

Gateway to a Cure

Education • Awareness • Support • Research

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1-877-AMYLOID

20th Anniversary of Stem-Cell Transplant Patient Lou Catania, *Father of the Bride!* By Linda Catania

There is no greater reminder that we should cherish moments, than nearly dying. A close call with death ensures that we become much more aware of what we have, what we need, and what we might miss. We were extremely aware this past July, that this year marked 20 years since we wallowed in fear, self pity, and continual illness. Lou was a married 42 year old healthy father of 3, with a house, a couple cars and a great job. And then, he was sick. It just wasn't the way it was suppose to be. We found ourselves faced with having to make horrible decisions about finances and house sitters as we traveled to out of town

doctors visits. Child care issues, pet care issues, etc all needing answers while our heads swam with thoughts of death and loss, outrageous grief and sadness. No one had answers. No one could get an accurate diagnosis. Doctor after doctor remained baffled about why Lou was sick. But we kept trying. My greatest fear was that Lou would die without knowing what killed him.

An answered prayer arrived when we learned that Boston was doing research in Amyloidosis. We knew we had to get there and convince them that they



could fix Lou. But we had not yet received a diagnosis.

Weeks went by until finally we learned that he indeed had Amyloid. And that is when our relationship with BUMC (now Boston Medical) began. I didn't think he would survive the flight to Boston from New Jersey. But we made it, and our future was filled with doctor after doctor, followed by teams of students and nurses asking question after question trying to learn as much as they could about this new, unusual patient.

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Remembering and Celebrating My Mom

By Cate Craig



While reading through some past Amyloidosis newsletters to get a feel for the type of article I should write for this edition, I came across an uplifting story of a woman who had been diagnosed in time to receive treatment and therefore, survive with the disease. My heart was

both elated and crushed all at once. My beloved mother, Elena Rusnak, died August 9, 2014 from AL Amyloidosis, only 4 months after she was diagnosed. She was 68 years old. My Mom's story, while similar in background, family life and age, had an ending that was quite different from this other woman's

story. For years, my mom had complained of various ailments. Time after time, my mother sought out help from her trusted doctors for everything from carpal tunnel to shortness of breath and heart trouble; only to receive the diagnosis that there was nothing wrong with her.

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Amyloidosis Foundation Updates

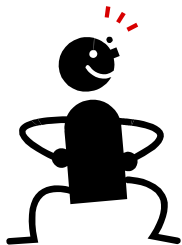


Patient Resources

The foundation has several activities that benefit patients and their families. All of these programs are provided free of charge upon request.

- Live Teleconferences with Experts (CD's available, and recording posted on website)
- Accurate Informational Pamphlets
- Website with information for both patients and physicians
- Toll Free Number 1-877-AMYLOID
- Listing of experienced physicians with amyloidosis, it's diagnosis and treatment

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Happy 10th Anniversary

to the

Northern California Amyloidosis Support Group

On October 4, 2014 the Northern California Amyloidosis Support Group will celebrate a *decade* of quarterly support group meetings. The first meeting was held at an Oakland hotel and included participants from all over the SF Bay Area, Sacramento Valley, and as far away as Southern California and Montana. Primary, secondary, and hereditary amyloidosis were represented in that meeting. Dr. Harry Saal, who lost his daughter to AA amyloidosis and attended that meeting and many others, very generously provided years of financial and moral support to our group. We are all very thankful for that support and for the on-going support of the Amyloidosis Foundation.

We are a great group of patients and caregiver heroes representing different types of amyloidosis, very successful organ transplants including five heart transplants, two liver transplants and a kidney transplant, autologous stem cell transplants, and varied chemo protocols. We also claim the very first patient accepted into the Prothena NEOD001 clinical trial for AL amyloidosis and the author of the book "The Middle of Infinity", patient and physician Kevin Anderson, MD who poignantly chronicled his journey with amyloidosis. We have long term survivors of almost ten years and we have all grieved as we have lost group members including my husband, Bill Finnegan, who was my reason for starting the group.

Since that first meeting the group now holds meetings at Stanford University Medical Center who supports our group with their amyloidosis expertise and Kaiser Medical Center in the Bay Area who contracts with Stanford for their amyloid transplants.

The upcoming October 4th meeting offers a different venue as it will be held at UCSF Medical Center in San Francisco. In addition to celebrating our own anniversary we will celebrate the introduction of the new UCSF amyloid team led by hematologist/oncologist Anuj Mahindra, MD. formerly of Massachusetts General Hospital. Joining us in addition to the UCSF doctors to help us celebrate will be Isabelle Lousada, Chairman of the Board of Directors of the Amyloidosis Foundation and a seventeen year survivor of amyloidosis, Anne Sherwood, PhD, from The Binding Site, and our Bay Area friends from Prothena.

On a personal note, I am very blessed to have coordinated and facilitated the entire decade of meetings and every patient, caregiver hero, family member, and amyloidosis medical team member has enriched my life in ways I never could have imagined.

Find me on Facebook: <https://www.facebook.com/pages/Amyloidosis-Support-Group-Northern-California/122627487760593>

Dena Heath
 Facilitator, Northern California Amyloidosis Support Group
 Patient Advocate
dena.heath@att.net

President's Corner

Fall is a beautiful time of year. This season always brings new colors, sights and smells. Here at the AF we wanted to share some of our own news with all of you.

We recently received an anonymous donation of \$60,000 specifically to support our Grand Rounds program. The AF sponsors Grand Round speakers in amyloidosis of all types and includes in its' speakers bureau some of the most knowledgeable cardiologists and hematologists involved in amyloidosis research and care in the US. We provide the speaker and cover all expenses. This is one of the many things that the Amyloidosis Foundation is doing to advance and improve awareness and the understanding of amyloidosis. This donation will be a great help in the development and implementation of these Grand Rounds proceedings for years to come.

Our foundation is currently participating in the **RiseDetroit Online Charity Challenge** on **CrowdRise**. Crowd fundraising is a new way for people to support various fundraisers via the internet. We have raised over \$2,000 so far & our goal is \$10,000. **The challenge runs through Thursday, October 30th.** The team that raises the most during the Challenge will win up to a \$50,000 donation. Here is the link: <https://www.crowdrise.com/amyloidosis-risedetroit/fundraiser/amyloidosisfoundation>. You can also start your own online fundraiser and be part of our team!

We want to thank all of the patients and families who have shared their stories with us for this newsletter. We appreciate your thoughts and pictures. You remind us all why it is so important to bring awareness and support to those affected by Amyloidosis.

Sincerely,

Mary E. O'Donnell

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Some of the most generous people in the world read this newsletter and are an important part of our giving community. Your generous contributions have helped amyloid patients, their families, caregivers, and medical community. Your gifts have also help fund important research to find treatments and a cure for this dreaded disease.

Few donors know how important their gifts can be. They give for a variety of reasons and the top five would probably be:

- A loved one has Amyloidosis
- A loved one had Amyloidosis
- A friend had Amyloidosis
- A business associate had Amyloidosis
- You have Amyloidosis

Three of these reasons for giving are past tense...an amyloid patient died before we received the gift. Memorial gifts account for over 45% of the total gifts we receive and most are first and only gifts.

Our programs and especially the research we fund are not one time events, they are ongoing...never ending...until a cure is found. If we are to have a successful outcome we need our one time memorial donors to remember the friend, loved one, or associate that was important enough to cause the first gift...and give again.

Amyloidosis is a complicated, rare disease but it can take a life as ruthlessly as any of the best known or most feared diseases. It is a rare disease until someone you know becomes an amyloid patient. This removes the, "rare," from the disease.

The Amyloidosis Foundation wants to fight the disease so that others rarely or never have to battle Amyloidosis again.

Will you please help us in this goal?

Boris Sellers

Development

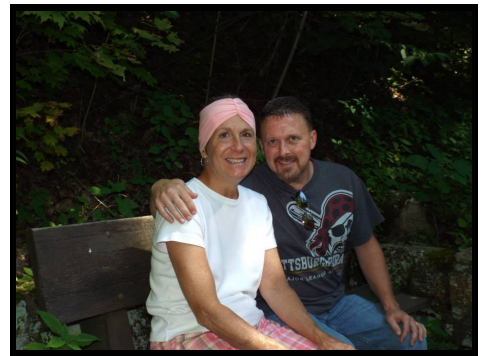
Vicki's Journey *by Vicki Sloan*

My story started in March of 2011. I came down with a flu bug that I never quite recovered from. After a battery of tests and blood work nothing could be found for why I was so fatigued and not able to do what I was used to. I had other symptoms as well, like a hoarse voice and tingling fingertips, and I was losing my fingernails. Because I had been told in the past by two Ear, Nose & Throat Specialists that my voice was the result of acid reflux, (I never believed that) my Doctor said "Let's settle this once and for all. I am going to send you to Dr. Miller, a very highly rated gastroenterologist in Hermitage for her to do an endoscopy of your esophagus and stomach and a Ph test for reflux." At that appointment I saw her associate to set up the procedure, but while waiting for her to come in the room I started reading some brochures on the wall and one about a stomach bacteria that could cause some of the symptoms I had jumped out at me. When she came in and we were talking, I asked her if that was something we could check into and what it would involve. She said "no problem, we'll just do a biopsy of the stomach lining at the same time as the scope. We're already in there, we might as well do it."

Three days later I went in for the scope & biopsy. Dr Miller came in to go over things with me in the surgery room as they were getting ready to put me out and talked about doing the scope and the ph test, never mentioning the biopsy. She turned to leave and I said "And the biopsy, right?" She turned back to me looking puzzled and started flipping the chart and said, "I don't have that on here." I said, "Well, your associate said a biopsy to test for stomach bacteria would be no problem because you're already in there." She smiled and said, "She's right, might as well do it, we're already in there."

The next week the Doctor called me to tell me that the stomach biopsy revealed the presence of amyloids and that she was referring me to a local rheumatologist.

My son called for an appointment with Dr Comenzo and two weeks later I was being aggressively treated for amyloidosis. When I arrived at Tufts Medical Center I was in 3rd stage congestive heart failure. However, my heart was determined to be strong enough to allow them to do the stem cell transplant, a vital part of my treatment. I had the stem cell transplant on Sept. 20, 2013 with chemo before and after.



Dr Comenzo told me that if I had been to see him two weeks later he may not have been able to help me, that's how bad my heart was. At a later appointment I was declared in remission and all my blood work was normal!

Today I am one year past my SCT and am almost completely back to normal! My cardiologist said that if she didn't know I had amyloidosis she would not have seen it on my ultrasound. Almost all the damage has been reversed! I even rode my bike 13 miles and I walk several miles a day with my dog. The fatigue is gone and I have no limitations! I feel like I am a walking "miracle" and I give God all the credit! We left it all in His hands and He took care of every detail of my diagnosis, treatment and recovery. I thank Him especially for directing my son to Dr. Comenzo, without whom I would not be here today. Praise the Lord! **AF**

Common Anti-Inflammatory Drug Can Test Amyloidosis

Reprinted with permission from Boston University School of Medicine Magazine, Spring 2014

A study led by researchers from the Amyloidosis Center at BUSM and Boston Medical Center demonstrates that diflunisal—an inexpensive, generic, and safe-inflammatory drug marketed over the past 40 years for arthritis and pain, successfully reduced the neurological decline and preserved the quality of life in patients with familial transthyretin amyloidosis (ATTR).

Published originally in the *Journal of the American Medical Association (JAMA)*, this study is one of the first examples of successful repurposing of a generic drug to treat a rare disease. The National Institutes of Health has advocated this research strategy as a way to increase the availability of treatments

for rare diseases such as amyloidosis. John Berk, MD, Associate Professor of Medicine at BUSM and Clinical Director of the Amyloidosis Center, designed the trial, led the international consortium of researchers, and served as the study's corresponding author. Jeffrey Kelly, PhD, a Biochemist at the Scripps Research Institute, and Peter Dyck, MD, a Neurologist at Mayo Clinic in Rochester, MN, were instrumental in developing the study.

Familial amyloidosis is a rare inherited disorder in which mutated transthyretin protein aggregates in the blood and forms insoluble fibrils that cause tissue damage. Patients with hereditary ATTR amyloidosis develop debilitating peripheral and

autonomic nerve damage, heart disease and weight loss.

Investigators found that diflunisal dramatically inhibited the progression of neurologic disease while preserving quality of life when compared to placebo treatment. Known to physicians as Dolobid, generic diflunisal is inexpensive and readily available. To date, no other drug treatment has achieved this level of benefit for this rare disorder.

"Our results show that diflunisal represents an alternative to liver transplantation, the current standard of care for this devastating disease," said Berk. "We hope that this study prompts the identification of other widely used generic drugs for treatment of rare diseases." **AF**

Nashville Support Group Leader—Honored Guest

Earlier this summer Charlotte Haffner, Support Group Leader of the Nashville Vanderbilt Amyloidosis Support Group*, was the honored guest and speaker at the annual Prothena Board of Directors meeting in San Francisco. Charlotte is a five year survivor of a heart transplant and stem cell transplant for AL Amyloidosis and she has been facilitating this support group for over four years now. She is a fierce patient advocate and is also the driving force behind the formation of the Vanderbilt Amyloid Multi-Disciplinary Program in Nashville. VAMP, as it is called locally, came about after Charlotte walked the halls of the medical center telling all of her doctors that they needed to start talking to each other about her case and the cases of all of the other amyloid patients. Dr. Doug Sawyer, MD, PhD at Vanderbilt, and an amyloidosis cardiologist and researcher, commented “Charlotte has made me a better doctor and Vanderbilt a center of excellence for amyloidosis patients”. No doubt Charlotte will do the same for Prothena! (Charlotte is direct center in the blue dress.) **AF**



**Support Group meets 2nd Tuesday of each month*

Remembering and Celebrating My Mom

As late as October 2013, her cardiologist confidently informed her that there was nothing wrong with her heart. My mother's cause of death, just ten months later, was heart failure brought on by years of unknowingly suffering from amyloidosis.

In the days after my Mom's death, it was easy to get angry and blame doctors for failing her, for not diagnosing her properly, for not saving her. After reading countless stories of others who have dealt with Amyloidosis, I realize that much more needs to be done to educate doctors about this terrible disease. Doctors need to be able to recognize the potential signs of Amyloidosis and properly treat or refer these patients to the centers that specialize in the constantly evolving treatments that are prolonging lives. By the time my mom was diagnosed and referred to the Boston University Amyloidosis Center, her body was too weak for a bone marrow transplant, her kidneys were operating at 20% and her heart was beyond repair. If she had been diagnosed 4 or 5 years ago when her symptoms began, I may be writing an article that is more in line with the inspirational story that I read in last month's newsletter.

Amyloidosis, like all rare diseases, is difficult to gain attention, money and awareness for. I often sit and contemplate what I can do to make a difference. I worry that the “Ice Bucket Challenge” that has raised so much money and awareness for ALS, seems to be one of those “lightning in a bottle” initiatives that is far too rare. I don't know if Amyloidosis will ever have the stage to make 100 million dollars in donations over one summer.

For now, all I can do is take the painful, sudden loss of my mom and attempt to prevent others from having to experience the same. Because my mom was a professor of dance at Naugatuck Valley Community College in Waterbury, CT for over 15 years, her group of hundreds of alumni dancers and I are celebrating her at the annual **5x5 Dance Festival in West Hartford, CT**. This event will take place on the campus of **University of Saint Joseph, Hoffman Auditorium**. The performances are **October 24 and 25, 2014 at 7pm**.



My mom was a huge champion of the arts in Connecticut. Her group of alumni dancers, **ATTAK Dance Company**, are performing at this show. Our hope is to pack the house with supporters of the arts, loved ones of my mom, and those who wish to bring awareness, research and funding for Amyloidosis. Perhaps together, we can see a day when Amyloidosis is correctly diagnosed, fully treatable, or even eradicated altogether from this world.

For more information about this event, please call (860) 231-5555. **AF**



What Amyloidosis Cannot Do

By Erik Radloff

This sign and story were a gift given to me and my father, Lon Radloff from a man my father unfortunately never got to meet. It is a story of struggle, sadness, and the amazing power of Love which can touch the hearts of a million strangers. We all have stories to tell, and we all can benefit from sharing our stories. This sign and this story is one of Hope.

I was working at Brady St. Futons in Milwaukee, WI when one day in January of 2013 a familiar customer of mine entered the store. I recognized Joseph as he has been a repeat customer of mine throughout the years. But on this particular visit he was using a walker, moving slowly yet determined, and was noticeably physically different than what I had remembered. Not that I had a crystal clear picture of what he “normally” looked like –whatever that means—but I could just tell, there was an almost fatigued air to his appearance that suggested he had been experiencing something that was wearing him out. It was a look that I was familiar with seeing on my father’s face and demeanor.

“How are you, Joseph?” I politely inquired though it was obvious to me that something was less than “pretty good.” But out of respect –and the general social graces I was taught by my parents—I didn’t want to pry into guarded territory. “Well, I’ve got to tell you. Getting old sucks. Don’t let anybody tell you otherwise.” He paused. “And getting old with cancer really sucks.”

In that instant I knew that everything prior to this moment had changed. It was that awful C-word. That word that makes us all pause and freeze up and think to ourselves “Oh my goodness.” They purchased a loveseat futon that was going to be put into Joseph’s home office so that he could take rests or naps or even sleep there as his days presented themselves.

When their order came in, I made sure to personally do the delivery and when I arrived to their home Joseph showed me to his office and where he’d like it set. I saw a sign in a frame on his desk and inside it said “What Cancer Cannot Do” and lists all the amazing and powerful things that cancer cannot do; like cripple love, shatter hope, quench the spirit, etc.

I looked to a picture of several boys in a lake with their Dad, and I see another picture of a young man with a baby and a Grandpa, and it just hit me that here is a person, full of Love, full of family and wonderful memories, and he’s dying, and yet he still has Hope and a radiant Spirit, and here I am putting together a futon in his room that he will very likely be napping on and resting during the remainder of his life. I didn’t know this man very well but in that instant I could feel his Love and Hope. I began to cry, thinking of my own father and realizing that he must be going through this exact thing. This totally bizarre, completely unfair set of circumstances, without any good reason, and you begin to examine your Life and gather the memories and the smiles and the laughs. You just accept what to everyone else is unacceptable. You fully embrace the Now.

A week later I received a card in the mail from Margene and Joseph thanking me for delivering the futon. As I read the card, I thought about everything I had been experiencing through my interactions with Joseph and Margene. I felt compelled to let them know how deeply they had affected me and had touched my spirit and helped me without even realizing.

My Dad had a friend who was dying of cancer and he (Dad) would write a letter to him about once a week or so. This writing of letters was a completely selfless act to reach out to someone so that they might get something from it; some bit of hope or happiness or joy. Inspired by this I wrote Joseph and his wife a letter explaining how thankful I was to Joe for his honesty.

I told them about my Dad and his letter writing and about his amyloidosis and what he had been going through and what I was going through and how completely unfair the whole thing felt. It was completely unfair that Joseph or my Dad or anyone for that matter should ever have to suffer at the hands of a disease. I said that it helped me to grieve differently and it made me feel better about what I was personally going through with my Dad’s amyloidosis. I mentioned the little “What Cancer Cannot Do” sign I saw and how it, too, helped me deepen my understanding of my Dad’s situation and touched me so dearly. It helped me to redefine how I was baring witness to my father’s Life. It helped. If only for that day, it helped me feel better.

What Amyloidosis Cannot Do

Amyloidosis is so limited.

It cannot cripple love.

It cannot shatter hope.

It cannot corrode faith.

It cannot eat away peace.

It cannot destroy confidence.

It cannot kill friendship.

It cannot shut out memories.

It cannot silence courage.

It cannot reduce eternal life.

It cannot quench the Spirit.

In April 2013, I was at work and Joseph came in, with his walker, looking tired but smiling, glowing, and he said he just wanted to stop in to let me know how touched he and his wife and whole family was by my letter and he said he had something for me and he handed me a small brown paper bag that had a card in it and some ribbon and tissue paper. I took the gift and said “you didn’t have to get me anything,” and Joseph waved his hand in protest and said “it’s for you. And for your Dad. Thank you.”

When I opened the bag there was a letter in the card and, wrapped in paper, a framed sign which started: “What Amyloidosis Cannot Do” Joseph had changed the words of the sign I saw on his desk and printed out a copy for me and one for my Dad.

In May 2013, Joseph passed away from his battle with cancer. Sadly, he and my Dad were never to meet in person, though I know they certainly met each other through the letters and stories we shared. And so I share with you this sign and this story so that everyone affected by this horrible disease can remember the power of community, of humanity. The power of reaching out to strangers and sharing your stories so that you will always know that you are not alone. The Now is neither good nor bad, and might seem to be both at the same time. It is just the Now and we can only accept it and embrace it and try to bring forth the Hope and the Love.

My father, Lon R. Radloff, passed away on Sept. 12, 2013, the age of 69, after a long struggle with amyloidosis. At his funeral, displayed on a table was a portrait of my father next to the framed sign given to him by Joseph. I miss you so much, Dad.

AF



2014 Foundation Golf Fundraiser

The annual Amyloidosis Foundation Golf Outing was held on September 12, 2014 in Clarkston, MI—a brisk Fall day that was full of fun and support! Our golfers enjoyed the prizes, raffles and silent auction items. Thank you to our sponsor Prothena and everyone who participated in this event!



Lou Catania, *Father of the Bride!*

How did it start.... how long had this been going on....when did his taste buds change.... how much weight had he lost? Did he eat, did he poop, could he sleep? We could only conclude that all of their questions would somehow end up with a cure and life would go on as we had planned. But, that didn't exactly happen. Lou got more and more ill. Lost more and more weight, lost more and more hope that he would ever be better again. No one held on to hope tighter than I did. I think I slept with my hands clenched thinking that if I held on tight enough, all would be well. Never let go of hope when it is all you have.

Decisions were made and medicines changed and doctors met to talk about the best approach to take, and we watched wondering if they knew what the hell they were doing. Sometimes the answer was - well, not exactly!

Lou was the first to make it through the Stem Cell Transplant. Michael had died a few weeks before in the middle of the procedure, and that weighed heavy on our minds. But slowly, things fell into place. Blood counts changed, proteins changed, medications changed, and Lou started to improve. We smiled with cautious optimism. We hoped, blended in with a lot of prayer.

As Lou slowly improved, talks began about what to do next. The doctors thought the Stem Cell Transplant was just a stepping stone to a Bone Marrow Transplant. Lou asked what the risks of the BMT were, and his doctor said, "well, it could kill ya", so we decided to take a "wait and see" approach to the BMT.

Lou became stronger and eventually went home and back to work. We communicated with more and more people who had heard about Boston, the work they were doing, and the successful stories

that followed ours. I can tell you that nothing puts a smile on a team of BU amyloid team doctors faces faster than when Lou walks down the hall. And there are always tears. Big tears of joy and happiness. And about those times that could be missed.....our daughter just got married in September. It was with great pride that we both walked her down the aisle and threw one of the most fun weddings that anyone could imagine. We knew the whole time that we had a team of doctors from BU to thank for making it possible. And life goes on, and on and on and on.....

Extensive work, and research have made great improvements in the field of Amyloidosis. We hope for the best to all that followed. And we are so thankful that Lou didn't miss the wedding of our daughter Dr. Sondra Catania to Dr. Ricky Feher. **AF**

2014 Amyloidosis Foundation Golf Fundraiser

Up-Coming Conferences

November:

The American Society of
Nephrology
Philadelphia, PA

December:

The American Society of
Hematology
San Francisco, CA



We Need Your Support!

We are truly thankful for the generosity of our donors. With this generosity we are able to provide all of our publications and services free of charge.

We have several volunteers who organize local fundraisers to support the foundation, golf outings, art exhibits, walk-a-thons and other activities. If you are interested in gathering your family and friends to organize a fundraiser please contact us (1-877-AMYLOID) and we will provide support and assistance.

The foundation's success is totally dependent on donations and these fundraisers.

Thank you

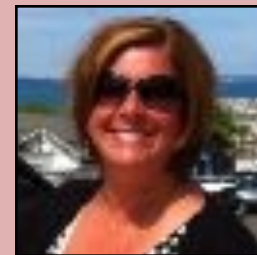


New Face at the Foundation

Please join us in welcoming the newest member to our staff, Kelly Pacifico-Loush. Kelly is the Communication & Marketing Manager for the foundation. She and her husband Mark have two teenage sons that keep them busy plus she enjoys reading, skiing, cooking & wine! Her focus will be all things media related: Web, Print, PR, Twitter, Facebook, LinkedIn, etc.

Please reach out and say hello-if you have a suggestion for a future newsletter article you may contact her below:

E-mail: kpacificoloush@amyloidosis.org



What Did You Think?

The Amyloidosis Foundation welcomes your feedback! We are always looking for letters, articles or any suggestions that you may have to make this publication better!

If you have something that you would like to share with the Amyloidosis Foundation community, please contact us at info@amyloidosis.org