Amyloidosis Foundation

"Gateway to a Cure"
Newsletter

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SUMMER 2013

CAN YOU PICTURE YOUR WORDS HERE?

The Amyloidosis Foundation is looking for patients, family members, and health care providers to contribute to our quarterly newsletter. Interested? Please email eallen@amyloidosis.org for information on deadlines. We look forward to your submission!

INSIDE THIS ISSUE:

The Role of the Caregiver

By: Emilia Allen, *Assistant Director of Development*

My mother tells of me of this beautiful memory she has of my grandmother washing my bisabuela's (great-grandmother's) hair: "Almost ninety years old and only a few canas (gray hairs)" my mother said. "You should have seen her; she was smiling and sloshing her legs, making waves in the bathtub". This memory is vivid for my mother and the story striking for me. Perhaps because it highlights joy and intimate love found in what otherwise could be a mundane and draining task. Better yet, the moment reflects my bisabuela happy in the last stages of her life, defying banal assumptions that facing mortality is always sorrowful.

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My bisabuela, Emilia - I am her namesake - received a late diagnosis of brain cancer. Together with their medical team, my family made the very personal decision to forgo chemotherapy and radiation treatments. Her quality of life was of utmost importance and they made the commitment as a family to provide for her care, with my grandmother designated as her primary caregiver.

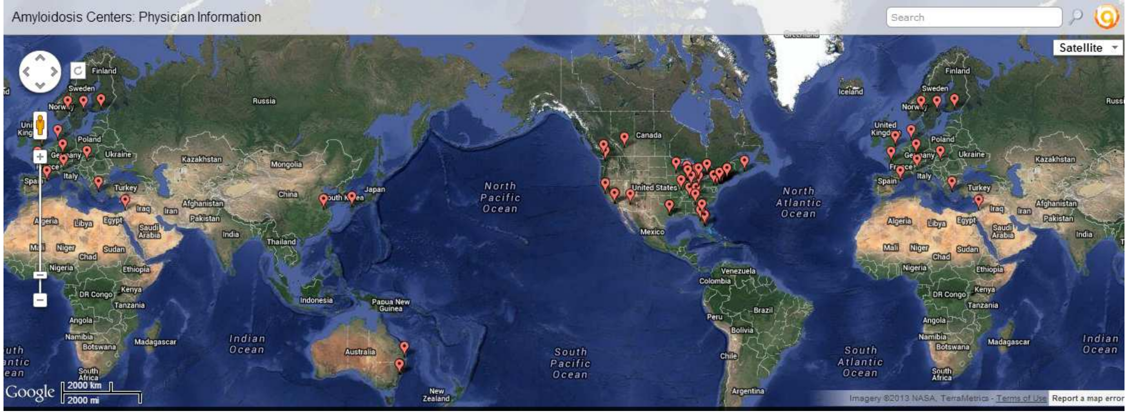
Violets are symbolically associated with constancy of love and intuition. These two characteristics are commonly reflected in caregivers.

It is not my intention to present this familial and role transition as seamless nor is it to suggest that taking the responsibility for the daily care of a loved one is the best fit for everyone's circumstances. However, if this arrangement is something that you are considering or is your current living situation I hope that you find some of the tips and ideas in this article helpful.

One of the most loving things that we can do for one another as humans is to take care of each other in our time of need. A caregiver is generally defined as someone who meets the needs of and provides support for the emotional, physical, and financial well-being of another person. Of course, every caregiving situation is unique and comes with its own share of uncertainties, frustrations, and rewards. As of November 2012, *The National Alliance for Caregiving and AARP* states that *"65.7 million caregivers make up 29% of the U.S. adult population providing care for someone who is ill, disabled or aged"*. With so many Americans fulfilling this vital role, it is important to know that you are not alone.

Caring for an amyloidosis patient can be especially challenging because as a rare disease, very little is known about it thus many prognosis' can change direction suddenly. This unexpected shift in course can be especially taxing on caregivers and their loved ones as it makes it difficult to maintain a routine in care. This is why it is especially important to stay educated about the disease and work closely with your health care team. The Amyloidosis Foundation is always a resource and can connect you with amyloid treatment centers across the country as well as put you in touch with other members of the amyloidosis community. *Continue to page 3*

Amyloidosis Treatment Centers - World View!



What are all of those little red dots? They are markers representing amyloidosis treatment and research centers all across the world! To find out specific information on a treatment center along with their contact information visit the website http://batchgeo.com/map/4adcd1f23f68ba8884cb6a099bb071e1.

Did you know that by simply visiting the website listed and hovering over each individual marker, you can gain information about any global center instantly!

Future Amyloid Researchers

At right is Liliana, age 3 and above is her new baby brother Nicholas.

Have you considered annually giving to the foundation?

Your support helps ensure that our research grant program continues long into the future so that the next generation of scientists can build upon and develop new treatments and therapies for amyloidosis.

Support Group Spotlight

Northern California Support Group

Date & Time: July 27, 2013 from 10am to 2pm

Location: Kaiser Hospital, 1425 S. Main Street, Walnut Creek, CA. 3rd Floor Medical Office Bld.

Room: Oak Room 2

Speaker: Prothena Biosciences' Chief Scientific Officer

Coordinator: Dena Heath

Tennessee Support Group

Date & Time: August 17, 2013 from 11am to 2pm

Location: Kern United Methodist Church, 451 E. Tennessee Ave., Oak Ridge, TN.

Room: TBA

Details: Luncheon Meeting

Coordinator: Charlotte Haffner/Susan Tupper

President's Corner

The Amyloidosis Foundation began as a "grassroots" organization created to serve and connect the amyloidosis community. To this day we have remained true to the fundamental ideas and leadership structure that spurred our creation. Because of this, we have been able to come from the people that we are committed to: amyloidosis patients and their caregivers. All of the foundation's founders, Terry O'Malley, Dennis Krysmalski, Don Brockman, and myself along with countless others who have joined us along the way believed that amyloidosis patients and their caregivers could be reached and support could be given to them.

We need you to help us continue to be the fundamental grassroots organization we always strive to be. We are so grateful for all of your support and look forward to your involvement with our programs to come.

Mary E. O'Donnell

The Role of the Caregiver: Care Giving Tips

1. **Be an Advocate:** Ask questions of your loved one's physicians to make sure that you fully understand their prescribed course of treatment. Do not be afraid to express any changes that you have noticed in your loved one's behavior or physical appearance. After all, you know them best so if something seems unusual make sure to share that information.
2. **Stay Organized:** Most amyloidosis patients are treated by a team of specialists. Keeping a notebook or calendar with you that contains important notes on your loved one's blood work and medications will help you effectively interact with different team members and enables communication.
3. **Involve Your Loved One in Decision Making:** Remember that your loved one is an adult and deserves to play an active part in the decision-making process concerning their health. Respect this right unless your loved one is deemed unable to cognitively participate.
4. **Allow Your Loved One to Do What They Can:** If your loved one is still capable of performing basic tasks such as dressing themselves or brushing their teeth, allow them to do so. Completing these activities on their own makes your loved one feel independent and will help ease you both into the new care arrangement.
5. **Take Time for Self-Care:** Caregivers become so busy providing for their loved one that they often times neglect their own needs. Be sure to take time for yourself to exercise, eat healthy, and take part in activities that you enjoy. If a tow truck runs out of gas, how helpful can it be to the car who has a flat tire? Be sure take care of your physical, emotional, and spiritual selves so that you can take care of your loved one in the best way possible.
6. **Accept Help:** Don't try to do everything alone - providing daily care for someone is not a one person job! If your spouse, relatives, or health care professionals offer to cook a meal or sit with your loved one while you run errands or go for a half-hour job, accept their help. AF

Stories by amyloidosis caregivers and patients are available on our website under "Patient Stories" we encourage you to visit and share your personal story.

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MISSION: The mission of the foundation is to increase education and awareness of amyloidosis within the community leading to earlier diagnosis and improved treatment.

VISION: Our vision is to be a leading organization working to care for and cure patients with amyloidosis

Your donations help us live up to our mission everyday and help us work towards our vision of tomorrow. Thank you so much for your support!

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The *Gateway to a Cure* newsletter is a publication of the Amyloidosis Foundation and is distributed as a service of the Amyloidosis Foundation with the understanding that the Foundation is not engaged in rendering medical advice or other professional medical services. The Amyloidosis Foundation is a 501(c)(3) tax exempt non-profit organization.

Fantastic Fundraisers!

A member of Paul's Possee, featured at left, participating in the New York City Triathlon. Paul's Possee is one of the foundation's premiere athletic teams and a major funding source for our research grant program. This year, they raised over $20,000.00 for amyloidosis research.

Laura Bryan, race director of the Little Falls, NY race "Miles 4 Amyloidosis Awareness 5k" is seen at right center at the finish line. This is the second year that Laura has organized the race in loving memory of her father, Paul C. Bryan. Great work, Laura!

Joe LaGuardia, pictured at left, passed from amyloidosis on May 14, 2012. In his honor, his family orchestrated the "Joe LaGuardia Amyloidosis Foundation 5k Run/Walk" held annual at the Inner Harbor in Syracuse, New York. We are so fortunate to have the opportunity to work with such wonderful people for a great cause.

A group of students from Oakland University and Wayne State University attending the First Annual Metro-Detroit "Art, Autos & Amyloid" Benefit held in Plymouth, MI