The sound of fingers typing on a laptop echoed around Carmine Negri’s hospital room on Milne 1. Next to his bed, his daughter, Victoria, sat writing a movie script. At first glance the pair looked like grandfather and granddaughter. Carmine was 87 and Victoria was just 25. A retired high school art teacher and piano instructor, Carmine had also been an avid runner. But with aging came Parkinson’s disease and a serious stroke in the fall of 2011. He was at Gaylord for rehab and hoping to go home.

Victoria and her father were very close. But even as a child she was acutely aware that her time with him was limited because of their large age gap. As a student majoring in acting at NYU, she started examining her fears about losing him in creative writing classes. Several years later, as Carmine’s health declined, she began writing the script while sitting in the Milford Hospital ICU after her father’s stroke. “I’d always known I wanted to write something about my experiences with an older father,” she explained. “His stroke spurred me to resurrect exploring that idea.”
**There are so many ways people make Contributions**

This is Volume 2 of our Winter 2017 *Contributions* looking at how writing is used by Gaylord patients and family members as they cope with illness or injury. In this edition, our authors have written poems, journals, books and a movie script (see our feature story about the film *Gold Star*).

Inevitably, a health crisis triggers unexpected emotions and a variety of responses from everyone involved. Sometimes patients and families cope well but there are also times when the journey becomes unbearably difficult and lonely. The personal insights, emotions and life lessons expressed through the writing process often provide comfort and guidance to authors and readers alike.

Most of us don’t know how we will manage a sudden accident or illness until we become a patient or caregiver. Victoria, Blanche, Eileen, Amy and Margaret have stories to share because Gaylord was here when they needed us most. We would be unable to offer our patients the possibility of recovery or a return to family and friends without the generosity of our donors. Thank you for your partnership in making each of these stories possible.

“Writing is an extreme privilege but it’s also a gift. It’s a gift to yourself and it’s a gift of giving a story to someone.”  

Amy Tan
Amy Nawrocki was on summer break from her freshman year at Sarah Lawrence College in June of 1992. The 19-year-old had recently returned home from what she described as a “very long and awkward” semester. Although Amy excelled in her studies and was surrounded by peers, the teenager felt lonely.

“I wasn’t homesick; I just didn’t connect to a lot of people around me,” she recalled. “Everyone was in their own little worlds and I didn’t quite fit in. My mom had died only two years earlier so I also was dealing with a lot of grief.”

The creative writing major found solace in an unexpected outlet: her notebook. “My poetry professor suggested that we keep a daily journal as a means of exploring potential writing topics. It wasn’t mandatory, but I took it up anyway. It was a suggestion, she said, that was life changing. “I wrote for myself. I could be funny, sarcastic … angry. I could write about anything I wanted. I discovered that writing is a way to be yourself in ways you’re unable to when you’re with other people.”

Amy’s journal entries came to a sudden halt one summer day when she was rushed to the hospital, disoriented and febrile. Her doctors diagnosed encephalitis. She slipped into a deep coma and emerged several weeks later into a state of fogginess and confusion. It wasn’t until early in the New Year, after being at Gaylord for rehabilitation for several months, that Amy became fully cognizant of her surroundings and situation.

“One of my first concrete memories from that period is being at Traurig,” she said of Gaylord’s eight-bed transitional living house for patients with brain injury. “It was around then that one of my therapists suggested I pick up my notebook again and start putting down words. Looking back at those early entries, it wasn’t pretty but I can see the improvement I was making by looking at the handwriting. The early ones look like chicken scratch, but they gradually improve and come back to normal.”

Far from the poems and deeply personal reflections she penned before illness struck, Amy tracked daily occurrences and details such as what she ate for breakfast and which exercises she did in therapy. “It was more of a log at the beginning, but I think just being able to do that was important for my recovery,” she said.

“It was a slow return to self. In my writing I could figure out who I was in the moment. I could be myself. I remember feeling a lot of frustration during that period, but I didn’t write about it. It was important for me to instead find something that resembled the person that I was before encephalitis ... and I could do that in my writing.”

Amy remembered quietly rejoicing to herself when she noticed that she was beginning to reintegrate certain catchphrases she used in college into her journal entries. “I’d recognize part of my old self as I wrote and think, ‘Oh, there … that’s me! I’m still myself.’ It was a relief.”

As Amy progressed in her recovery, she returned to school and resumed her life. More than just a hobby and an expressive outlet, writing is now her life’s work. She is a professor of poetry, composition, creative writing

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Other than a sudden excruciating headache, Blanche Feero remembers nothing about what happened after her brain aneurysm burst on December 30, 2006. A middle school English and reading teacher, Blanche was just 54 years old when the stroke dropped her to the floor as she was reaching for a book.

“There were no warning signs, no headaches, no signs whatsoever,” she wrote, describing that day, in her book Remember to Smile: My Brain Aneurysm and Recovery. “All that I can remember is that I went to my bookshelf, reached out my right hand to get the book off the shelf and suddenly screamed ‘Ouch’ in reaction to the terrible pain that was enveloping my head. I then lost consciousness.”

Fortunately, Blanche’s husband, Bill was at home that day. She was rushed by ambulance to a local hospital and was then airlifted to Yale New Haven Hospital where surgeons performed a craniotomy—the surgical removal of a bone flap in the skull and the repair of the aneurysm.

After the surgery, Blanche remained in an induced coma to allow her brain time to heal. She woke up two weeks later with no memory of where she was or what had happened. To help family and friends stay updated, her nephew, Brian, set up a web site where Bill published regular blogs about her condition. Her brother, Gerard, kept a diary of everything that occurred, hoping that it would some day help Blanche understand what had happened.

About three and a half weeks after the stroke, Blanche came to Gaylord for rehab. Because the aneurysm occurred on the left side of her brain, it affected her right arm and leg. “My daily therapy was a lot of work. Everything they had me do—except for speech therapy—hurt,” she said. “At first I cried a lot, but it got better as time went by.”

The stroke also caused expressive aphasia. This meant Blanche could understand language but had trouble speaking. She struggled with retrieving words or making a complete sentence. “I thought I was speaking just fine,” she recalled. “But people looked at me with absolutely no idea about what I said. Inside I knew what I was saying, but it wasn’t coming out of my mouth right!”

After a month at Gaylord, Blanche was transferred to a skilled nursing facility and then home. She was determined to get back to teaching but the aphasia was still a problem, so she created her own therapy strategies. “I started doing word searches and puzzles in the paper. I didn’t just do the word search, I said it out loud. If I didn’t say it correctly, I had someone say it to me,” she said.
Remember to Smile, continued from page 4

One reason Blanche wanted to write a book was to encourage other people facing a similar health crisis. “Don't give up on therapy. Don't give up on yourself,” she said. “God will see you through it all.” But with almost no memory of the stroke or the months of recovery, writing a book meant relying on the details from her family and insights from her medical records. Thanks to Gerard’s diary, Bill’s postings and her medical information, she was able to piece together what happened.

It took six years to write Remember to Smile, which Blanche self-published in 2016. The writing process helped her understand how close she had come to death and how very far she had come in her recovery.

There are permanent reminders of the stroke: a dent in her head from the craniotomy, her mouth can’t fully open, her nose runs constantly, and she has a slight limp. Blanche has made amazing progress with the aphasia but there are still moments when it can be a problem. But these are all issues that she has adapted to.

Blanche is deeply thankful for how normal her life is and for everything she has. She says the life lessons from this brush with death are succinct—to let go of perfectionism and do what is within reach, to remember the love of family and friends, to thank God for sparing her life while embracing what is next and…to always remember to smile.

GIVING UPDATES:

How You Can Help

Meeting the needs of our patients 365 days a year/24 hours a day is our mission and goal. But just as your home requires constant maintenance or new items to meet the needs of your family – so does Gaylord. Creating new spaces and updating our facilities gives us the freedom to provide more efficient and comprehensive care to the whole person. Below are a few of the projects that we need your support to accomplish in 2017. Our donors are the difference and every gift matters!

The Traurig Challenge
The Traurig Challenge is just $10,000 away from its $120,000 goal! We are grateful to every one who has responded to this important need. Your gift will allow Traurig patients and our staff to live and work in an environment that is up-to-date and reflects our high standards of care. To donate to the Traurig Challenge online: www.gaylord.org/traurigchallenge

Lyman & Hooker
Another key fundraising effort is raising $1 million dollars to refurbish the Lyman and Hooker wings of the hospital. While functional, the rooms need fresh paint, updated cabinets and countertops, new baths, and easy to manage window treatments. Updating these areas will help patient morale and increase the function of patient rooms for patients, families and staff.

New Guest Cottages
With more patients coming to Gaylord from far away, the need for families to have a place to stay on hospital grounds is increasingly important. Family members are often under great stress when a loved one is hospitalized and being able to stay on campus is a way to support the family unit. To meet this need we are raising $400,000 to build additional guest cottages that will be located near the current Crockett Guest cottage.

New Chapel
Our goal is to treat the whole person. To better accomplish this task we are raising $150,000 to create a proper chapel at Gaylord. The space currently dedicated for that use is in a noisy atrium that provides no privacy. Amid the stresses of a busy hospital setting, patients, families and staff need a quiet place to reflect. The need for this space is indicated by numerous requests from patients, families and staff.

For information on giving contact Development at (203) 284-2881. To give a gift online: www.gaylord.org/donate
A MOTHER’S JOURNAL:

A Work in Progress

The sounds of blades on ice, mingled with the crack of hockey sticks. It was the weekend before Thanksgiving in 2005 and Eileen and Gary Mendez were watching their son Garrett, a 19-year-old college freshman, playing hockey. As an opponent sent the puck flying toward the goal, Garret dove to block the shot and slid head first into the boards.

Eileen and Gary sat stunned. They thought their son’s neck was broken or he was dead. “He’d played hockey ever since he was four,” said Eileen. “It was the worst thing I’d ever seen him do.” But Garrett got up, was checked by a trainer and with no signs of a concussion, finished the game.

Six days after slamming into the boards, Garrett played a second game without any problems. “But that evening he said his legs were weak, his head ached, the side of his face was a little numb and he started to vomit,” said Eileen. “We thought his hockey cage or the vomiting had caused the numbness.” When asked if he wanted to get checked over, Garrett insisted it was the flu and that he just wanted to go to bed. His vision was blurry but he didn’t say anything—knowing that detail, Eileen said, would have changed their response.

When Eileen checked Garrett the next morning, he was making strange noises and could barely respond to her questions. She screamed for Gary and ran to dial 911. At the hospital they were told that Garrett had a severe form of encephalitis and should be better in a few days. Instead he got much worse. It was a misdiagnosis.

More tests showed that Garrett had suffered a brain stem stroke and there was little hope of recovery. “A brain stem stroke is the best and worst stroke you can have,” Eileen explained. “Because it is low on the stem it doesn’t affect cognition or memory. But the brain stem controls major body functions including heartbeat, respiration, body temperature, seeing, hearing, swallowing, moving and speaking.” They later discovered that when Garrett hit the boards he tore the artery in the back of his neck, which bled slowly. Six days later, a blood clot formed causing his stroke.

Garrett miraculously survived the next few days. Now the goal was to keep his body functioning while his brain formed new connections. He was put on a respirator and had a feeding tube inserted. After two weeks in the ICU there were signs that made everyone cautiously optimistic.

After 20 days in ICU he had improved enough to come to Gaylord for rehab. “Garrett was at Gaylord for two months and had to relearn everything from swallowing and sitting, to standing and taking his first steps,” Eileen said. “We went through the whole developmental process with him again. I don’t know where our family would be today without Gaylord. It is an amazing community that does incredible things.” In February of 2006, Garrett left Gaylord using only a walker. But years of rehabilitation still lay ahead.

Three years into Garrett’s recovery Eileen needed to find a way to cope. The long-term emotional and financial stresses began taking toll on the family. “I couldn’t afford to go to a psychologist, so I had to figure out how to help myself get through

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WHEN TRAGEDY STRIKES:

Laugh a Lot Cry a Lot

It was the middle of January 2005, when 67-year-old Whitney (Whit) Morse had a sudden, unbearable headache while working at a hardware store in Guilford. The pain made it hard to move or speak but he managed to ask for a ride home. His wife, Margaret, met him at the door unaware that this was the beginning of a life-altering journey.

Whit’s physician examined him later that afternoon, and said it was a bad virus and to go home and rest. But Margaret was worried. Her husband was pale, had trouble moving and kept complaining about his head. Then, Whit walked into the wall while leaving the doctor’s office. “I was stunned that we had been dismissed so quickly,” Margaret wrote in her book Laugh a Lot Cry a Lot: When Tragedy Strikes – A Journey through Stroke/s and Healing. “All of these small incidents, we now know, should have pointed all of us to think stroke and/or a bleed. Not one of us thought ‘stroke.’”

That evening, Whit grew disoriented and his breathing became labored. Margaret was terrified and dialed 911. The ambulance rushed him to a local hospital where the diagnosis was a sub-cranial bleed at the base of his neck—this meant that Whit’s brain was slowly filling with blood. After being stabilized, he was transferred to a larger hospital for further care. Thankful that Whit was alive, Margaret assumed the worst was over.

A week later, Whit was transferred to a rehab hospital affiliated with the acute care facility. The bleed had affected his left side and he needed extensive physical therapy. However, he was sent back twice to the ER with complications. During the second visit, as Margaret watched in horror by his bedside, Whit had two simultaneous strokes. These bleeds caused further brain damage resulting in Global aphasia, a condition that impairs speaking and the processing of spoken words but leaves intelligence intact.

Eventually Whit came to Gaylord for rehab that included several weeks of extensive physical, occupational and speech therapy. “The nurses, physicians and therapists at Gaylord were outstanding and gave Whit incredible care,” Margaret said.

In May of 2005, after returning home, Whit had a neurological exam. The doctor told Margaret that there was “no comprehension here.” Distressed with the doctor’s rushed assessment the Morses were determined to persevere. As a retired elementary school teacher, Margaret worked daily with Whit to enhance his language and cognitive

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Margaret and Whitney Morse on vacation about nine years after his strokes.
Gold Star, continued from page 1

“I wanted to make a movie that was really honest to what I went through and what other people go through. The script went through many, many iterations. I sent it to some filmmakers to get notes. I had table readings where actors read it out loud. I took my time with the writing process. Even up to and on the day of shooting I changed words here or there. A script is never really done.” Victoria Negri

When Carmine was ready to go home it was clear that his wife, Deanne, would need help caring for him. He couldn’t walk, talk or eat so Victoria and her siblings stepped in to help their mother. But for Victoria the dual role of daughter and caregiver was stressful. She had conflicting feelings and there were days it was hard for everyone to stay positive. “It wasn’t easy. It’s such a paradox because I wouldn’t trade it for the world,” Victoria said. “I felt honored to care for him because I loved him so much. But I also felt trapped—like I couldn’t have my own life for a long time. The longer I cared for him the more honest and truthful the script became to my experiences with him and confronting loss.”

On November 18, 2016 Gaylord hosted a red carpet screening of Gold Star. Over 90 people attended including community members, staff, patients, family and friends. The event also included a wine and cheese reception and Q & A with the director and casting director.

Cast and crew of Gold Star at Gaylord

Even after her father’s death in the fall of 2012 the script continued to morph and evolve. Victoria (who plays herself in the movie) felt that her characters needed opportunities for dramatic tension and room for self-exploration and growth. “I think my character became a little angrier after my father passed away. Aging and death just make me angry,” she said. “In the movie my character isn’t close to her father and struggles with caring for him. But eventually they are vulnerable with each other and able to find common ground.”

In the summer of 2013, Victoria moved ahead with making the movie. She set about raising funds from investors, did fundraisers and ran a Kickstarter campaign. In the midst of hiring a film crew and interviewing directors, she realized that she wanted to direct the movie. Then her casting director, Judy Bowman, brought on Robert Vaughn, known for his roles in The Magnificent Seven and The Man from U.N.C.L.E., to play her father and Catherine Curtin, from Orange is the New Black, to play her mother. Vaughn was intrigued by the challenge of expressing his character through physicality alone. “I still can’t believe that he said yes,” Victoria said. “He really trusted me and took a huge chance on me.”

Another great boon was being able to film scenes at Gaylord for several days. “Shooting not far from the room where I watched my dad struggle and then being there at a different place in my life to tell this story was cathartic!” she said. “I’m forever in debt to Gaylord for letting us film there and how great they were to my father.”

Filming also took place at her parents’ home in Orange. In one scene Victoria is moving Vaughn in a lift. “I’m forever in debt to Gaylord for letting us film there and how great they were to my father.”

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Victoria Negri and Robert Vaughn

shot it I realized I was still processing taking care of my father.”

Victoria said that the authenticity of these kinds of scenes helps to open up conversations. Some people completely understand the emotions that occur in those moments and others wonder why her character is upset with her father. “I tell them that is what happens!” she said. “You get angry sometimes and so does the person you are taking care of. It’s reality.”

Gold Star reveals the complexities of caregiving, generational differences and the power of difficult circumstances to transform those involved. The movie’s title comes from the theme of perfectionism that runs throughout the film, specifically Victoria’s efforts to be the perfect daughter and realizing that there is no such thing. “I tell them that is what happens!” she said. “You get angry sometimes and so does the person you are taking care of. It’s reality.”

Gold Star, continued from page 3

and literature at The University of Bridgeport and has published several original poetry compilations.

Amy recounted how she recently revisited one particular poem she had written in graduate school in the late 90s, and how she had “polished” it for publication in her collection, Four Blue Eggs. The poem’s title, Losing the Summer (see right-hand column), is a figurative translation of her illness in the summer of 1992.

“I was shy and embarrassed about my illness and my trach scars for a very long time,” she said. “I remember being told that although I was making great progress, there would be things that I’d probably never be able to do again. As a 20-year-old, your brain interprets that, as ‘you’re sick, you’re broken, you’re wrong.’”

Amy said that writing was a long-term way of dealing with her illness and that it was a growing experience. “Once I could change my perspective from ‘I have these scars or short-term memory problems,’ I could go to ‘this part of my life could make for a good poem and maybe by writing about it I can still own the experience and disown it at the same time’.”

Losing the Summer

Winter enters the body and it collapses, the blood cells attack, the fever leaves the brain with its patterns of coils and discs like a red stovetop, an alphabet of rivers and branches. This landscape, contoured for activity, settles into animal hibernation, while remnants of ancient languages howl from the hospital monitor.

Like dried sap on a tree, crusted, yet viable, a small scar has left itself after the coma – such a thing is not a deformity, but a bud: a seed replanting its succulence, an isthmus back to the world.

(published in Four Blue Eggs, 2014)

“In poems, I sometimes deal with issues that will affect me as MS progresses. For example, mobility–I wrote a poem based on a hike my husband and I did in Scotland. The background of the poem is about the struggles of being able to make the body do what it should do naturally–walk without pain or awkwardness. There are allusions in the poem that have nothing to do with MS or me but writing helped me to deal with the idea of loss (particularly of mobility and of lost opportunities). I’ve dealt with the idea of losing memories, losing mental focus, losing time–themes that connect, hopefully, to any reader.”

Diagnosed with multiple sclerosis in 2011, Amy continues to use poetry as an outlet.
Garrett with his sister, Jenn

Each year Garrett plays in the Gaylord Golf Tournament with his dad, Gary, and his best friend, Jeff.

**Excerpts from Eileen’s Journal**

**Grieving to Heal**

Christmas was over, another hurdle passed. I was the most emotional person that day. I couldn't hold it together. I found it very difficult to stop crying…I have a close friend who was at one time a practicing psychiatrist helping stroke patients and their families. She gave me some advice that finally cleared my head and let me move on. She told me our family had suffered a loss. We needed to mourn the loss of the life we once knew, the life our child had before. She said I would not be able to move on until I accepted that and grieved. It helped me understand why I felt the way I did. Once I admitted that our life would never be the same again, I was able to stop crying and move on.

**The Future**

When I reflect on the past, it is as though I am looking at someone else’s life, telling someone else’s story. It often seems surreal that we were able to go on in spite of the catastrophic event that changed our lives forever.

[Garrett] has come to terms with the fact that he cannot change the past. There is no explanation why he had to suffer these circumstances. He instead looks ahead to the limitless possibilities in his life that he has now. Ten years ago, we were uncertain if he would even have a future.
skills and independence. They did jigsaw puzzles and word games and discovered that Whit had a knack for Sudoku. Margaret also enrolled him in a speech therapy program at a local university.

Their lives had permanently changed. But Margaret continued to push the boundaries to see what was possible with Whit’s limitations. As Whit recovered, he grew more independent and could even drive. But the aphasia was an ongoing challenge. “Whit can look at pictures and read occasional key words but can’t read an article or book,” Margaret explained. “His spontaneous speech is good but his processing is about ten minutes behind so having a conversation is hard. He also has cognitive issues that impair our communication.”

This life change was emotionally and physically exhausting but Margaret’s strong faith buoyed her and gave her hope. She thought that writing about their experiences might help other people in similar circumstances. This wasn’t the first time she had tackled a writing project. Their daughter, Torrey, was diagnosed with a rare form of lymphoma when she was eight and Margaret had written a book about the unconventional care that had saved her life.

Several other self-published books followed and then the story of Whit’s illness and recovery. In Laugh a Lot Cry a Lot, Margaret shares the feelings of loss and the many challenges and joys encountered when a loved one is permanently changed by illness. Her goal is to convey “the importance of believing, caring and hope when one is faced with a crisis…”

Arthur describes his novel, “Sampson and Delilah” and its sequel, “When Fear Knocks” as thrillers that follow a string of mysterious murders targeting several young women in a small New England town.

“I’ve been writing most of my life, but not since five years ago have I found something worth publishing,” he said. “Mostly only songs and poems for my children before that.”

Arthur, who has few memories of the grandfather who died while he was still a young boy, enjoyed the tales his mother recounted of the childhood she spent growing up and living on the Gaylord campus. Dr. Lyman served as the hospital’s Medical Director for 50 years and the Lyman wing of the hospital was named in his honor. “He was always spoken of as a wonderful, generous man,” Arthur said.
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Gaylord in the Community!

Join us at one of these upcoming events