



News and Stories - Winter 2023

Amyloidosis and the Kidney

By: Dr. Omar Maarof

Amyloidosis is a rare illness involving the deposition of amyloid proteins in various tissues. These amyloid proteins cannot be processed and recycled as normal proteins. These proteins are generated by abnormal white blood cells in the bone marrow or lymph nodes. These proteins can then precipitate in tissue as amyloid deposits leading to tissue injury. These amyloid deposits cause harm in various tissue involving one or several organs at the same time.

Thus, the symptoms and severity of amyloidosis depend on which organs and tissues are affected and the burden of this deposit. Amyloidosis usually affects the kidneys, heart, nervous system, liver, and gastrointestinal tract.

These symptoms can include:

- Weakness and/or fatigue
- Unintentional weight loss
- Swelling in lower extremity and abdomen
- Numbness in hands and feet
- Increased bleeding after minor injury
- Large tongue
- Shortness of breath



Amyloidosis has several types and the most common type of amyloidosis in the United States is called AL amyloid affecting approximately 40 out of every 1 million Americans. It can be more common in people over the age of 65. Another type of amyloidosis, called AA amyloid, occurs in people with a prolonged infection (like tuberculosis) or a chronic inflammatory disorder (like rheumatoid arthritis). There are several other types that are less prevalent.

In the kidneys, the accumulation of these amyloid proteins can lead to features of nephrotic syndrome. The symptoms of this syndrome manifest as too much protein in the urine leading to low levels of protein in the blood. It also involves swelling in your body, especially the lower extremities, among other symptoms. These patients are usually anemic leading to complicating symptoms of fatigue or tiredness. If a healthcare professional suspects this disease, preliminary work up includes blood work and urine analysis. If the suspicion is high, your primary care provider should refer you to an oncologist (a cancer specialist) who will likely perform a bone marrow biopsy.

(Continued on page 4)



Shopping for a Good Cause!



Show your awareness and wear your Amyloidosis Foundation gear proudly!

T-shirts— \$25
Wristband— \$5
Lapel Pin— \$8
Awareness Bulb- \$6
Notecards (set of 12)— \$15



BACK

Show off your amyloidosis awareness!

TYPE THIS LINK IN YOUR BROWSER TO VIEW OUR LIST OF PRODUCTS:

<http://amyloidosis.org/products/>

Patient Resources

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

- Webinar recordings posted on our website
- Updated informational pamphlets
- Listing of experienced physicians that specialize in amyloidosis. Email us anytime with questions: info@amyloidosis.org
- Treatment Centers (US / International)
- Support Groups
- Newsletters
- Webinars
- Caregiver/Patient Binder
- Fundraising Toolkits

Follow Us!



Stay connected for all the latest information on Amyloidosis:

Web: www.amyloidosis.org
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President's Corner

Mary E. O'Donnell



As we begin the new year 2023, the Amyloidosis Foundation is quickly approaching our 20th Anniversary. It was on October 13, 2003, that the foundation was officially established. Much has changed in the last 20 years. Just recently, (in the last few years), there have been approved drugs for ATTRv, ATTRw and AL amyloidosis, with many others in the pipeline. The foundation is very proud of the scientific research that we have supported over the years. By we, I mean you, as the support would not be possible without your generosity. As of the publication of this newsletter we are approaching \$4 million supporting research, trying to better understand and treat the systemic amyloidosis diseases. We thank all of our supporters and those who help to raise awareness of amyloidosis. We look forward to our 20th year!

Mary

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YOU are the best!

Once again our gracious community stepped up in a big way. We surpassed our #GivingTuesday goal of \$20,000 between our donation link, Facebook fundraisers and mail-in donations.

These funds will go toward amyloidosis research. We can't put into words how thankful we are for you!

GIVING
TUESDAY

Thank You

Gracias

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Merci

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Our newsletter is published quarterly (Spring, Summer, Fall and Winter) by the **Amyloidosis Foundation**. We welcome letters, articles and suggestions.

Please contact us anytime at: info@amyloidosis.org, (248) 922-9610
or 7151 N. Main Street, Ste. 2, Clarkston, MI 48346

If you wish to receive an electronic version, please send us an email:

info@amyloidosis.org

www.amyloidosis.org



Amyloidosis and the Kidney

(Continued from page 1)

If there is a suspicion of kidney involvement, as it is the most common organ to be affected, you will see a kidney specialist known as a nephrologist. The kidney specialist will likely order a kidney biopsy to confirm the disease and its involvement in the kidney.

Other testing in this disease involves imaging as the bones are commonly affected. X-rays can show bone involvement. More detailed and specific imaging also involves Computed Tomography (CT) scans and Magnetic Resonance Imaging (MRI). Treating this disease will primarily aim at stopping or slowing the production of these amyloid protein to prevent further depositions in tissues and subsequent damage. The treatments will alleviate the symptoms and improve one's quality of life. In AL amyloid, treatment involves chemotherapy to abolish those abnormal cells producing amyloid proteins. These abnormal cells are also destroyed using corticosteroids and other newer generations of therapies involving immunomodulators.

After destroying these cells, an oncologist will then perform an autologous stem-cell transplant which uses the body's healthy stem cells to replace stem cells abolished by the chemotherapy. In this process, healthy stem cells are collected from your blood and safely stored. A patient will then receive chemotherapy to destroy abnormal stem cells after which the stored healthy stem cells are infused back to these patients. In AA amyloidosis, health care providers treat the underlying chronic condition, like chronic infection or inflammation. Medications can include biologic agents that block pro-inflammatory ligands like Tumor Necrosis Factor (TNF) to decrease inflammation. Other agents to fight chronic inflammation include corticosteroid and nonsteroidal anti-inflammatory drugs (NSAIDs). Antivirals or antibiotics can be given to treat chronic infections. All of these medications have to be taken under close supervision of your physician given their side effect profile if given over a prolonged period of time.

Your health care professional will prescribe additional medication to control certain complications of amyloidosis. In kidney disease, medications like Angiotensin converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs) can lower your blood pressure and slow the progression of kidney disease. If this disease causes swelling, especially in lower extremities, diuretics will be prescribed to help remove excess fluid from your body. Anemia is another known complication of amyloidosis especially in kidney disease. Your health care provider will then prescribe iron supplements and erythropoiesis-stimulating agents to aid your body to make more red blood cells and improve anemia. Attending to a healthy lifestyle is always better for your body in health and disease. Eating habits and physical activity do not have a role in preventing or treating amyloidosis. However, a healthy life style becomes important in kidney disease to prevent symptoms of this disease and prevent further progression.

About the author: Dr. Omar H. Maarouf is a nephrologist in Philadelphia, Pennsylvania and is affiliated with Jefferson Health-Thomas Jefferson University Hospitals. He received his medical degree from American University of Beirut Faculty of Medicine and has been in practice for more than 20 years.

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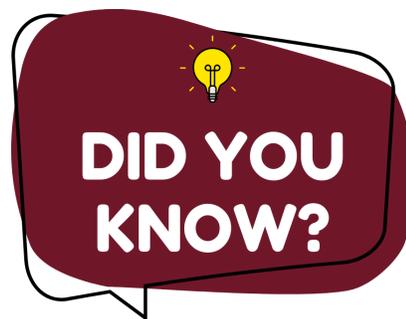


Resources

We have an abundance of resources for our patients, caregivers and their families. These resources range from financial help for medication to a binder to keep everything in one place. Below are just some of the resources we provide:

- Websites and Support Groups
- Treatment Centers
- Clinical Trials
- Brochures
- Amyloidosis Foundation Newsletters
- Webinars
- Videos
- Vietnam Veteran Resources
- RARE Toolkits
- Exercises
- Travel
- And more!

Go to www.amyloidosis.org and click on the **Resources** tab at the top of the page.

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Coming This March To A Town Near You!

LIGHT THE NIGHT FOR AMYLOIDOSIS

March 2023



“Light The Night For Amyloidosis” is our annual amyloidosis awareness campaign. It was created to draw attention to symptoms, diagnosis, treatment, and hopefully someday, a cure!

Since ‘Amyloidosis Awareness Month’ also occurs in March, we are asking everyone to light their entryway, home or business with red bulbs for the month of March.

We have also contacted sites across the globe to do the same. Last year we had over 100 sites in 5 countries light for our cause!

We have red bulbs available for purchase on our website.

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www.amyloidosis.org



We Need YOU To Help Create More Awareness

People are always saying that doctors need more awareness of amyloidosis. Of course, we could use help with this. What are YOU doing to help spread awareness? We have a successful Grand Rounds Program to help with awareness among medical professionals (<https://amyloidosis.org/research/#grand-rounds>).

Ways that you can help:

- * Deliver/Send brochures to medical professionals in your area (we provide these)
- * Reach out to local legislators to tell your story
- * Invite people to "like/follow" our Page
- * Attend/Speak at your states Rare Disease Day
- * Talk about it online. Leverage social media to create a wide audience
- * Create a challenge or event benefiting the Amyloidosis Foundation
- * Reach out to local sites to "Light The Night For Amyloidosis" in March
- * Join platforms to share your journey within the broader ecosystem. Advocacy comes in many forms, from donations to a loud voice.
- * Attend Rare Disease Week in Washington D.C. in February
- * Wear clothing or accessories that get the word out
- * Start a Facebook fundraiser and invite all of your friends to it. Tell your story briefly
- * Recruit like-minded people
- * Contact your local news media to pitch your story
- * Reach out to a local medical school to share your story
- * Publish a blog series or podcast

These are just some of the ways you can help. With over 10,000 rare diseases, it's almost impossible for physicians to know about every one of them. That's where YOU come in. Make them aware! If you need help with this, email kathi@amyloidosis.org or call Kathi at 248.922.9610.



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Meet our 2023 Research Grant Recipients



Oshrat Rokah, MD

Drug Repurposing for AL Amyloidosis: Exploring New Mechanisms

Amyloidosis Foundation Research Grant, 2023
Assuta Medical Centers Hospital, Tel Aviv, Israel



Shilpa Vijayakumar, MD

Molecular Imaging of Myocardial Fibrosis in Transthyretin Cardiac Amyloidosis

The Charlotte L. Haffner Memorial Research Grant, 2023
Brigham and Women's Hospital, MA, USA

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Rare Disease Day is February 28!

Rare Disease Day is the globally-coordinated movement on rare diseases, working toward equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.

Rare disease day is about raising awareness and generating change for the 300 million people worldwide living with a rare disease, their families and caregivers. Follow us on Facebook for more information on how you can participate!

I SUPPORT
RARE DISEASE DAY
28 FEBRUARY 2023
#RAREDISEASEDAY RAREDISEASEDAY.ORG



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Wishing you good health, happiness, and brighter days!

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