

CARE CONNECTIONS

Newsletter for the Karen Ann Quinlan Memorial Foundation

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A crowd pleaser at Polka Night.

No Fear?

Reflections by Cecelia T. Clayton, MPH

In the 1990's "No Fear" was part of an advertising campaign and was featured on T-shirts, and even was the name of an energy drink. The wearers and the drinkers of "no fear" were probably trying to show their willingness to go beyond the norms of life experience by participating in extreme endeavors. I imagine they were also trying to advertise their courageousness. Living without any fears might sound good but is it possible for most of us? And, is it necessarily a good way to exist?

Years ago I learned how to ride a motorcycle, got my license and a bike. I went straight pretty good, but darned if I could do a decent left turn. Sometimes I was "balanced," sometimes I wasn't, and when I wasn't I went down. Fear grew within me (as bruises grew on the outside). Many said, "it takes practice." But one elderly man said something else...he simply said to me: "lose the fear, or lose the bike." He knew that fear could ruin the bike, keep me from enjoyment, or at worst could cause myself or someone else to be seriously hurt or even cost a life. So, lose the fear - or lose the bike - or lose your life. For a while pride kept me trying but then it became, as they say, a "no brainer!"

So, I lost the bike -now no fear and more enjoyment riding as a passenger, more life to my life.

We also have to contend with the newest, latest and greatest "fear of the moment." What has been recently discovered as bad for your health, destructive, or dangerous. What food was good for you but now not, what sport kept you healthy but now destroys the bones, what clothing, dishes, soap, perfume is now on the banned list. Do we go out in the sun or not, do we eat or not, do we play or not, do we discipline or not, do we teach or not. The list goes on and on and is amended year to year. A medication or treatment is touted as the newest and the best and then is banned from the market. Abbott and Costello would have a field day trying to explain the who's and what's and where's of it all!! Plus, it is most likely a good thing to recognize that, like my experience with the motorcycle, fear can come from our perceived ability to control our lives - or those of others. And unfortunately once we admit that we really don't have the control we thought we had, we are faced with the fear of what happens when we aren't in control!! Is there any wonder that we have fears? And what are we to do about it? Should we:

Forget Everything And Run?

Maybe not, hopefully not, because while many fears are not real, our lives are real. And we can't run away from life. There are many resolutions and remedies for fears - Spiritual beliefs, Prayers, Meditation, Social behaviors, Alternative Medical, Physical, Musical - name your favorite, and then put it into action. It's pretty easy to do - all it takes is a willingness and ability to change pretty much the way we live and think. And, failing that, a willingness and ability to accept what we can't. And, failing that, a willingness and ability to ask for help!! So, maybe it isn't really all that easy to do, but it is doable. We have the skills, we have the methods, we have the knowledge. At the bottom of it all, we have those who have taught through the ages - we have the wisdom that is in our faith, in our hearts, in our own personal histories. Plus, we have the obligation to those who walk the journey of life with us to keep each other safe, to bring peace to ourselves and others, to help ourselves and others fully experience all the gifts of life - in the physical present, in the memories of the past and in the hopes of the future.



Joseph T. Quinlan Foundation thanks the Biggs Kids Foundation for bereavement donation of \$5000.00.

Sparta, NJ -August 6th--Steve Bieganousky of Sparta, who lost his only child, is no stranger to the pain of grief. His son Steven at the age of 21 died suddenly in a car accident on Easter Sunday, March 27, 2005. 'A fun-loving and spirited individual, he always enjoyed making people laugh.' Young Steven strongly believed in standing up for those who could not stand up for themselves, particularly children. To continue Steven's devotion to helping children, the family founded The Steven P. Bieganousky Foundation for Children, also known as BIGGS' Kids. The foundation is dedicated to raising funds to benefit less fortunate children and monies are distributed to organizations providing physical, emotional, educational, and spiritual needs of suffering children.

Cecelia Clayton and Roxanne Seigel along with Diana Sebzda presented the work of the Joseph T Quinlan Bereavement Center, especially the children's art program to Steve who then wanted to learn more. "I found my professional niche in the world of graphic design and have enjoyed much success, so the children's grief art program did get my attention." Bieganousky started his Sparta graphic design company, the SRD Group in 1984, which primarily creates consumer packaging for many Fortune 500 companies and brand directors. "Art is in my blood" he continued.

"When a family member is lost though death, children are often the "forgotten" grievers as adult family members are busy picking up the pieces and often don't understand how children process grief" Diana Sebzda, Director of the Joseph T. Quinlan Center explained to the audience. The Children's grief art program is unique to the area with Sebzda and her skilled team of counselors constantly developing innovative and playful means to reach children suffering from the death of a parent, grandparent, sibling or any loved one. Many different methods and themes are used to encourage children to unveil their emotions.

Sebzda described a themed board, 'It's a Jungle out there' which let children pick a jungle animal that most describes how they are feeling about the loss of their loved one, while in another room, the parent is asked to do the same. "Parents are amazed to see that

their child has expressed their pain very differently from the jungle animal the parent chose."

Another recent theme was The Seashore and the Waves of Grief where the children were asked to write down one of the many coping strategies they learned in the program that would be helpful to someone else who has lost a loved one and put it in a bottle (message in a bottle) and offer it to that person when the time was right.

When Steve toured the center last month, Diana pointed out how parents have expressed their grief over the loss of a child. Hanging on one of the walls was artwork of a rose, on another a poem.



Diana Sebzda, Joseph T Quinlan Bereavement Center Director explains to the attendees of the Biggs' Kids Foundation Golf Outing held Monday, August 6th at the Lake Mohawk Golf Club how grieving children are helped with their art programs.

Both of these pieces represented two different avenues the grieving parent acquired to demonstrate their love for their lost child. "Grief and tragedy changes people, and it all depends what you do with it." Steve pointed out "I can see now how art has a place in the world of grief."

The Steven P. Bieganousky Foundation for Children, Inc. www.spbfoundation.org holds its annual golf outing every August at the Lake Mohawk Golf Club in Sparta.

The Joseph T Quinlan Bereavement Center offers individual grief counseling and monthly support groups in Newton and Hackettstown, NJ and Milford and Lord's Valley, PA. For group details visit www.KarenAnnQuinlanHospice.org. You may also call the Bereavement Center in Newton (973) 940-0413; Hackettstown (908) 852-8730 or the Milford Hospice, PA (570) 296-3591. or 800-882-1117 for any office.

Diana Sebzda with Steve Bieganousky at the Center's Newton location showing him the workings of sand play as part of the children's grief art program.





What is in store for Medicare—Roxanne Debski-Seigel, PhD

Medicare plays a huge role with our hospice community of patients and Karen Ann Quinlan Hospice has departments dedicated to assisting the family chart through this medical labyrinth.

In 2010 when US Democratic House Speaker Nancy Pelosi said “We have to pass the (health care) bill so you can find out what’s in it.”, she wasn’t kidding. Since then the medical industry has been trying to unpeel the onion layers of the 2700 pages Affordable Care Act to make sense of all the new requirements and regulations. *According to an ABC News’ Report by Chris Good and Shushannah Walshe’s : In February 2011, the CBO estimated that Obama’s health-reform law would reduce the deficit by \$210 billion over 10 years. Part of that reduction will come from slowing the rate of Medicare spending growth and imposing taxes.*

Benefit spending:

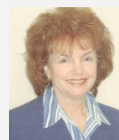
- By 2020 the new plan will have phased out the part D *doughnut hole* prescription benefit thereby reducing Medicare beneficiaries’ payment portion for their prescriptions.
- Coverage for preventative services and annual wellness program on approved plans that receive a grade of A or B from the US Prevention Services Task Force.
- Payment increase for family physicians and other primary-care doctors.

Reductions or “cost savings”:

There will be Medicare reductions of \$716 Billion over the next ten years, but over the same time, Medicare enrollees are expected to increase by 26% according to the AARP Public Policy Institute. This likely collision course of increased demands meeting decreased services is projected by some in the industry to negatively impact Medicare patients.

- 40% of cuts will reduce annual increase of payments to providers such as hospitals, Home Health Care agencies, and skilled nursing facilities.
- 25% of cuts will be reduction of payments to Medicare Advantage plans and according to the CBO it is expected to result in fewer enrollees into these plans as well as fewer plan benefits and possibly fewer plans available.
- Premiums and taxes will increase for higher income beneficiaries including a new capital gain tax on primary residence home sales.
- An Independent Payment Advisory Board will be created to hold down costs in Medicare. Beginning in 2015, IPAB will have the power to make arbitrary binding recommendations to reduce further spending.
- Delivery systems reforms such as Accountable Care Organizations, (ACOs) bundled payments for hospitals and physicians, medical homes, incentives to reduce hospital readmissions are part of the payment reforms to reduce costs and spending.
- Reduced reimbursements for many types of specialists.

It is safe to say most doctors study medicine with a passion to cure and provide patient care; however the increasing heavy handiness of government regulations are making “government” workers out of doctors or chasing them away all together. According to an article in the Washington Times by Dr. Adam Dorin, MD, with the mandated government electronic filing plus government-empowered non-physicians administrators making de-facto medical decisions, the new law is likely to lead to a weakening of the doctor-patient relationship.



From QAPI/ Education Corner

Mary Pugliese,
RN, BSN, CHPN

Home Health Aide Classes were held

9/10 to 9/21. Students from the class will be able to support all of our patients and we are looking forward to mentoring these new staff members.

Certified Hospice and Palliative

Nursing. Some of our hospice nurses will be sitting for the examination to be a Certified Hospice and Palliative Nurse this fall. Having a large number of certified nurses increases the level of quality care given to our community. We have an excellent staff and we applaud the nurses for accepting the challenge.

Professional CEU’s . We have been out in the community offering nurses contact hour programs this summer on topics like “Five Rights of Pain Control” and “Collaboration of Care with Nursing Facilities for Hospice Care”. It is a pleasure to be able to share with our nursing peers throughout the county the topics we know are important and on which we have gained expertise through our hospice work.

Good News! We have improved our reported statistics on Falls through Peer forum this quarter. We have been concerned that many of our patients fall during their care continuum due to weakness. The staff has put together a Falls Prevention Task Force to investigate just what we are able to do to prevent the injuries associated with a simple fall. So many great ideas have been offered and put into play. Our success has resulted in a significant drop in the number of falls. We will continue to educate the staff through a train –the- trainer program in each office that will be available throughout the year.



Dear friends,

I am always happy to share news about Home for Hospice with our newsletter readers.

Our approval for a low-interest, 30-year mortgage by the USDA assures that we will have a groundbreaking for the home sooner than we had thought. I like to remind people that this is not a grant or a gift from the government. It is a loan which carries with it the obligation of monthly payments that most of us have with our own mortgages. For that reason, we must continue with our efforts to raise the necessary dollars to pay for this wonderful project.

The other news item is that we have created a means by which large numbers of people can help financially in building the home. Now you can pick up your cell phone and with the ease of pressing a few keys, text your way to making a contribution to the Karen Ann Quinlan Home for Hospice. Simply text the word HOSPICE to **24104** and follow the prompts and you will be able to indicate a contribu-

tion in the amount of your choosing.

The new Text 2 Donate option of making a contribution to the new home is one of several ways to show financial support. The Capital Campaign gift pledge form can be found on the hospice's website: www.karenannquinlanhospice.org (click on Karen Ann Quinlan Home for Hospice to download and print the pledge form).

Please send to Glenn Lewis,
Karen Ann Quinlan Hospice
99 Sparta Ave., Newton, NJ
07860.

Please remember texting while driving is dangerous and illegal.

Thank you,
Glenn Lewis
Director of Development

TEXT TO DONATE

TEXT: HOSPICE to 24104



THANK YOU

for Helping us build a
Home for Hospice

All donation amounts are welcome.
Payment instructions will be sent via SMS.



The 6th Annual Joseph and Julia Quinlan Award presented at

Rutgers. Julia Quinlan, pictured left, gave the opening greeting at the Rutgers College of Nursing for the 7th Annual conference of the New Jersey End of Life Nursing Education Consortium (NJ-ELNEC) held in Somerset on June 22nd.

In addition to Mrs. Quinlan greeting all the attendees, she presented the sixth annual Joseph and Julia Quinlan Award to Lorraine Sciara. The Karen Ann Quinlan Hospice began in 1980 and in 1981 The Hospice Inc., which also began as a fledgling community health care provider, began its journey. Today that hospice is known as the Barnabus Health Hospice & Palliative Care Center located in West Orange, NJ.

Under the leadership of Sciara, who took responsibility for the small hospice at a time when there was little public awareness of hospice, the agency grew. Starting with only five employees and five patients, she transformed the agency to a system with over 200 employees, 300 volunteers and an average of 260 patients daily.

The Joseph and Julia Quinlan Award honored her dedication and devotion to the work of hospice which never faltered through the challenging and difficult times many non-profit hospices faced. "For her integrity, compassion, and unending quest for excellence it is a privilege to present Lorraine with the Joseph and Julia Quinlan award for 2012" Julia Quinlan announced.

At the same conference the Quinlan documentary "Saying Goodbye, the Legacy of Karen Ann Quinlan" (Mirage Productions, 2010) was shown and is soon to be released with extra educational dialogues.



Cecelia Clayton named Hospice Director of the Year.

Eatontown, NJ- June 6th, 2012 -The New Jersey Hospice and Palliative Care Organization and the New Jersey Hospice Foundation presented Cecelia T. Clayton of Karen Ann Quinlan

Hospice with the Hospice Director of the Year award at their 15th annual Spirit of Hospice Awards Dinner held on June 6th at the Sheraton Eatontown. Clayton has been with the Karen Ann Quinlan Hospice for over 20 years and as Executive Director administers over the three hospice locations located in New Jersey and Pennsylvania. Prior to being appointed Executive Director, Clayton worked in many capacities including Volunteer and Bereavement Director. Under those titles she initiated many programs including the Joseph T. Quinlan Bereavement Center, a teen grief camp, children’s art grief program, a widow/widower workshop, and a grief lecture series of her own design. With her husband Rich, both avid motorcyclists, she participates in the annual Chilly Chili run sponsored by the Blue Knights chapter IX held every New Year’s Day, and along with the Ogdensburg Fire Department raised this year alone \$11,000.00 for the hospice. Clayton’s leadership in the use of technology for nursing staff led to Thornberry LTD naming her system manager of the year in 2010. Having served as Executive Director of the hospice for the past decade, the agency has quadrupled its patient census. “This award is not about me, but with the people with whom I am surrounded and come to do the work of hospice everyday”. Clayton continued, “I could not accomplish this on my own”.

Hospice with the Hospice Director of the Year award at their 15th annual Spirit of Hospice Awards Dinner held on June 6th at the Sheraton Eatontown. Clayton has been with the Karen Ann Quinlan Hos-



Cathy Shane, RN, BSN, and our Director of Nursing has been appointed on behalf of the Home Care Association of NJ to State Appointment.

serve on the Infection Control Work Group and the Home Health Aide Committee for the term of 7/1/12-6/30/13. This is a state committee to which Cathy will

bring her knowledge and expertise of the industry as well as learn and share from the other members. Infection control in both the hospital and home setting is a critical element in keeping recovering patients on the mend “We are the life-line for so many people” Shane commented with respect to home care. Her presence on the committee will also enhance the staff of Karen Ann Quinlan Hospice and Home Care by bringing the most up to the minute findings in the industry back to our clinical staff.



New Comfort Suite Available.

Karen Ann Quinlan Hospice, in partnership with Belle Reve Senior Living, now

has a very special Comfort Suite that will deliver much needed options for hospice patients in the Pike County area. The Comfort Suite, designed with the Karen Ann Quinlan Hospice patient and family in mind, features a comfortable living space along with room for family and friends. The Comfort Suite, located at Belle Reve Senior Living (404 East Harford St, Milford, PA), offers area Karen Ann Quinlan Hospice patients and their families’ emergency or back-up choices including temporary residency for

their loved one who needs respite care or living quarters while permanent arrangements are being made. An average stay for patients ranges 4-5 days. “Also for the hospice patient who needs skilled symptom management, the new Comfort Suite can be a temporary safety net to get the patient’s symptoms under control” Darrin Adams, Karen Ann Quinlan Hospice Administrator, explained.

Prior to this collaboration patients had to travel out of county to access a similar facility. Now they can stay close to home and family members can be as close as possible to their loved ones. “This is an alliance of top-notch professionals and care-givers from each organization working together to fill an unmet need in the area,” commented Sharon Loganzo, Belle Reve Executive Director. “The high level of commitment between our two groups enabled us to jointly provide these services,” continued Loganzo.

“The addition of the hospice Comfort Suite in a highly rated facility such as Belle Reve is exciting for Karen Ann Quinlan Hospice and the Pike County Community,” stated Cecelia Clayton, Executive Director of Karen Ann Quinlan Hospice.



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Dear Friends,

It is my pleasure to share good news! We at the Karen Ann Quinlan Memorial Foundation continue to move forward with enthusiasm and excitement in realizing our dream of the Karen Ann Quinlan Home for Hospice.

We have been approved by the USDA for a loan to build the home for hospice. It will be the first hospice they have funded. It will be the first home for hospice in Sussex County, NJ. We have raised over 2 million dollars toward our goal of 5 million. The future of hospice in our community depends on you. With your continued support and generosity we will meet our goal.

We will have the ground breaking in November, 2012 and hope to be open to accept patients late 2013. We at hospice and the community are looking forward to a home where our loved ones will receive the special care they require around the clock by our dedicated team of professionals and volunteers. We will be there for their family. At times to sit quietly and share their grief or give a gentle touch or a hug. The Karen Ann Quinlan Home for Hospice will be their home, there will be no set visiting hours, family, friends and children are always welcome.

I have a special and perhaps unusual request for our supporters. Care Connections is a wonderful way to connect with supporters from coast to coast. As a not-for-profit hospice, we depend on fundraising activities and projects throughout the year. I am sure many of you have helped to raise funds for schools, churches or other worthy causes. We are searching for new ideas and ways to raise funds and I invite you to share your fund raising activities and experiences (large or small). I look forward to hearing from you and will enjoy reading and learning from your experiences, I am sure you have many great ideas to share.

November is Hospice Month. It is also the start of the holiday season.

Thanksgiving, Christmas and Hanukah is a time for sharing memories, an abundance of food, and gifts with family and friends. I realize it may be a difficult time for those that have lost a loved one. The holidays always hold special memories. Some we keep locked in our heart, some we will share with family and friends. At hospice we hold a Candle Lighting Memorial service to remember our loved ones. We always light a candle in memory of our hospice patients and everyone who has lost a loved one.

My sincerest wishes for love, peace, and joy through the holiday season.

Together, we look forward to peace, good health, a very happy and joyful New Year and the opening of our beautiful hospice home!

Julia Quinlan, Co-Founder

Karen Ann Quinlan Hospice

MT. LAUREL, August 20, 2012 – USDA Rural Development State Director Howard Henderson announces Karen Ann Quinlan Memorial Foundation in Sussex County will receive a \$2,300,000 mortgage through the Community Facilities program to construct a 10 bed hospice care inpatient facility. The State Director made the announcement during his visit to the

Front cover photo: Julia Quinlan (L) with State Director Howard Henderson and NJ State Assemblywoman Alison McHose at press conference announcing the USDA support.





Fall 2012

If you wish to be removed from the Karen Ann Quinlan Memorial Foundation Care Connections Mailing List please call 800-882-1117. We apologize for any inconvenience.



www.KarenAnnQuinlanHospice.org

**LIGHTS
of
LIFE**

Warren County-November 27
Pike County-November 29
Sussex County December 7

All events held at 7:00 pm

For details Call 973-383-0115 or email Jsmith@karenannquinlanhospice.org
Visit our website for Memorial forms.

Karen Ann Quinlan Hospice showcased their Home for Hospice by sponsoring Polka Night at the New Jersey State Fair in August.



The Friends of Hospice and hospice volunteers also sold tickets all week in the County building for the Harley raffle.

MORE COMING EVENTS!! For details visit our website!

- Heart of Hospice Music Fest, Branchville American Legion 10/13/2012
- Dental Day for Hospice, Sparta Dental Design 11/2/2012
- SK Paper Shred at Goddard School, Sparta 11/3/2012
- Krogh's Dine to Donate 11/4/2012



Saturday, December 8 2 & 7 pm
Sunday December 9 3 pm

Don't miss this exciting Concert that gets better every year! Held at the Performing Arts Center, Sussex County Community College, Newton NJ. Tickets are available at the PAC box office; call for box office hours (973) 300-3171 or to order on-line:

www.sussex.edu

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