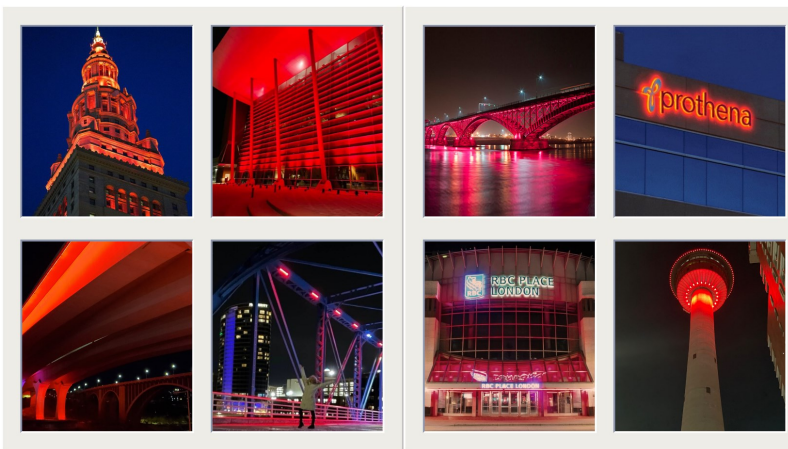




News and Stories - Spring 2023

4th Annual 'Light The Night For Amyloidosis' Brought Awareness!



We started our 'Light the Night for Amyloidosis' initiative in 2020 to coincide with 'Amyloidosis Awareness Month', which occurs in March. Every year, our awareness campaign gains more support.

This year was our largest event yet, with over 120 illuminations across the globe. The countries that participated

were the United States, Canada, New Zealand, Australia and the United Kingdom. We had many that had participated in previous years and many new ones that we hope will shine a light on amyloidosis awareness for years to come.

(Continued on page 4)

Rare Disease Week on Capitol Hill

At the end of February and the beginning of March, one of our team members participated in Rare Disease Week on Capitol Hill. While there, she attended a legislative conference, a Congressional Caucus Briefing, and a deep dive into legislative policy geared toward rare diseases. She met with Congressional and Senate legislative staff to gain support and advocate for initiatives that affect the amyloidosis community. FDA hosted a day about clinical trials, advancing product development, teaching medical student how to spot those in the rare community, and how to engage with the FDA. The next day was filled with learning about programs and resources, gene-targeted therapies and inclusion at the NIH.



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Education • Awareness • Support • Research

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Multiple Myeloma and AL Amyloidosis

By: Michael Rosenzweig, MD

The monoclonal gammopathies are a spectrum of diseases ranging from monoclonal gammopathy of undetermined significance (MGUS) with a low plasma cell burden to multiple myeloma. AL Amyloidosis occurs when monoclonal proteins fold abnormally to form amyloid fibrils. Because amyloid formation can occur with any degree of a plasma cell abnormality, AL (immunoglobulin light chain) amyloidosis may occur as a disease entity alone or as an additional complication of active multiple myeloma. Studies report an incidence of symptomatic AL amyloidosis in approximately 10 -15% of patients with active myeloma ^{1,2}.

Patients with active multiple myeloma and AL amyloidosis face unique challenges. First, patients with multiple myeloma and AL amyloidosis contend not only with myeloma defining events including bone lesions, anemia and kidney dysfunction but also with amyloid related organ damage including, nephrotic syndrome (protein loss in the urine), congestive heart failure, peripheral neuropathy or gastrointestinal mucosal damage increasing the risk of bleeding. Amyloid related organ disease can make anti-myeloma treatments difficult to tolerate. Specifically, lenalidomide, a backbone component of anti-myeloma therapy, is poorly tolerated by patients with AL amyloidosis so doses need to be adjusted.

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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

Our comprehensive website has information for patients, caregivers and physicians featuring:

- Treatment Centers (US / International)
- Support Groups
- Newsletters
- Webinars

Follow Us!



Stay connected for all the latest information on Amyloidosis:

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President's Corner

Mary E. O'Donnell



As we proceed through 2023, we are quickly approaching the foundation's 20th anniversary in October. It has been an exciting and interesting 20 years. We have awarded nearly \$4 million in research grants to help understand the mechanism of all types of amyloidosis. We have provided information and moral support to hundreds of patients and caregivers as they travel through the amyloidosis journey. We have watched the medical community's knowledge of amyloidosis grow by leaps and bounds. Alas, there is still a long way to go in raising awareness, and that also is one of the main efforts of the foundation.

We thank you for your continued support,

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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



Light The Night...

(Continued from page 1)

Amyloidosis warriors and supporters united globally shining a red light outside of their homes. Many helped by asking local sites to light for us. The goal of lighting up the 120-plus buildings, landmarks, bridges, monuments, billboards and falls in red throughout the world is to get people wondering why they are lit up this way, and look it up, which will, of course, lead them to information about amyloidosis. Our goal is simple, to give light and hope to those affiliated with amyloidosis. With more awareness comes knowledge, and more people being diagnosed earlier.

Here are some highlights:



Rock and Roll Hall of Fame
Cleveland, Ohio, USA



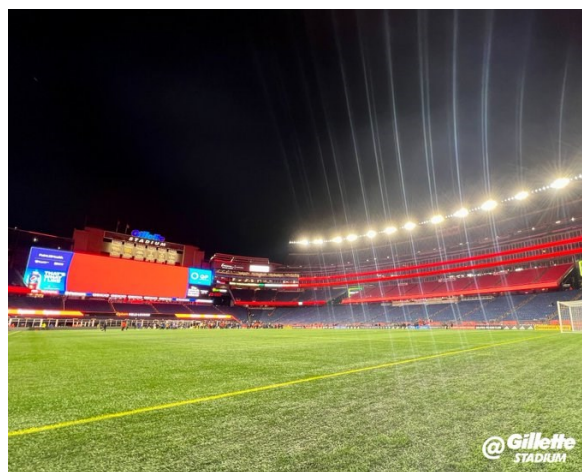
Aloha Tower
Honolulu, Hawaii, USA



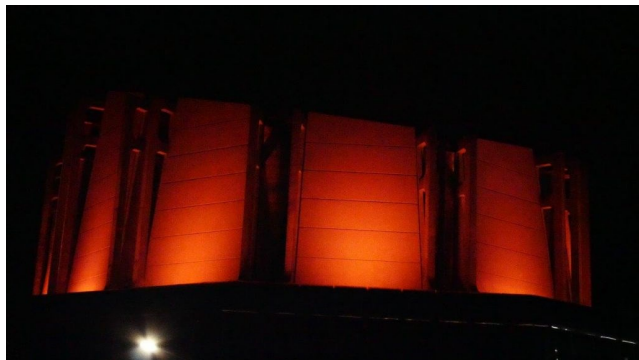
Lytham Windmill
Lancashire, England, UK



Calgary Tower
Calgary, Alberta, CAN



Gillette Stadium
Foxborough, Massachusetts, USA



Michael Fowler Centre
Wellington, New Zealand



Niagara Falls
Niagara Falls, New York, USA
Ontario, CAN



Multiple Myeloma & AL Amyloidosis (Cont'd)

(Continued from page 2)

Furthermore, amyloid related neuropathy can complicate the use of bortezomib and congestive heart failure make high dose steroids challenging to tolerate. In reality, all anti-myeloma strategies must be used cautiously in patients with associated amyloidosis.

Second, patients with multiple myeloma and AL amyloidosis have a higher clonal cell disease burden compared to those with AL amyloidosis alone. Treatment of multiple myeloma is intensive and continuous. Therapies includes induction chemotherapy, followed by consolidation, often with an autologous stem cell transplant, followed by indefinite maintenance chemotherapy. In contrast, initial treatment for AL is often the Dara-CyBorD regimen as outlined in the ANDROMEDA study³.

A minority of patients who fail to achieve a deep response will go on to an autologous stem cell transplantation. The role of long-term maintenance therapy is unclear in AL amyloidosis so many patients can be followed without therapy after just 2 years of treatment. The burden of treatment for a patient with multiple myeloma and amyloid related organ disease tends to mimic that of multiple myeloma alone which can be particularly challenging.

Third, patients with multiple myeloma and AL amyloidosis are often excluded from clinical trials. Despite significant advances for the treatment of multiple myeloma, a cure remains elusive and most patients develop relapsed disease. Once standard of care options are exhausted, clinical trials are available for patients to receive new, unapproved agents. (Continued on page 7)

Rare Disease Week...

(Continued from Page 1)



There are many new Congressional members who are not familiar with historical issues that face amyloidosis patients and their families. It is vital that we start early to cultivate their support for legislation that affects our community, such as advancing drug development and making treatment accessible and affordable. Rare disease is a public health crisis that affects all of us. A recent study found that the cost of rare diseases in 2019 was a devastating \$1 Trillion dollars.

Participating in Rare Disease Week is one of the ways we strive to change policy and save lives in our amyloidosis community.

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Multiple Myeloma & AL Amyloidosis (Cont'd)

(Continued from page 6)

Many clinical trials for multiple myeloma exclude those patients with associated amyloidosis. Furthermore, trials for relapsed AL amyloidosis often exclude patients with active myeloma. This quandary often imposes limitations for patients with both diseases limiting treatment options.

In summary, patients afflicted with both multiple myeloma and AL amyloidosis face a difficult predicament and one that warrants special consideration by hematologist/oncologists as well as the amyloid community.

1. Rajkumar SV, Dispenzieri A, Kyle RA. Monoclonal gammopathy of undetermined significance, Waldenström macroglobulinemia, AL amyloidosis, and related plasma cell disorders: diagnosis and treatment. *Mayo Clin Proc.* 2006;81(5):693-703.
2. Kyle R, Greipp P. Multiple myeloma and other plasma cell disorders. *Hematology: basic principles and practice.* 1995;2:1354-1374.
3. Kastritis E, Palladini G, Minnema MC, et al. Daratumumab-Based Treatment for Immunoglobulin Light-Chain Amyloidosis. *N Engl J Med.* 2021;385(1):46-58.



Dr. Michael Rosenzweig, MD is a hematologist/oncologist in Duarte California and an Associate Professor in the department of Hematology and Hematopoietic Stem Cell Transplantation at City of Hope National Cancer Center. He is chief of the Multiple Myeloma division and director of the Amyloidosis Treatment and Research program at City of Hope Duarte.

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VIRTUAL Run for Your Life!

Run, Walk, Roll or Bike at your leisure to help raise awareness of amyloidosis, in your local park, or your neighborhood. Encourage your family and friends to register and participate.

You can complete your run/walk/bike/roll anytime between May 1, 2023 and July 31, 2023.

Registration is OPEN:

<https://bit.ly/Run23>

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RUN • WALK • ROLL • BIKE

may 1 - july 31



REGISTER TODAY!



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