mary while performing the hernia repairs.

After Mary's post surgical recovery she returned home, has begun driving a car again and has resumed life interests and pursuits. She continues to visit the program on occasion to stay in touch with staff and share her ongoing success. She has not regained the weight.

**Is there anything you would like to add related to serving people needing long term care who are not an aging population?**

*Two thoughts:* Significance of Language and Physical Plant Design Language. The language we use when characterizing our organization to business partners, our Board and the community is important when trying to change perceptions and acceptance among all ages of potential consumers. We do not refer to ourselves as a nursing home; we are a nursing center. I have never presented to a group where a single hand was raised when asked if anyone looked forward to one day living in a nursing home. The term nursing home generally evokes negative imagery attributed to a perception that it is a place where the aged go to die. There is greater acceptance of the concept of a nursing center.

We represent ourselves as a residence in which needed long term care services can be received whether the individual is 19 or 99 without unreasonable loss of lifestyle. We believe in relationship building and have permanent staff assignments to honor resident preference profiles that reflect normalcy of waking, sleeping, bathing and eating and social engagement routines. Preserving the ideal of individuality makes it possible for younger residents to preserve identity and accept the environment.

We have tremendous flexibility in our physical plant layout to convert any 12-bed Family Unit for homogeneous services to discreet programs including those that may serve younger, non-traditional patient types. We are well positioned to meet the needs of any future patient type, regardless of age. 🌈

# ELIZABETH SETON PEDIATRIC CENTER

Interview with Lisa Pascanzer, vice president of operations

## **What is the mission of Elizabeth Seton Pediatric Center?**

Established in 1988, our mission is to be a center of pediatric rehabilitative and palliative care for the most vulnerable children in New York City's five boroughs and surrounding counties. The children have medical complexities, multiple medical conditions and cognitive impairments. We serve children from birth through 21 years old. Over the years the acuity of the children has really intensified. When we first started, our children were a little more cognitively aware and now they have a lot of medical complexity and multiple diagnoses. We see a lot of prematurity that leads to underdeveloped systems including respiratory and digestive, cardiac issues, cerebral palsy and more. We seek to take care of them and their families because when you take care of pediatrics you take care of the whole family, not just the child.

## **What changes have you noticed over time?**

The children were not as acutely complex as they are now. We are seeing more children with respiratory issues and we see a lot of children with ventilator dependent needs. Those are the kids that we have chosen to focus on with the development of our ventilator program.

## **Why do you think that's increased so much? Prematurity?**

The advancements in medical, pharmaceuticals and technology and being in the New York City

area we are surrounded by hospitals who have the most cutting-edge technology and the best resources available. So many children are saved at birth and thrive because of the care that's available to them now.

## **That creates some challenges for the system.**

It's challenging but we like to think it's a blessing. Our kids are the most innocent, loving, wonderful children you could ever hope to meet. Every day we are very happy that we can help them. They give to us as much if not more than, we give to them.

## **Do you specialize in any areas of care within that core mission?**

We have done very well with comprehensive feeding programs. For children who are born with a lot of difficulty with oral intake, we're able to help wean them from a feeding tube and help them get to the point where they can go back home and be with their families. Approximately 20-25 percent of our children go back home. We have a lot of little babies that come to us for nutrition therapy.

Of course the other area that we're currently expanding is our ventilator dependent care. We currently are able to care for 18 ventilator dependent children and we're actually planning to expand to care for an additional 32 ventilator dependent children. We hope to have those beds ready in early 2017. We currently have a total of 137 beds organizationally and these

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additional beds will bring us to a total of 169 beds. About 84 percent of our beds are occupied by children in need of long term care on a long term basis and the rest are more subacute and the goal is to get them home.

We have the assisted feeding program. When a child is medically complex, it can be very overwhelming at first for a family. Teaching them and helping them understand how their child can thrive at home is something we are very proud of and happy to do. A lot of families want to learn so we do a lot of teaching with our families.

Also, every family that goes back to the community is hooked up with support services, from medical homecare to schooling and early intervention if it's appropriate for the child. We really don't discharge anybody if we don't have the services in place. That's an important part of the discharge planning process. We work with the community depending on where the home of the child is. We try to set up support services in that area. If the child is from Brooklyn we will try to find services in that area for them. Most of our children come to us from the boroughs but we also serve Long Island, Westchester, Putnam and Rockland counties. We really serve any area where there's a need.

### **What challenges are unique to serving your population?**

One of the biggest challenges that we see, and one of the reasons we're expanding our ventilator dependent program, is that lot of the children needing this type of care are going out of state because of lack of available services or placement options. That's heart wrenching for the family! I can't imagine what it must be like for



someone to not be able to see their child easily because they are in another state.

Also, Medicaid managed care is the big unknown. It hasn't been implemented for pediatrics yet and our population is a challenge because they do have multiple hospital stays over the course of their lives because they have chronic long term needs. Managed care is still trying to figure out how to handle the pediatric inpatient population.

Schooling is also a challenge for medically complex and fragile children. We have a school onsite so all of our kids go to school. The John A. Coleman School provides an education for our children. Most of the children attending are long term residents but we do have a few kids who attend from the community. They are bused to the school by their school district when they cannot accommodate their needs. Monday through Friday the kids are in school all day where they receive both education and socialization. We have early intervention, preschool and school age programs.

### **What happens when they turn 21?**

There are lots of challenges in that area. When a child turns 16-18 we start looking for adult placement because it often takes years to find an acceptable location. Some children clearly need nursing home level care but it's very difficult because they need a significant amount of nursing and respiratory care and not all facilities are able to accommodate that

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level of care. Going from a pediatric facility to a geriatric facility has its own challenges in terms of programming. It's hard for a child to go from being in a pediatric environment to being the youngest in a facility by 60 years. The other option is a medical model group home through the New York State Office of People with Developmental Disabilities (NYSOPWDD) but there simply aren't enough of those homes available. My understanding is that New York State budgeted for three pilot programs for young adults and we are anxiously awaiting the outcome of those projects because the need is great. We are excited to see what they come up with as we have several children right now in need of an appropriate place to go when they reach age 21.

**If you could pick one thing that keeps you up at night, what would it be?**

It is knowing there are these high acuity children who are being cared for out of state, who need to come home, who need to be with their families, and that there aren't enough facilities that can accommodate them. Where are they going to go? There are just not enough resources in New York.

Also, where they are going to go when they age out? There are not enough group homes nor investment in new ones but for many of our kids it is a medical model group home that is needed. There just aren't enough group homes to be able to accommodate gastronomy tubes, tracheostomies, wheel chair accessibility and ongoing rehabilitation to maintain really sick children in this level of care. It is a challenge that hopefully we will see some movement on with the pilot projects in the works.



There is a waiting list for ventilator beds so hopefully, with the addition of some new ventilator beds, we can bring some of the kids currently cared for out of state, back to New York. Primarily, we are focused on chronic long term ventilator dependent children who have failed the weaning program. That is not to say we wouldn't take children likely to be weaned but there is a significant need for somewhere to go for the children who aren't able to be weaned. It is important to bring these children back in state for several reasons, including cost, but none more important than allowing families to be with their child.

**In light of the radically changing landscape, where do you see your organization in 5-10 years?**

I think our core mission will always be to care for the vulnerable population that we serve, for the sake of the children and their families, in a holistic way.

I think the changing landscape in health care, the advent of managed care, DSRIP and other programs, will force partnerships and affiliations, some of which we don't know about yet. Becoming a part of the continuum is the future of all health care. It's all still a bit nebulous and we're not quite sure what we'll be but our core mission of caring for children and families in a holistic way won't change. That's who we are – the Sisters of Charity of NY – really focused on our mission.

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**Tell about a success story that speaks to your mission.**

We have many success stories both for children who have gone back home and those who have stayed here on a long term basis. I'll tell you a story about Max. He was our first ventilator dependent child. Max was born prematurely and he had a lot of trouble with his breathing and swallowing and spent a lot of time in the Neonatal Intensive Care Unit (NICU) when he was first born. At eight months, he was sent to a rehabilitation program. After that he was sent home. His mother really felt that he needed to be in a facility because of the level of care he needed and began an exhaustive search to find an appropriate setting. She contacted the New York State Department of Health and she talked to legislators in search of a program but quickly found out there really was nothing available. The DOH contacted us to ask if we would consider opening some vent beds and in 2006 we opened our first four beds. Max was our first resident and he is still here with us.

We subsequently added four more beds and then 16 more when we moved to our new building. Max is really the reason we have a ventilator dependent program. There was an unmet need and we were able to fill it. Max goes to school. He had been in a facility that didn't have schooling and enough programming for him. It's been a really good experience for his mother because she is able to visit and spend a lot of time with him. She can be his mom. We are the caregivers but she is the mom. She is able to hug him and kiss him every day, as well as read to him and participate in school with him and just be there with him as a mom. It really important. It speaks to our core mission – let the parent be the parent with us helping

as the care giver. We just celebrated Max's Bar Mitzvah. It was a big celebration.

**Is there anything I didn't ask you that I should have asked?**

A pediatric center is such a special place. We try to provide quality medical care and childhood experiences so that our children experience the same thing that children in the community experience. We celebrate every holiday, some that we make up. We celebrate life. We try very hard to help our kids get the most out of life because they deserve it; they are special. They really deserve to have as good a life as they could have had without the challenges they have faced.

**Here are a few examples of life experiences we offer to our children:**

Every August we have a portrait day. We have a grant that pays for it. We put together a professional photo package like one would see at a photo studio. We set up our classrooms like photo studios. For many of our families, it is the only picture they have of their whole family with their medically fragile child and the pictures are just beautiful. We do this every year for our families. It's just an amazing day. The spirit is unmatched.

We also have a resident and sibling holiday party. As I said, we take care of the whole family here so having occasions for the whole family to visit is something we like to offer often. At the holiday party, we have photos with Santa and we give presents to all of the children who come. For some children, it's the only present they'll get. It's simply a warm and wonderful day. It's a special day we have here- all staff come to help. This is really a special place! 🎄



# ST. MARY'S HEALTHCARE SYSTEM FOR CHILDREN

Interview with President and CEO Dr. Edwin F. Simpser, MD and Assistant Vice President/ Inpatient Administrator Vivian Figueroa, LNHA

The mission of St. Mary's Healthcare System for Children is to improve the health and quality of life for children with special needs and life-limiting conditions and their families. We are New York's largest and most experienced provider of long-term care to children with medically complex conditions and New York City's only free-standing post-acute care facility for children.

## **Has your mission changed over time?**

Our mission has definitely changed over time. Historically, our mission has followed the evolutionary landscape of care. If you look at St. Mary's 25-30 years ago, the in-patient skilled nursing facility was pretty much a long term care facility with most young people living there for years. Some went home but the percentage of those going home was relatively small. There wasn't a lot of turnover.

Over the last 10-15 years, we've restructured our physical plant, our staffing model and our capabilities to be able to care for much sicker children largely to be more responsive to hospitals that wanted to send us very sick children needing shorter stays but that could possibly go home, for example, kids with brain injuries, respiratory problems or feeding needs. It might be called sub-acute care if we were going to give it a designation.

For a pediatric skilled nursing facility we have considerable turnover. We have 97 beds for

which we have over 200 admissions and discharges per year. Our average length of stay for the children we discharge is somewhere between three and five months. However, the children occupying about half the beds in the organization stay long term, with some never going home. So when you look deeper into the numbers, you realize that those 200 admissions and discharges really represent only 50 beds turning over four to five times a year. The discharge numbers really speak to the success of this approach.

The other evolution is that 30 years ago we were just a skilled nursing facility and now we have this broad continuum of care with a focus of moving children from the acute care environment to home while using this wonderful array of programs. Some programs that we offer in addition to the skilled nursing facility to help move children back to the community include:

- A licensed medical model adult day care program with over 100 registrants for only 31 slots. While we are open seven days a week some children come for two days, some for four and some all seven. This is an ideal transition tool to help move children out of the facility and into living in the community.
- A special education preschool on campus for medically fragile preschoolers. We are able to handle children with complex medical needs who otherwise could not attend regular special education preschools

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*We believe in*  
**POSSIBLE**



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because of their medical needs. About 85 percent of attendees are children from the community and about 15 percent are our own inpatients.

- A school on campus for our inpatients. Public School 23Q provides teachers, para-professionals and therapists right on site for approximately 30 school-age children. Staff, curriculum and schedules are governed by the NYS Department of Education.
- An array of community-based services including a special needs Certified Home Health Care Agency (CHHA), a Licensed Home Care Services Agency (LHCSA) and a Case Management Program. The case management program is a Care at Home (CAH) and Medicaid service coordination program; CAH is a Medicaid waiver program for medically fragile children and their families. This case management expertise will be the basis for our upcoming foray into the Children's Health Home arena.

Another progression of our mission is our response and action related to an emerging

population of children that are aging into adulthood and out of our facility and services. Their needs are still complex and they are faced with a choice between adult long term care that is not really designed to meet their needs or being discharged to the community where there are not a lot of services available. So our strategy going forward is to provide an array of services to provide for these young adults.

To support transition to the community, we have started an adult day health care session for 18-25 year-olds, some who have aged out of our in-patient services and others from the community. Most of the referrals come from high schools that care for the special needs population.

We have hundreds of children in our homecare programs that are going to age into young adulthood and eventually their parents aren't going to be able to care for them at home and we're going to need to find residential options for them. The State is also beginning to recognize that this is a real problem. We recently received a state grant

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to convene a summit to look closer at this issue. We have gathered demographic data and are in the process of developing a medical group home model through the NYS Office of People with Developmental Disabilities (NYSOPDD) for this population.

Beyond the overall mission that has evolved to serve a larger continuum, we have a host of specialty service areas that include:

- Treatment of pediatric respiratory issues including vent-weaning but also complex pulmonary issues. We have full-time respiratory therapy 24 hours a day, seven days a week for 365 days a year.
- Full time medical staff that allows us to care for very sick children and avoid rehospitalizations.
- An intestinal rehabilitation program for children with short bowel syndrome.
- A neuro-rehabilitation program which has some of the most state-of-the-art neuro-rehab equipment in the New York City metropolitan area.
- A feeding program for infants and toddlers that refuse to eat, where we not only get kids to eat but train parents in the feeding modalities so they have long term success. We even use technology such as Skype to train families that come from a distance
- An award winning palliative care program that has been very active for over 30 years.

**What are the challenges you feel are unique to serving your particular niche? What are your challenges in terms of funding? What has the move to a long term**

**care managed care environment meant for your organization?**

We really expected to get bombarded with these transitions from fee-for-service Medicaid to managed Medicaid but we currently only have about a 20 percent penetration on the medical model adult day health program. On the inpatient side there's only about 25 percent but that 25 percent really takes its toll both on the bottom-line and on outcomes.

Outcomes are directly affected because we are often forced to discharge children earlier than we would like and the next thing that you hear is that they are back in the emergency room, or readmitted to the hospital, and then back to us. These are classic cases of premature discharges that happened because there is no recognition of the unique needs of these children and families as part of managed care plan operational procedures. In addition, the managed care plans require considerable communication including weekly updates in order to continue to authorize coverage on the outpatient side requiring a lot of staff time that really impacts our bottom line.

Managed care is a challenge for every provider, both adult and pediatric. What might be unique is that in our attempts to move children through the continuum we are finding there aren't enough services for children in the community that are as robust enough for medically complex situations. The challenges associated with getting kids home include housing issues, social supports or finding private duty nursing and the lack of understanding by managed

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care organizations about the needs of this populations and what needs to be covered for payment (Such as Home Health Aide services). Poor Medicaid reimbursement for Private Duty Nursing is a particular issue that limits our ability to discharge patients as well. We spend a lot of effort, both for in-patient and at-home pediatric patients, to provide education to others about the unique needs this population requires.

**So, in light of those challenges what keeps you up at night?**

Like most providers, we live on a reimbursement roller coaster and the uncertainty of future dollars is really troublesome. I cannot predict exactly how we're going to get paid, or estimate what we're going to get paid, three to five years from now. I worry that the contracts that the managed Medicaid plans are going to have with the State won't be adequate to cover the costs of services that we provide and therefore the plans are going to try and cut back on services. Right now we have a mortgage that we have to pay which is covered, by

regulation, by Medicaid. If that capital cost gets passed over to plans it becomes a factor of negotiating with each plan. It will be difficult to ensure that I'll be able to pay our mortgage much less our operating costs.

Also, we are a very tiny, downstream provider and within many different Performing Provider Systems (PPSs) through Delivery System Reform Payment Incentive Payment (DSRIP). Right now, I have no idea how and if, money is going to trickle down to us from the PPSs. We're putting an enormous amount of time and energy into being good partners and bringing creative ideas but I have no idea what it's going to mean for us. So it is really the uncertainty of the dollars in the future that most often keeps us up at night.

I think that when they wake up to the true needs of moving medically complex kids to the community, ultimately, we're going to be a very important player within these PPSs because of our continuum of care, our in-patient and community-based programs and case management capabilities. But ultimately we have no control. It's just a matter of "how well

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we perform” and “how well we negotiate”.

This population is growing, not shrinking, and I think there’s going to be increased need. We have positioned ourselves with our ability to care for sicker children and to serve the growing need. The Children’s Health Association data indicate there’s going to be a five percent a year growth in medically complex kids over the next 10 years as a result of improved technology, improved ability to save kids and keep kids alive. Statistics show an increased number of premature babies, for example, those associated with mothers who are older during their pregnancies. And so you have more medically complex kids.

**Do you have a success story you want to share? Something that spotlights a best case scenario.**

We’ve had so many children who were success stories. We have a young lady who’s been here a long time; I’ll call her “Linda”. It’s an amazing story! She’s had a brain infection – the same disease from which her mom died. Her dad never thought that he could bring her home. She was bed/chair-bound for a period of time, not communicating at all. Between a combination of working with surgeons and to do a little bit of surgery, and then getting her into some of our

newer state of the art neuro-rehab equipment, we now have her using her upper extremity and able to use a communication board and to communicate. She’s able to feed herself, she’s beginning to ambulate with assistance of a lite-gate device; and she actually recently went home for a weekend for the first time ever. Now we’re contemplating getting her home permanently. Our staff just doesn’t give up; we just keep trying.

**Is there anything else that I didn’t ask that I should have asked?**

When working with a sick child you work with the entire family. It’s a totally different dynamic and effort as you focus on bringing the patient back into the home. We’re very, very family centered. We have even developed a new department of Patient and Family Services in our in-patient program combining the traditional Social Work, Pastoral Care, Behavioral Health and Palliative Care departments. We also started a program here called *Patient Navigation*, to help our families navigate through the healthcare system so they can get the services they are entitled to and care for their children. It is so very important to remember that caring for our population provides challenges unique to long term care. 🧩



# PEOPLE, INC.

Interview with Rhonda Frederick, CEO

## What is the mission of People, Inc.? Has it changed over time?

People, Inc. is just under 50 years old and our mission has been tweaked over the years. Currently, as written, it states that People, Inc. exists so that individuals with disabling conditions or other special needs have the support they need to participate and succeed in an accepting society. The organization began as an agency providing services to the developmentally disabled. We began as a grassroots initiative by parents with children who were aging out of the school system and who had no options for services as adults with disabilities.

In the late 1980s and early 90s we were actually approached by the U.S. Department of Housing and Urban Development (HUD) because they were looking for not-for-profit developers to build senior housing. They'd had some bad experiences at that time with for-profit developers and were interested in People, Inc., a non-profit with a successful track record of building group homes for persons with disabilities.

Our board spent about a year researching and considering if our mission was broad enough to undertake senior services. After carefully vetting the question, we decided this area was in

sync with our mission. We knew how to develop housing and our core mission is to serve people and, in fact, in many states senior services and disability services are run under the same umbrella. That's how we began serving seniors and persons with development disabilities. I am thrilled to have been part of that evolution.

From there we continued to grow, as the need is incredible. I can't talk enough about the need for affordable housing for seniors. We also found some other niches where the services are similar. For example, we took over an adult day care program for individuals with Alzheimer's, which is just about the same as a day program run for people with disabilities. So we had some who had Alzheimer's and some who were just aging and they're now co-located in a building. People go back and forth between the two programs.

We also provide case management through the county in the same manner we use for providing it for individuals with disabilities; funded two different ways but with the same philosophies. We started our health center to provide a service lacking in the community. We were having a hard time finding good quality doctors for people with disabilities, people that would spend the time needed to serve our population.

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Now we've grown so much and have so many specialties that 50 percent of our population is non-disabled; that is, seniors. So the basic strategies and the kind of staff you need is really the same in both systems. There's so much crossover. From an efficiency stand point, we understand how to build an apartment building for people with disabilities and, using the same skill set, we're able to develop an efficient project for people over age 62.

**What has been your experience working with two different sets of regulations?**

Well, there's incredible frustration! On the senior side, HUD 202 projects are what we've developed and managed very successfully for years. It is incredibly frustrating that the program is no longer funded by the federal government because there such impact per dollar spent and the waitlist in other affordable housing is just incredible. So that has been a real source of frustration. It's hard to understand why that program would not continue because it's been so incredibly successful throughout the country.

On the disability side we are moving into a managed care world which is going to be a huge change in the way we do business and the way we provide services and how services are offered to people. As part of this transition,

there is a real push to do more integration of people with disabilities into the community, something we've been doing for 40 years, but to a greater extent. To further accomplish community integration, managed care plans are looking at some of the systems we've already set up including group home systems and day programs and considering whether those two should be segregated? Should people be living in other situations or attending programs differently?

It seems that under current conditions, it's allowable to develop senior housing but it's not to develop just housing for people just with disabilities. There's a lot of history on both sides but we are getting two different messages both with implications under the Olmstead Act and other federal and Centers for Medicaid and Medicare Services (CMS) regulations. We're working our way through the ambiguity and cuts in funding.

We are currently working on a school in a suburban location here in western NY that will be affordable housing but will have some set aside units for people with disabilities. The balance of that property will all be income based. We expect to see seniors and we expect to see working families, it'll be an interesting project with a mix of a lot of different

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populations so we're looking forward to seeing the result.

**Would there be more efficiency if different populations could be integrated?**

You would definitely see efficiencies across the board but you have to be a little mindful. For example, the first senior housing project that we completed, opening in 1992, had set aside units that were for people with disabilities. Representing a percentage of total units, six out of 49 units were set aside for people with broadly defined disabilities of any age. And about two months before the building opened, HUD changed their philosophy about the age limit requiring all residents be 62 or older. This new requirement was as a direct result of the problems that were happening with integration and younger people in senior living. So this change was made in 1992 and has continued to the present. Developers can have set aside units for disabilities, but only for people who are age 62 or older. This has created a significant barrier.

**What do you think the challenges are as you move more into senior housing?**

There is a real shortage of affordable senior housing and funding is the biggest challenge to creating more. The waitlist for the 19 People, Inc. complexes is about 1,000 people of which about 700 are non-duplicated numbers, meaning not on multiple lists. When someone needs an apartment, they don't usually want to wait on a waitlist for a couple of years. Our apartments don't turn over very quickly. Great locations and the availability of case management services help people age in place by providing access to community resources. As a result, people are staying and not having to leave as they require more support. So, this is probably the biggest issue we face on the housing side.

Housing is also the biggest nut to crack on the



People Inc

disability side too. Once we can get a good roof over someone's head, then we have all sorts of services that we can provide with the good case manager. I think that's essential to keeping people in the community.

**How do you fund your case manager?**

HUD allows some of our units to fund it as part of our service provision (services coordinator). For people with disabilities it's funded through Medicaid. We also have a county contract for senior outreach for people who don't live in our own senior complexes. So we've been successful in figuring out ways to provide this service and we have been fortunate to have found some fabulous case managers/coordinators.

**Do all of your buildings have access to case management?**

Yes, there are some great services here in Western New York and, internally, we have our health center and a Certified Home Care Agency (CHHA), so we also get good referrals for those services.

**What are your plans for the next five to 10 years?**

We are currently working on a housing project funded through tax credits, both state and federal. We actually have a lot of different funding sources for the project and we hope to be under construction in January. It's a complicated process that takes quite a bit to get it going but we'd like to develop more using this funding strategy.

I'd also like to expand our case management services to the senior community. My social

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worker background reminds me that this is a crucial need. Whether you're living in affordable housing or in the community, having somebody to help you understand and access resources is so helpful. It's just so difficult for one person to stay abreast on what is available and how to access the services.

So I think you'll see us doing quite a bit with the two populations together, using our expertise in aging to help our disabilities population and vice versa. We're also exploring how to integrate technology to help people stay independent. We've already had some great success in this area with medication management, with monitoring blood pressure and with diabetes management. The technology has been really critical to successful outcomes. From an efficiency and cost saving perspective, technology is really going to be helpful but regulation has not kept up with technology and that needs to be addressed to allow these types of tools. We want to use our money so we can provide services to as many people as possible and I think that technology is an important piece.

I also believe that the focus is managed care plans will be turning to senior housing because safe, affordable housing with services is a critical piece for successful outcomes for seniors. If you look at the Delivery System Reform Incentive Payment Program (DSRIP) projects and the New

York State Department of Health's (DOH) interest in reducing unnecessary Emergency Room (ER) visits and unnecessary hospitalizations, having a good living situation is key because it will automatically reduce those things. I think here in Western NY our hospital systems are starting to recognize that and have come to us with some creative housing alternatives for folks. The reality is that hospitals have people sitting in beds who can't leave because they don't have anywhere to go. People, Inc. is actually the housing piece of a grant that Erie County received to provide senior service to that very population. So if someone is in the hospital, we're helping them find an apartment, get their security deposit, get the apartment furnished, move their furniture and do whatever else needs to be done. It's such a huge savings.

We are also involved with the Ombudsman Program for people who need residential long term care services. We're very happy to have gotten that designation to provide advocacy and help people know what their rights are similar to what we've done for people living independently. The reality is that there does come a time where some folks can't be maintained in the home and we have to be cognizant of the fact that sometimes the needs just become too complex. It really a case of applying everything we've learned to the entire continuum.

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Conversations are key to creating a better future. Look to community partners, look at regulatory barriers. The big systems need to talk to each other just like DOH needs to talk to the New York State Office of for the Aging (NYSOFA) and OPWDD and private providers. There's a role we can play; we know what to do, we just need to be properly funded and be allowed to be innovative and creative without so many barriers.

**So if I had to ask you what's the one thing that keeps you up at night, what would it be?**

All those people that are on our waiting list for safe, affordable housing. I know the model works for the seniors we are already serving but what are all those other people doing? We're not only a housing agency. We're a human service agency that does housing. We're the landlord but we also take great interest in our tenants and what we can do to provide them quality services and not just the roof to make sure they're safe.

**Do you have one specific success story?**

I love my Libby story! I had a woman who was living in such sub-standard housing. She had a life tenancy in her home from her husband who had passed but few repairs had been made and it was really just a terrible situation. She watched one of our buildings be built and she kept calling and saying she wanted to get on the list. She knew just what apartment she wanted. As it turned out, she was high on the waiting list so she was able to choose her dream apartment, which was right

under an oak tree. She was such a sweetheart and become such a part of the community. She had a four-pronged walker that she would decorate for different holidays. She happily participated in the many activities the complex offered. Her family was incredibly appreciative and every time I saw her she would say tell me how happy she was with her new home. Then her daughter turned 62 and she was also moved in. So we had Libby living in one apartment, her daughter living in another. It was amazing. The woman went from this horrible existence with no money and no ability to fix her environment or do anything to a fantastic life. The last 10 years of her life were fabulous. I think of her so often, I still picture her, and that's what it's all about.

The beauty of the Libby story is that she was so incredibly appreciative and when she got that opportunity to have a nice place to live, she took advantage of everything else that was there and just lived life, always with a smile on her face. She was like the poster child of success. And in spite of the many roadblocks in each new project we undertake, we think of her and keep going because there are a lot of people like Libby out there. That's what keeps us going.

There are a lot of organizations like People, Inc. out there that can work collaboratively to solve situations for people like Libby, working together. We're not in competition with one another, we need to share our successes and share our resources. We're all here to help people. 🌈

# COBBLE HILL LIFECARE

Interview with Tony Lewis, president/CEO and Donny Tuchman, administrator

**Our mission has always been to be the provider of choice for the elderly and disabled adults we serve; to provide exceptional care that enhances quality of life and respects individuality.**

Our mission has changed over the life of the organization because we have expanded our services beyond the walls of 380 Henry Street. We now provide quality services across a continuum of care with an emphasis on short term patients and home care. As a successful health care organization we are driven by the emergence of value based care. Cost, quality care and patients' choice are paramount.

**Our services and their challenges are:**

**Long term care:** increasing number of people we serve are who do not have appropriate housing in the community or mental health support services.



**Short term rehab:** requires greater interdisciplinary approach to care; a high level of involvement and collaboration with hospital surgeon, home care and managed care companies. Shorter stays bring gaps in our system into sharper relief. This has made the need for strong team leadership and clear communication with patients and families about insurance coverage, more imperative.

**Medical subacute care:** patients have more co-morbidity; they are released from the hospital much sooner.

**Hospice/palliative care:** families often have unrealistic expectations about the benefits or lack thereof, in procedures and treatment. We continue to work closely with doctors and families to secure advance directives.

*(continued on page 36)*

(continued from page 35)

**Home care:** delivering good outcomes “remotely”. Finding the right people to deliver the kind of care we are known for although we are not physically there to oversee the care.

**Care management coordination:** delivering services under strict cost constraints.

**What keeps us up at night:**

***Keeping our eyes on quality care.***

***Today's health care financial uncertainty.***

***The future of managed care.***

***Ensuring we do the right thing for every patient in our care.***

The future looks as if it will bring further attempts to drive down health care costs, less money to provide more care, bundling payments, and pressure for us to become even more like a step down unit

Ms. F. was a vibrant and active woman living in Brooklyn. Throughout her life, she was involved in many community organizations and held a high level job in a financial



institution. When she began to experience mild cognitive decline and had a fall, her niece who lived on Long Island had her moved to a nursing home near where she lived. One day, we received a call from a local elected official who had worked closely with Ms. F. on various community projects. She had gone to visit Ms. F. and was shocked at how badly she had physically and mentally deteriorated. She called us and with the niece's consent, Ms. F. was transferred to our facility. After several months of rehabilitation therapy, Ms. F. was well enough to return to her own home with home care. 🧩



# HOSPICE TODAY

In October, just ahead of National Hospice & Palliative Care month, National Hospice and Palliative Care Organization (NHPCO) released their annual report on hospice care in America: NHPCO's Facts and Figures. The 2015 edition, based on 2014 figures, provides an annual overview of important trends in the growth, delivery and quality of hospice care across the country. The report concludes that in 2014, an estimated 1.6 to 1.7 million patients received services from hospice providers.

Although over the past decade, the hospice community has been marked by substantial growth in the number of hospice programs and patients served, Hospices continue to struggle with a short length of stay. The total number of days that a hospice patient receives care is referred to as the length of service or length of stay. Length of service can be influenced by a number of factors including disease course, timing of referral and access to care. The median length of service in 2014 was 17.4 days. This means that half of hospice patients received care for less than three weeks and half received care for more than three weeks. In 2014, approximately 35.5 percent died or were discharged within seven days of admission, up from 34.5 percent in 2013. As well, slightly larger proportion of patients died or were discharged within 14 days of admission when compared to 2013 (50.8 and 48.8 percent, respectively) and about the same proportion of patients remained in hospice care for more than 180 days - 11.4 percent in 2011 as compared to 11.5 percent in 2012.

The majority of patient care is provided in the place the patient calls "home". In addition to private residences, this includes nursing homes and residential facilities. In 2014, 58.9 percent of patients received care at home. 31.8 percent of hospice patients received care in a hospice inpatient facility. This is an increase over 2013 when 26.4 percent of patients were served in an inpatient facility.

53.7 percent of hospice patients were female and 84 percent were 65

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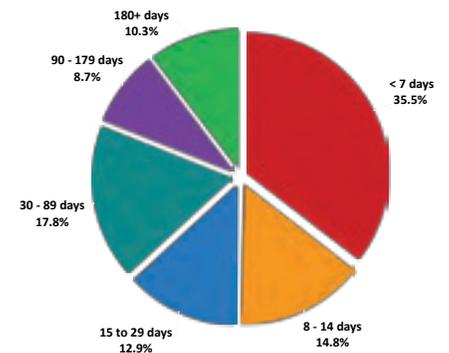


Figure 5. Proportion of Patients by Length of Service in 2014<sup>1</sup>



years of age or older. In fact, 41.1 percent were 85 years of age or older. In 2014, 76 percent of hospice patients identified as being white/Caucasian, compared to 80.9 percent in 2013.

When hospice care in the United States was established in the 1970's, cancer patients made up the largest percentage of hospice admissions. Today, cancer diagnoses account for just 36.6 percent of hospice admissions. The top three non-cancer primary diagnoses for patients admitted to hospice in 2014 were dementia (14.8 percent), heart disease (14.7 percent), and lung disease (9.3 percent). "Debility unspecified" was disallowed as a primary diagnosis in 2014.

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. NHPCO estimates that in 2014, 430,000 hospice volunteers provided 19 million hours of service. In 2014, most volunteers were assisting with direct support (60.8 percent), 20.2 percent provided clinical care support, and 19.1 percent provided general support. In 2014, 5.2 percent of all clinical staff hours were provided by volunteers. The typical hospice volunteer devoted 46.3 hours of service over the course of the year and patient care volunteers made an average of 20 visits to hospice patients.

The Medicare hospice benefit, enacted by Congress in 1982, is the predominate source of payment for hospice care. The percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 85.5 percent in 2014. Managed care or private insurance paid for 6.9 percent of patients, while Medicaid covered 5 percent of hospice patients.

To access the full report, please visit [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2015\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf)

**Table 6. Percentage of Hospice Admissions by Primary Diagnosis<sup>1</sup>**

Primary Diagnosis	2014	2013
<b>Cancer</b>	36.6%	36.5%
<b>Non-Cancer Diagnoses</b>	63.4%	63.5%
Dementia	14.8%	15.2%
Heart Disease	14.7%	13.4%
Lung Disease	9.3%	9.9%
Other	8.3%	6.9%
Stroke or Coma	6.4%	5.2%
Kidney Disease (ESRD)	3.0%	3.0%
Liver Disease	2.3%	2.1%
Non-ALS Motor Neuron	2.1%	1.8%
Debility Unspecified	1.9%	5.4%
Amyotrophic Lateral Sclerosis (ALS)	0.4%	0.4%
HIV / AIDS	0.2%	0.2%

**Table 1. Location of Hospice Patients at Death<sup>1</sup>**

Location of Death	2014	2013
Patient's Place of Residence	58.9%	66.6%
Private Residence	35.7%	41.7%
Nursing Home	14.5%	17.9%
Residential Facility	8.7%	7.0%
Hospice Inpatient Facility	31.8%	26.4%
Acute Care Hospital	9.3%	7.0%

1. 2014, NHPCO National Data Set and/or NHPCO Member Database.

# Grief During the Holidays: Hospice Can Help

The winter months are here, and with this time of the year comes the celebrations inherent in the holiday season. The winter holidays are generally perceived as “the most wonderful time of the year.” For those who are facing new grief after the death of a loved one, the holidays may instead be a time filled with pain and sadness.

Even those for whom grief is not as fresh, the holidays may serve as an annual reminder of the loss – not only of that person, but of tradition and celebration. Tradition provides constancy, comfort and security, but to those experiencing the loss of a loved one, once-cherished

traditions can be a sharp reminder that things are not the same, and never will be again.

Bereavement professionals working in hospice and palliative care understand how difficult this time of the year can be. They support families coping with loss all year long.

Bereavement counselors stress the importance of making decisions that feel right to the grieving person, and giving oneself permission to make new or different choices at the holidays.

## **Grief experts remind us that:**

- Holidays are often centered around certain traditions and rituals. For some, continuing these traditions without a loved one may be an important way to continue sharing their memory. For others, it may be more comforting to develop new rituals to help lessen the pain and immediacy of the loss. There is no right or wrong way to handle the holidays.
- While the holidays can be filled with meaning, they can also be filled with pressure and stress because of additional tasks such as shopping, cooking and decorating. Grieving people should be encouraged to prioritize what needs to be done, and focus on those projects that may bring them pleasure. Perhaps the gift list can be pared down, or another family member can host the family dinner this year.

*(Continued on page 40)*





- The holidays can bring opportunities to remember the person who has died in a way that is personally meaningful. Some families choose to participate in holiday events at a local hospice. Others may choose to share special family stories over a meal. Some may find that making a donation to a special charity or volunteering time to help others in need may be a comforting way to honor their loved one.
- Grief does not progress along a predictable timeline. Conventional wisdom holds that after the first year, one should be “over it.” In reality, even those who feel that they have worked through their grief can still feel an overwhelming sense of loss during this season.

Holidays often magnify feelings of loss. It is natural to feel sadness. The need for support is often greater during holidays. Hospice and palliative care professionals have always recognized the need to provide emotional and spiritual support to those who are grieving, at any time of year. If your grief feels like too much to bear, call us. An experienced grief counselor can help.

### **Tips to help a grieving friend get through the holidays**

If your friend, neighbor, family member or

co-worker has recently experienced a loss, here are some things you can do to help them weather the “joyous” season:

**Acknowledge their loss.** Let them know that you understand that this is a difficult time of year and that you recognize that the holidays will not be the same for them this year.

**Trust in their decisions.** Let them tell you what they feel up to doing. Don’t force the bereaved to do anything because you think it will make them feel better.

**Use the deceased’s name.** Often there’s a fear of saying the name of the person who’s died, as if somehow saying the name will cause more pain. However, phrases like, “So sorry for your loss,” and even using only pronouns like, “She was so wonderful,” and “He will be truly missed,” tend to negate the person’s existence in the first place.

**Offer comfort and reassurance without minimizing the loss.** Listen sincerely and openly. Don’t attempt to change the subject if the conversation gets uncomfortable for you. If you’ve gone through a similar loss, share your own experience if you think it would help. However, don’t give unsolicited advice, claim to know what the person is feeling, or compare your grief to theirs.

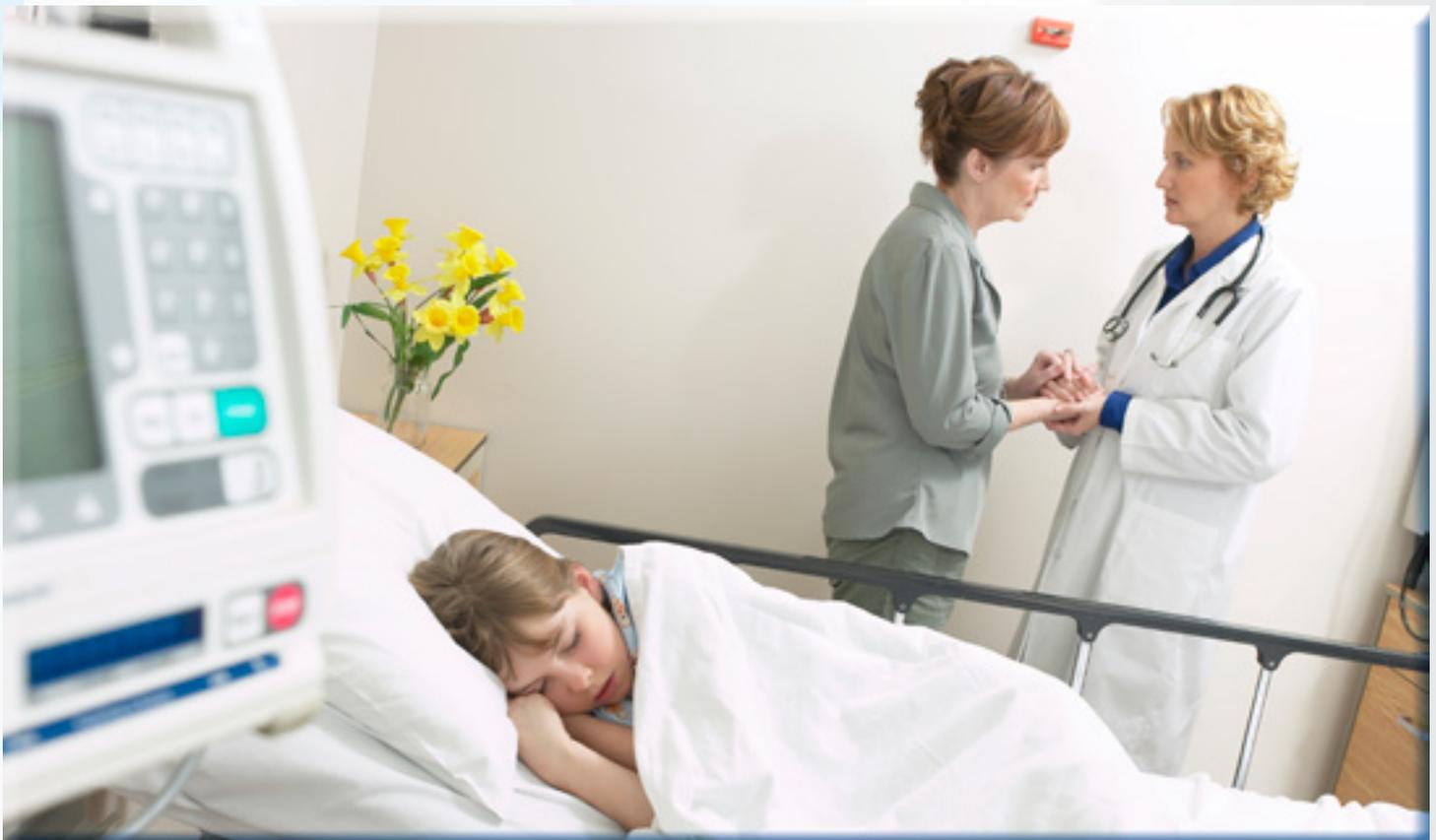
**Offer practical help.** Sometimes what the bereaved need most during this time of year is help getting things done. Maybe setting up the Christmas tree or baking the special family cookies are some things that your friend would like to do but doesn’t have the energy for. 

# Concurrent Care for Children

When a child is diagnosed with a life-limiting illness, it upends many of our core beliefs. Children are not supposed to die. Yet each year, approximately 53,000 American children and infants die, 20,000 of them from congenital and chronic conditions, including cancer. Providing care for this vulnerable population is a challenging endeavor.

Children with life-limiting illnesses suffer from a wide range of conditions and it is difficult to accurately predict the way a disease will progress in a child. This uncertainty hampers the providers' ability to accurately predict the child's response to treatment or overall chances for the child's survival. It also affects decisions that parents or medical professionals may make concerning the child's treatment options. This uncertainty may confuse the goals of care, resulting in "cure versus care" thinking, rather than encouraging the two types of therapies to be provided simultaneously. Uncertainty about disease progression encourages parents to pursue curative treatments until the medical staff members are "sure" of the child's imminent demise, and children are referred to palliative care only when curative treatments are exhausted. However, experts advise that children can benefit from palliative care early in their courses of illness.

*(Continued on page 42)*





For many years, healthcare professionals and families with children living with life-limiting or life-threatening conditions had few options for Medicaid coverage when children were very seriously ill. Parents were faced with forgoing curative/ life prolonging treatments for their children to be eligible for hospice services. Or conversely, they were not eligible for beneficial interdisciplinary hospice services while getting curative treatment.

The Patient Protection and Affordable Care Act (PPACA) changed that situation, and now requires the state Medicaid program to pay for both curative/life prolonging treatment and hospice services for children under age

child's right to be provided with, or to have payment made for, services that are related to the treatment of the child's condition, for which a diagnosis of terminal illness has been made. This provision affects children who are eligible for Medicaid or the Children's Health Insurance Program, New York State's Child Health Plus. This new provision, termed Section 2302: "Concurrent Care for Children" Requirement (CCCR), went into effect upon the enactment of the PPACA, on March 23, 2010.

Hospice and Palliative Care Association of New York State (HPCANYS) has worked hard over the last dozen years to define and support the unique discipline of Pediatric Palliative Care. A holistic philosophy of care and method of care delivery, Pediatric Palliative Care is an individualized plan of care with children and their families at the core. Pediatric Palliative Care emphasizes quality of life, minimizes suffering, optimizes function and promotes opportunities for personal and spiritual growth. Care is provided by an interdisciplinary team represented by doctors, nurses, home health aides, volunteers, social workers, child life specialists, grief and bereavement counselors and pastoral counselors. Music therapists, massage therapists and art therapists often play a part. The model incorporates the child's and family's community, as community activities, such as school, church and friends are often much more extensive among children than among adults. Siblings and grandparents are not forgotten in the plan of care. Family centered care is the cornerstone for palliative and hospice care for children.

*We are in need of medicine with a heart . . .  
The endless physical, emotional, and financial  
burdens that a family carries when their child  
dies . . . makes you totally incapable of dealing  
with incompetence and insensitivity.*

Salvador Avila, parent, 2001

21 who qualify. On March 23, 2010, President Obama signed PPACA into law enacting a new provision, Section 2302, termed the "Concurrent Care for Children" Requirement (CCCR). Section 2302 of the PPACA amended the federal Social Security Act. The new provision states that a voluntary election of hospice care for a child cannot constitute a waiver of the

HPCANYS continues to work with the New York State Department of Health to ensure that children and their parents who are faced with a serious life-limiting illness will no longer have to make the difficult decision to pursue curative treatment at the expense of forgoing the holistic, family-centered services provided by hospice and palliative care teams. ■

# New York State Laws Promote Information and Access to Palliative Care

Being diagnosed with a life-limiting, chronic or terminal condition can be a traumatic experience marked by anxiety, uncertainty and confusion. Such a medical diagnosis has a major impact upon our lives; it can affect us physically, emotionally and psychologically. It can leave us feeling overwhelmed and fearful about what the future holds, how we will cope, what health care choices to make or how to help and support our loved ones. It is hard to live with a serious or life-limiting illness. We may feel lonely, angry, scared or sad. We may feel that our treatment is doing more harm than good. We may have pain or other disturbing symptoms. For individuals and families who are faced with a serious diagnosis, palliative care can help you and your loved ones cope with all of these things.

Palliative care services can be provided early in the course of illness, along with other therapies that are intended to treat a person's illness or condition, such as chemotherapy or radiation therapy. What palliative care does is provide individuals and their families with an extra layer of care and increased access to specialized teams of palliative care doctors, nurses, social workers and chaplains. The team supports both the patient and the family every step of the way, by not only controlling pain and symptoms, but also by helping them to understand treatment options, supporting them as they set goals of care and make decisions that match those goals. Working with your doctor to provide an extra layer of support, the palliative care team provides:

- Time for communication
- Expert management of pain and other symptoms
- Help in navigating the healthcare system
- Guidance with difficult and complex treatment choices
- Emotional and spiritual support for you and your family



## Legislative advances in the provision of palliative care

In recent years, there has been a great deal of conversation and discussion among health care professionals and our State legislators about the benefit of providing palliative care services to residents of New York State. Over the past two years, two new laws have passed that not only affirm palliative care as a valuable component of health care, but also create greater access to palliative care for all New York state residents. These new laws provide opportunities for individuals to work with their own doctors or health care providers to take control of their health care decisions by providing them with information and counseling about their palliative care options and access to palliative care professionals and services, allowing patients to make informed decisions about their treatment and care. The

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Palliative Care Information Act (PCIA) went into effect on Feb. 9, 2011. This measure provides that when a person is diagnosed with a ‘terminal illness or condition,’ that person’s health care provider must offer to provide information and counseling about palliative care along with information about standard treatments for their condition. The law defines a ‘terminal illness or condition’ as one that is expected to cause death within six months. The PCIA applies to health care providers in all settings including private practices and health care facilities. However, it is important to note that any person has the right to refuse the offer of information and counseling; there is no requirement to accept.

The goal of receiving information and counseling about palliative care options, as well as information about standard treatments, is to empower patients faced with a terminal or life-limiting conditions to make informed decisions about the kind of treatment(s) and care they would want to receive. The information offered is not limited to the following, but will include:

- The prognosis (probable outcome of the illness or condition)
- The range of treatment and care options appropriate for the patient
- The risks and benefits of these treatment and care options
- Legal right to comprehensive pain and symptom management at end-of-life

While it is beneficial for all persons diagnosed with a terminal illness or condition to talk with their doctors about palliative care as a health care option, the PCIA has made it easier than ever to begin the conversation.

- The Palliative Care Access Act (PCAA) became effective on Sept. 27, 2011. Like the PCIA, this law provides opportunities for residents of New York State to receive information and counseling about palliative care services and to work with their own doctors or health care providers to make informed decisions about future

treatment and goals of care. But, there are three very important differences in the PCAA:

1. It also applies to residents in nursing homes, home care agencies, enhanced assisted living residences and special needs assisted living residences, not just patients in the community and the hospital
2. It applies to all patients with “advanced life-limiting conditions or illnesses,” not just those with a terminal illness
3. It requires that access to palliative care consultations and services must be provided, not just information and counseling

The goal of the PCAA is to ensure that every person with an advanced, life limiting condition or illness (not just those with a terminal illness), regardless of where they are living or being cared for, will now be able to receive not only information and counseling about palliative care but also access to palliative care services if they so choose.

For more information about palliative care or to find a palliative care provider in your area, please visit [www.hpcanys.org](http://www.hpcanys.org)

# Reinventing Family Traditions: Talking About Advance Care Planning

Advance care planning is the process of thinking about, talking about and planning for future health care – including end of life care. Advance care planning gives everyone a chance to say what's important to them. It helps people understand what the future might hold and to say what treatment they would or would not want. It helps people, their families and their healthcare teams plan for the future. This makes it much easier for families to know what the person would want – particularly if they can no longer speak for themselves.

Advance care planning is not just about old age. At any age, a medical crisis could leave someone too ill to make his or her own healthcare decisions. Even if you are not sick now, making healthcare plans for the future is an important step toward making sure you get the medical care you would want, even when doctors and family members are making the decisions for you. The more thoroughly you communicate, the easier it will be for everyone to respect your wishes.

*(Continued on page 46)*





Family gatherings can be turned into opportunities to improve understanding of the role of advanced care planning, here are some tips for making conversations about future health care needs easier.

**Start with a story of someone else's experience.** An anecdote about what happened to someone else is a safe way to dip a toe into potentially tumultuous conversational waters. Illustrating what could go wrong (or right) in a critical healthcare situation can be a useful segue to talk about your own expectations.

**Express your gratitude.** Give thanks for the good things in life and celebrate friends, family and connection. Use this time to express your values, priorities, and what you feel comprises quality of life. Tell your loved ones what you value most about your physical, mental and/or spiritual well-being.

**Pick a quarterback.** Just as your favorite team needs a quarterback to advance the ball, you will need to designate someone you trust to act as your health care agent or proxy. This is the person best suited to speak for you in a medical crisis in the event that you are unable to speak for yourself. Although there may be many members on the team, it is important to have one person who calls the plays. The person you choose should be able to make decisions that are in keeping with your values wishes and choices.

**Blame the lawyers.** If your family is not quite comfortable with sharing feelings, this strategy might work well for you. In fact, most estate attorneys and family law advocates strongly encourage their clients to execute a health care proxy and living will.

**Make it a family affair.** Many hospices make available health care proxy forms that are the size of a place card, designed to fit in one's wallet. Use these to designate holiday seating arrangements and have the whole table fill them out together.

**You can always (ex)change it.** Don't worry that this is carved in stone; Just as your hairstyle might change as you age, so might your preferences. Your first living will might state that you want all care focused on sustaining your life and at some point later in your life you might change your mind. Later on you might decide your priority is to try life-extending treatment for a period of time and then transition to a focus on comfort care. And at some point, you may or may not choose strictly comfort care, like hospice, to allow for a natural death in the setting of your choice with friends and family around you. Therefore, as your preferences change, you may update your documents as you so choose- and make sure your health care proxy knows what you want.

**Give a gift.** Although it may feel awkward to initiate such a discussion with your loved ones, think of it as a gift that you are giving, both to yourself and to your family. Without an advance directive, friends and family struggle with the moral burden of complicated medical decision-making in a time of crisis. By making your health care preferences known and documented, you are giving a gift to your loved ones – the certainty that they are following your wishes.

For more information on advance care planning, please visit [www.hpcanys.org/community-resources/advanced-directives](http://www.hpcanys.org/community-resources/advanced-directives)

# We Honor Veterans

More than one-quarter of all Americans who pass away this year will be veterans of our Nation's armed services. Nearly 1,600 veterans die every day, and in this year alone, more of them will die than did during all four years of the Second World War. These heroic Americans deserve recognition for their military service – particularly at the end of life's journey.

The Hospice & Palliative Care Association of NYS, along with our New York State VA partners, is supporting an on-going program from the National Hospice and Palliative Care Organization and the Department of Veterans Affairs (VA). We Honor Veterans is a pioneering campaign to help improve the care Veterans receive from hospice and palliative care providers. The needs of veterans are far more complicated than most people realize. Did you know:

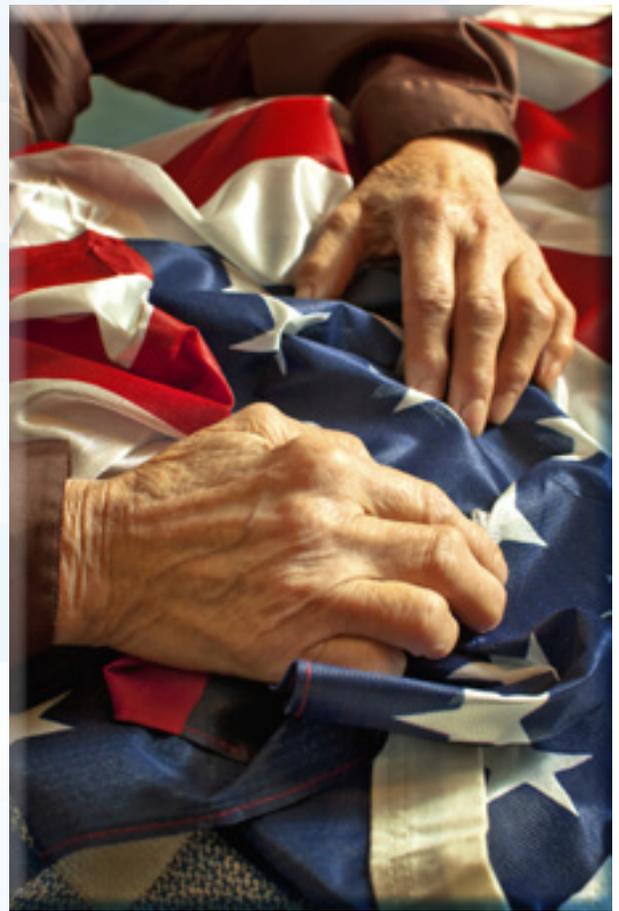
- Nearly 40 percent of enrolled veterans live in areas that are considered rural, where VA palliative care programs are not readily available.
- On any given night more than 107,000 veterans are without shelter and lack basic healthcare.
- Veterans age 18 to 25 are more likely than older veterans to have higher rates of substance abuse disorder.
- The United States National Comorbidity Survey Replication found that the estimated lifetime prevalence of post traumatic stress disorder (PTSD) among Vietnam Veterans was 30.9 percent for men and 29.6 percent for women.

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By recognizing the unique needs of our nation's Veterans who are facing a life-limiting illness, hospice and palliative care providers will be able to accompany and guide America's veterans and their families toward a more peaceful ending. The magnitude of the issues presented by aging veterans is underscored by the sheer weight of their numbers. And in cases where there might be some specific needs, related to the Veteran's military service, combat experience or other traumatic events, providers will find tools through We Honor Veterans to help support the veterans in their programs. For example, veterans of each military conflict present a set of potential health risks that may not be shared by the general population:

- **World War II:** WWII Veterans today are all over 80 years old and subject to all the diseases of aging: cardiovascular diseases, cancer, dementias of the Alzheimer's type, etc. However, in the early 1940's, they were among the nation's fittest and participated in modern warfare that coincided with major advances in modern medicine.
- **Korea:** Cold injuries including frostbite and immersion (trench) foot constituted a major medical problem for U.S. service personnel during the Korean War. Veterans of the Battle of the Chosin Reservoir are recognized as having suffered especially high rates of severe cold injuries. Cold accounted for 16 percent of Army non-battle injuries requiring admission and over 5,000 U.S. casualties of cold injury required evacuation from Korea during the winter of 1950-1951.
- **Vietnam:** In addition to the risks inherent to combat, troops experienced many environmental hazards. Pesticide and herbicide spraying was commonplace. In addition, Vietnam is a tropical country with high temperatures, high humidity and a monsoon climate. Approximately 20 million gallons of herbicides were used in Vietnam between 1962 and 1971 to remove unwanted plant life and leaves which provided cover for enemy forces during the Vietnam Conflict.
- **Gulf War:** Depleted uranium is a by-product of the uranium enrichment process that makes nuclear fuel. The U.S. military uses tank armor and some bullets made with depleted uranium (DU) to penetrate enemy armored vehicles. Depleted uranium has approximately 60 percent of the radioactivity and the same chemical toxicity as natural uranium. The U.S. military began using DU on a large scale during the Gulf War in the early 1990s.



The resources of We Honor Veterans focus on respectful inquiry, compassionate listening, and grateful acknowledgment, coupled with Veteran-centric education of staff caring for Veterans. The website can be found at [www.wehonorveterans.org](http://www.wehonorveterans.org).

America's Veterans have done everything asked of them in their mission to serve our country and it is never too late to give them a hero's welcome home. Hospice staff may provide the last opportunity for Veterans to feel that their service was not in vain, and that they are appreciated. Simple acts of gratitude at the end-of-life can make up for a lifetime since some Veterans were never welcomed home or thanked.

As Americans pay tribute to the men and women who have served our country, HPCANYS, NHPKO and the Federal and New York State VA systems are proud to make this commitment to our veterans. 

# Caring for Alzheimer's Patients at End of Life

There are more than 5 million Americans living with Alzheimer's disease and it is the sixth leading cause of death in this country. In fact, in 2014, 14.8 percent of patients admitted to hospice had a primary diagnosis of dementia. Dementia is a group of disorders involving mental decline that typically interferes with activities of daily living and affects at least one core mental function, such as memory, language, visuospatial or executive functioning; Alzheimer's disease accounts for 70 percent of all dementias.

Being a caregiver for someone with Alzheimer's requires flexibility and patience. It can require making changes in everyone's lifestyles in ways that they don't like and can't imagine. As the abilities of a person with Alzheimer's change and functioning independently becomes more difficult, caregivers take on greater responsibility. Sad to say, Alzheimer's only gets worse. There will be good days and bad days, but the bad days will get worse and the good days will become more and more rare. While it is important for everyone to plan for the future, it is especially critical for those with an Alzheimer's diagnosis to consider advance care planning. Early planning allows the person with dementia to be involved and express his or her wishes for future care and decisions. This eliminates guesswork for families, and allows for the person with dementia to designate decision makers on his or her behalf. In addition to sharing the patient's wishes with family, advance directives should also be discussed with doctors and other health care providers to ensure they're aware of their patient's wishes.

During the late stages of Alzheimer's disease, the patient generally loses the ability to walk, speak and even swallow. Since care needs are extensive during the late stages of the disease, this may mean moving the individual into a skilled nursing facility where intensive, around the clock care can be provided. Approximately 80 percent of all people with Alzheimer's disease live in a nursing home. At this point in the disease progression, the role as a caregiver can shift to focus on preserving quality of life and the dignity of the individual.

For those dementia patients at end of life, hospice care is an option that promotes dignity and quality of life by focusing on keeping the patient comfortable and pain-free until life ends naturally. Hospice includes an

interdisciplinary team comprised of physician, nurse, social worker, home health aide, spiritual counselor and trained volunteers. They work together to address the physical, emotional and spiritual care of the person as well as the family. Care can be provided at home or in a

*(Continued on page 50)*





residential care facility and is covered by Medicare as long as the patient's physician attests that the patient is terminal.

Even in the last stages, patients with Alzheimer's disease communicate discomfort and pain. Pain and suffering cannot be totally eliminated, but the hospice team can help make the patient comfortable.

Managing pain and discomfort for a patient with late-stage Alzheimer's disease requires careful monitoring and reassessment of subtle nonverbal signals. Slight behavioral changes can signal unmet needs. The hospice team, from the physicians to the volunteers, are experts in recognizing symptoms of distress and experiences in both pharmacological and non-pharmacological interventions to manage pain. The soothing properties of touch, massage, music, fragrance, and a loving voice can help ease distress. Hospice team members can utilize a variety of techniques, traditional and non-traditional to keep the patient comfortable.

The impending death of a family member is an emotional time for everyone and hospice professionals are there to provide support for the family during the very last stages of the disease. They also provide bereavement support for up to 13 months after the patient's death. This is because the families may find that they need bereavement support up to and through the one year anniversary of their loved one's death.

Bereavement counselors can make recommendations of various local support systems throughout the community, a resource that caregivers may not realize is available to them. Whether it is through direct conversations, support groups or various remembrance ceremonies, hospice professionals can help caregivers connect with the support system that's right for them.

Caregiving for a friend or relative with dementia can be overwhelming. Memories of how a loved one used to be and the stress of the current demands placed on the caregiver may make the caregiver feel sad, angry or guilty. Caregiving can be socially isolating as well as mentally and emotionally stressful. People often feel intensely uncomfortable talking about death and dying and this is further intensified if the loved one is suffering from Alzheimer's. The anxiety this causes may mean that the caregiver is avoided - further increasing the feeling of isolation. Well-meaning friends and acquaintances may also avoid conversation about the patient to "protect" their friend from further pain, or may inadvertently say insensitive things.

Ironically, the extended journey of a disease such as Alzheimer's gives families the gift of preparing for, and finding meaning in, their loved one's end of life. When death is slow and gradual, many caregivers are able to prepare for its intangible aspects and support their loved one through the unknown. Even with years of disease progression, others find themselves unprepared and surprised when death is imminent.

Talking with family and friends, consulting hospice services, bereavement experts and spiritual advisors can help caregivers work through these feelings and focus on the loved one. Hospice and palliative care specialists and trained volunteers are able to assist not only the dying person, but also caregivers and family members.

Caring for a loved one with Alzheimer's disease is a long and difficult road. Even with years of experience, caregivers often find the last stages of life uniquely challenging. A hospice team can provide medical, emotional and spiritual support according to the wishes and beliefs of the patient. They also offer emotional support to the patient's family, caregivers and loved ones, including grief counseling. Let hospice help ease the journey from care and grief towards acceptance and healing. 

As part of an ongoing effort to include as many member stories and photos as possible, and to make access to member news easy, dates have been added to each member story headline. These dates refer to the release dates as posted on the **LeadingAge New York** website. All Noteworthy stories will link to the main "Member News" page where stories are listed by date, with the most recent postings first. Send us your news stories and be featured in the next issue of *Adviser*.

# MEMBER NEWS NOTEWORTHY

## RIVERSPRING HEALTH

### *RiverSpring Health's Overnight Program Helps Both Dementia Sufferers and Families*

Sleep deprivation inspired the development of an overnight program for seniors with dementia 10/6/15



### *Outstanding Scout Projects at St. Johnland Nursing Center*

Two scout projects were completed to benefit the residents at St. Johnland Nursing Center in Kings Park 09/28/15

## ANDRUS ON



Barbara Fleischer

Vincent Bonadies

### *Andrus on Hudson Hires*

**Two New Directors** Andrus on Hudson is pleased to announce the appointment of Barbara Fleischer as administrator on Oct. 26<sup>th</sup> and Vincent Bonadies MS, CTRS as director of community life and volunteer services (known as director of recreation in other nursing homes) on Nov. 16<sup>th</sup>. 11/24/15

## HUDSON

## WARTBURG

### *Wartburg Kicks off 150<sup>th</sup> Anniversary with the Return of the Fall Festival*

Wartburg kicked off its 150<sup>th</sup> anniversary with an event-filled Fall Festival. This festival was held to honor the past, celebrate the present and build for the future. 10/19/15

### *Wartburg's Executive Chef, Kevince Pierre-Louis, Wins the Kraft Food Fight Eastern Region Championship*

Forty contestants vied for the top slot at this year's event in Buffalo. Mr. Pierre-Louis beat the fierce competition with his recipe for Cheesy Devilish Deviled eggs for the sought-after title of Eastern Region Champion. 04/11/15

(See Noteworthy on page 52)

## HEBREW HOME AT RIVERDALE

**The Power of Touch** Hebrew Home at Riverdale resident Beverly Herzog is quoted in the article's opening paragraph, which also includes quotes from President and CEO Daniel Reingold and background about our sexual expression policy, described as "shifting thinking about sexual intimacy as a civil right for residents in long-term care." 12/15/15

**Elder Abuse: The Only Elder Abuse Shelter in NYC** The Weinberg Center at the Hebrew Home in Riverdale currently houses 16 elder abuse victims. Joy Solomon tells the story of an eighty-seven year old woman who was physically and financially abused by several young adults she helped raise. 12/30/15

**When Making a Call has Life and Death Consequences - for Staff** Congratulations to Joy Solomon, director and managing attorney of the Weinberg Center for Elder Abuse Prevention, for her featured guest blog on McKnights Long Term Care News website. In it, Joy discusses the need for domestic violence prevention and intervention programs for employees, such as the Hebrew Home's effective "It's Your Call Program." 12/16/15

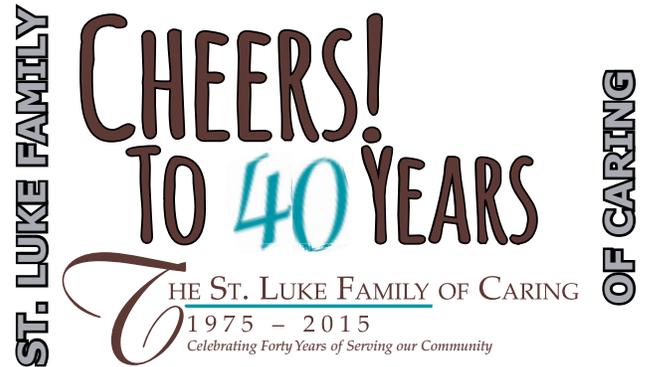


**United Hebrew of New Rochelle Presents: Art Fired Up** featuring the work of 20 artists from across the New York metropolitan region and drawn from a collaboration. The exhibition consists of 40 works including sculptures and paintings in both figurative and abstract forms, wall art, and glass. 10/12/15

## BAPTIST HEALTH SYSTEM

**\$2,000- to Be Donated to Things of My Very Own, Inc. from Baptist Health System!**

Things of My Very Own, Inc. is a local not-for-profit that provides crisis intervention services and programs to children who have experienced extensive abuse and/or neglect 10/8/15



**Cheers! to 40 Years for the St. Luke Family of Caring** Thanks to everyone who helped us mark our 40<sup>th</sup> year as not-for-profit, community-based healthcare providers serving the greater Oswego County community. Attendees enjoyed samples from local wineries and distilleries, seasonal beers, food pairings from local establishments and a silent auction with fabulous prize packages. 10/13/15

## JEWISH SENIOR LIFE

**Jewish Senior Life Enhances Palliative & End of Life Care Program** Jewish Senior Life has secured funding for an initiative that will enrich the palliative and end-of-life care services provided to its residents. Initiative includes: increasing the satisfaction of residents' family members related to the end of life care that their loved ones received at Jewish Senior Life. 11/12/15



**Oct. 28<sup>th</sup> is Declared "David J. Gentner Day" in Westchester County to Honor Wartburg's President and CEO** County Legislator Lyndon Williams declared Oct. 28, David J. Gentner Day in Westchester County. This honor was bestowed upon Wartburg's president and CEO while he accepted the Award for Excellence in Adult Care. 10/28/15

## ST. JOHNLAND NURSING CENTER

**St. Johnland Appoints a New Recreation Director** St. Johnland Nursing Center is pleased to announce the appointment of Carolyn O'Brien MS, CTRS as director of recreation. She is responsible for managing all of Recreation Therapy staff. 11/18/15

**Our Lady of Mercy Academy Choir Visit** Students from Our Lady of Mercy Academy's Choir made a first-time appearance at St. Johnland Nursing Center to present a Christmas show for the residents and staff. 12/15/15

(See Noteworthy on page 53)



ST. LUKE

HEALTH SERVICES

**New Rehabilitation Technology More Than a Game for Patients at St. Luke and Michaud** For patients in the Rehabilitation Departments at either St. Luke Health Services in Oswego or Michaud Residential Health Services in Fulton who experience dysphagia, this latest therapy technology is about improving their ability to swallow and be able to enjoy many of the activities we take for granted every day. 10/03/15

**JEFFERSON'S FERRY**

**Jefferson's Ferry Recognized for Outstanding Business Achievement**

Jefferson's Ferry Lifecare Retirement Community was recently recognized for *Outstanding Business Achievement* at the HIA-LI 21<sup>st</sup> Annual Business Achievement Awards luncheon. They were evaluated extensively on every aspect of the way they conduct business, from the quality of life for residents, to workplace programs, financials and community service. 10/5/15

MEMBER NEWS  
**NOTEWORTHY**

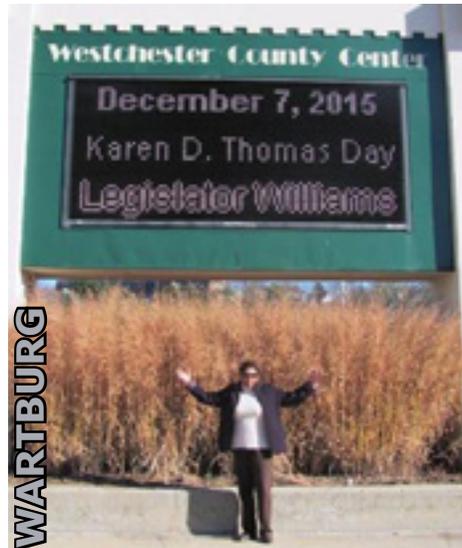
PRESTWICK



Helen Sperling

**Thou Shalt not be a Bystander** Helen Sperling, 95 years old and still independent, spoke to residents of Preswick Glen. Sperling is a survivor of one of the darkest times in our history, and over the years has been a regular speaker on the topic. 10/16/15

GLEN



WARTBURG

**Dec. 7<sup>th</sup> is Declared "Karen D. Thomas Day" in Westchester County** Dec. 7<sup>th</sup> is declared "Karen D. Thomas Day" in Westchester County to honor Wartburg's development assistant and prominent community advocate for Mt. Vernon. 12/8/15

**SELFHELP COMMUNITY**



Hanan Simhon

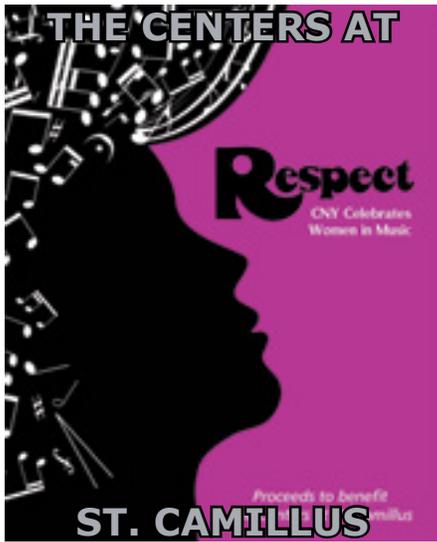
**Selfhelp Community Services Appoints Hanan Simhon vice president of Selfhelp's Nazi Victim Services Program** Hanan Simhon, a 16-year veteran at Selfhelp Community Services, has been named Vice President of the organization's internationally renowned Nazi Victim Services Program 10/16/15

**SERVICES**

**GUILDNET**

**Guildnet Expands Leadership Position As New York State's Largest Managed Long Term Care Plan Provider**

GuildNet, the leading provider of Managed Long Term Health Care (MLTC) plans, announced that almost 2,000 members are being successfully transitioned from Emblem Health. 12/22/15



**2<sup>nd</sup> Annual "Respect: CNY Celebrates Women in Music" Benefit Concert Held on Nov. 13 at The Palace Theater** Harbor Pharmacy presented the 2<sup>nd</sup> annual "Respect: CNY Celebrates Women in Music" concert to benefit The Centers at St. Camillus, at The Palace Theater. Central New York's finest female artists paid tribute to women in music who inspire them in the mother of all live music events! 10/26/15



**Students and Elders Celebrate Chanukah Together** They played Chanukah games and enjoyed a festive Chanukah meal, but most importantly, the participants gained wisdom from a different generation. 12/10/15



**Hidden Talents: Local Wood Sculptor Bill Whitehill Still Learning, Sharing** New Hartford's Preswick Glen residents and staff discovered recently that one of their own, Bill Whitehill, is an accomplished wood sculptor when he gave an in-depth look at some of his magnificent work. 10/26/15

**AMSTERDAM NURSING HOME CORP.**  
**Independent Tray Service: A Program To Enhance Meals** Amsterdam Nursing Home introduced an independent tray service for its residents to demonstrate that modifying how residents with dysphagia are served can improve their health and restore their dignity. 11/5/15

**ST. JOHNLAND**  
**St. Johnland Nursing Center Announces the Appointment of Marie Chantale Philippe, LMSW, as Director of Social Work** St. Johnland Nursing Center is pleased to announce the appointment of Marie Chantale Philippe, LMSW, as director of social work. 10/19/15



Marie Philippe

**NURSING CENTER**

**LEADINGAGE NEW YORK NEWS NOTEWORTHY**

**LEADINGAGE NEW YORK STAFFING UPDATES**

LeadingAge New York would like to welcome the newest member of our team: **Cathy Bongermimo**, receptionist. We would like to congratulate **Sarah Daly** who was promoted to Value First marketing and sales coordinator.

**CHANGES AT LEADING AGE NEW YORK PROCARE**

On Jan. 4, **Nancy Truland** joined Leading Age New York as a ProCare nurse consultant and policy analyst. Nancy has extensive experience as a director of nursing and, with her organizational and clinical skills, will be a tremendous resource for members. In Feb., **Michelle Synakowski** will take over as director of ProCare in addition to her responsibilities as a policy analyst. **Elliott Frost** will continue in his role as senior policy analyst and a member of the ProCare team, but has reduced his work schedule.

(See Noteworthy on page 55)

# NOTEWORTHY

## LEADINGAGE NEW YORK NEWS

### Welcome New Members

#### Primary Members:

Concerned Home Managers for the Elderly: Licensed Home Care Services Agency  
Kalos Health: Managed Long Term Care  
Wartburg MLTC: (Under Construction)

#### Associate Members:

Tom Gagliardi, senior account manager,  
McKesson

### Upcoming Conferences and Educational Events

#### Conferences

**April 7-8, 2016**

##### Adult Day Health Care Annual Conference

Embassy Suites by Hilton, Saratoga Springs

**April 12-14, 2016**

##### Housing Professionals Annual Conference

DoubleTree Hotel by Hilton Syracuse

**May 23-25, 2016**

##### Annual Conference & Exposition

The Saratoga Hilton & Saratoga Springs City Center, Saratoga Springs

**Aug. 30 - Sept. 1, 2016**

##### Financial Managers Annual Conference & Exposition

The Saratoga Hilton & Saratoga Springs City Center, Saratoga Springs

#### Educational Events

**March 31, 2016**

##### HR Summit - NYC

Jewish Home Lifecare, Manhattan

Leading-U is offering many audio conferences and seminars. Check out our line-up by [clicking here](#).

To feature your news items with LeadingAge New York send press releases to Kristen Myers at [kmyers@leadingageny.org](mailto:kmyers@leadingageny.org)

### Don't miss your chance to advertise in the **2016 Membership Directory!**

#### WHY ADVERTISE?

- ◆ We represent **nearly 100%** of the state's non-profit and government health care providers
- ◆ Members spend more than **\$3.3 billion** on products and services on an annual basis
- ◆ Advertising allows you to engage with **key decision makers**
- ◆ Our guide reaches **nearly 100%** of all discharge planners in the state
- ◆ You **double your exposure** by being featured in both print and online

For more information, contact:

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