



## News and Stories - Fall 2023

---

### *Nashville Support Group Meeting*

Our support group meeting was a great success! It was held at Connor's Steak & Seafood at Cool Springs Galleria in Franklin, TN on August 28, 2023. Dr. Berkman spoke and presented some slides. Thank you to all who attended, and thanks to Joe for sharing his patient story!

We appreciate your willingness to help other patients, caregivers and family members.



AF

---

### **SAVE THE DATE!**

#GivingTuesday is a global day of philanthropy when the world comes together to give. We are teaming up with our amazing community with a goal to raise \$20,000, which will go toward #AmyloidosisResearch. Will you join us? Be involved and make a difference!

**Donations for #GivingTuesday can be made at:**

<https://secure.giv.com/for/2023givingtues>

*Give thanks. Then give.*

[www.amyloidosis.org](http://www.amyloidosis.org)

**#GIVINGTUESDAY**

**11.28.23**



AF

---

**Education • Awareness • Support • Research**

[www.amyloidosis.org](http://www.amyloidosis.org)



## ⚡ FLASH SALE ⚡

All T-Shirts Are On Sale Now!

Don't miss out! Get your T-shirt today and help to spread awareness of amyloidosis in your community. **On sale for only \$15.** We have five different shirts available - white with logo on front, white with zebra graphic, gray with logo on front with graphic on back, maroon run graphic shirt, and gray run graphic shirt. Only while supplies last!

Order today - limited sizes available!

ORDER HERE 

<https://amyloidosis.org/products>

The prices listed below are for US shipping only!

*\*If you would like to order from outside of the United States there will be additional shipping charges.*

Please email us at [info@amyloidosis.org](mailto:info@amyloidosis.org) to finalize your purchase.

AF

## 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](mailto:info@amyloidosis.org)

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

- Treatment Centers (US / International)
- Support Groups
- Newsletters
- Webinars
- Caregiver/Patient Binder
- Fundraising Toolkits

AF

## Follow Us!



Stay connected for all the latest information on Amyloidosis:

Web: [www.amyloidosis.org](http://www.amyloidosis.org)  
 Twitter: [@Amyloidosisfdn](https://twitter.com/Amyloidosisfdn)  
 Facebook: [@amyloidosisfdn](https://www.facebook.com/amyloidosisfdn)  
 Instagram: [@amyloidosisfoundation](https://www.instagram.com/amyloidosisfoundation)



[www.amyloidosis.org](http://www.amyloidosis.org)



## Advocating With A Purpose

We were excited to join PAN (Patient Access Network) Foundation to advocate for access to healthcare and affordability for all on September 28, 2023! Together, advocates from across the nation demanded timely and affordable access to prescription medications.

We urged Congress to make Medicare Telehealth flexibilities permanent. Without Congressional action, Medicare's telehealth flexibilities, put in place during the pandemic, will expire by the end of 2024, potentially cutting off crucial healthcare access.

We advocated for Congress to require health insurance plans to apply all financial assistance received by or on behalf of a patient to count toward their deductible and annual out-of-pocket maximum. To do so, Congress must ban harmful co-pay accumulator programs.

We also urged Congress to eliminate step therapy to get medications without delay. Step therapy—or “fail first” policies—and prior authorization rules can delay or undermine a patient's prescribed treatment plan.

**AF**

### Board of Directors

**President**

Mary E. O'Donnell

**Treasurer**

Dante Burchi

Stacey Goodman, MD

Lori Lawter, MPH

Daniel J. Lenihan, MD, FACC

Adrienne Molteni, RN

Mark Sutherland



### Scientific Advisors

Raymond Comenzo, MD

Morie Gertz, MD

Mathew Maurer, MD

Giampaolo Merlini, MD

Vaishali Sanchorawala, MD

Douglas Sawyer, MD, PhD

Jonathan Wall, PhD

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**



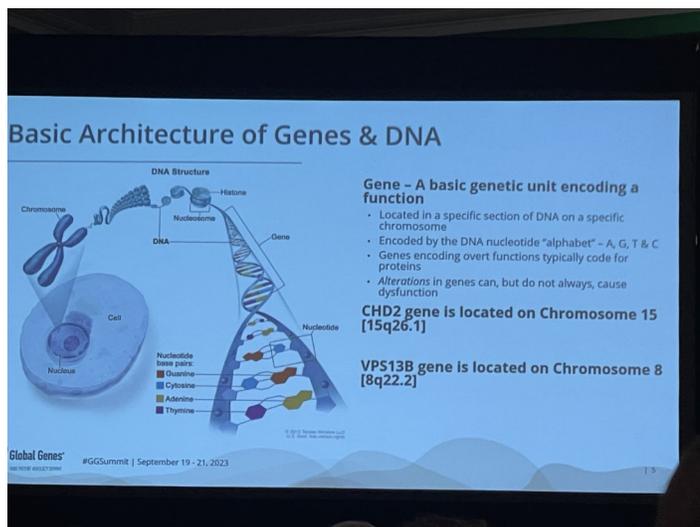
## Week In Rare

One of our staff members attended a conference for a week geared toward rare disease health equity and advocacy. While there, she participated in a Health Equity Forum and an Advocacy Summit. To say that this conference was jam-packed with information is an understatement!

The sessions during day one of the Health Equity Forum were geared toward systemic disparities in healthcare, building equity through community engagement, addressing strategies to successfully establish relationships in underserved and under-resourced communities, positive health outcomes in underserved populations, and ended with a talk on leveraging underutilized health services to support underserved populations.

Day 2 started off with a keynote address about “Disease, distrust, disparities and direction. The panel discussions shed light on the unique challenges and opportunities that arise when incorporating the Hispanic population into rare disease advocacy and research efforts. Next on the agenda was a great session on improving diverse engagement in clinical trials. This has been a much talked about issue ranging from women to people of color. The day ended with an understanding of the patient perspective. Barriers to patient participation and access were discussed. Strategies were identified to address specific issues at each level.

During the Advocacy Summit, she participated in sessions about how patients are driving research to find cures, coordinating complex care, helping newly diagnosed patients, how to improve our research strategy, the rare disease experience (including perceptions and support needs of the patient and their families, and lack of knowledge by providers). She also attended sessions about drug repurposing and



(Continued on page 5)



# Week In Rare...

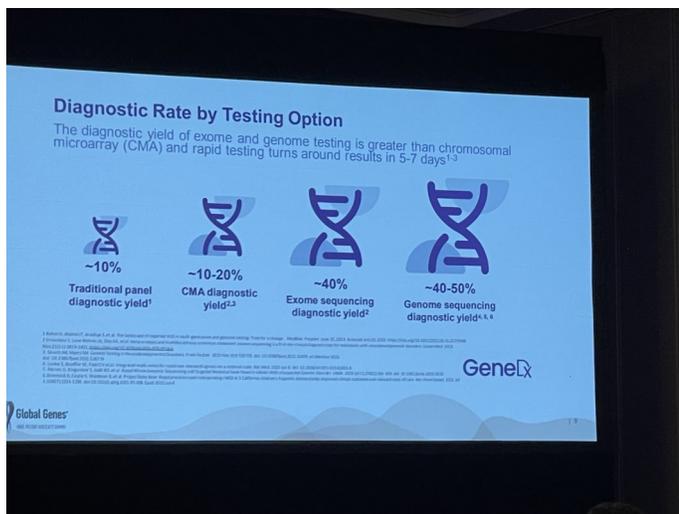
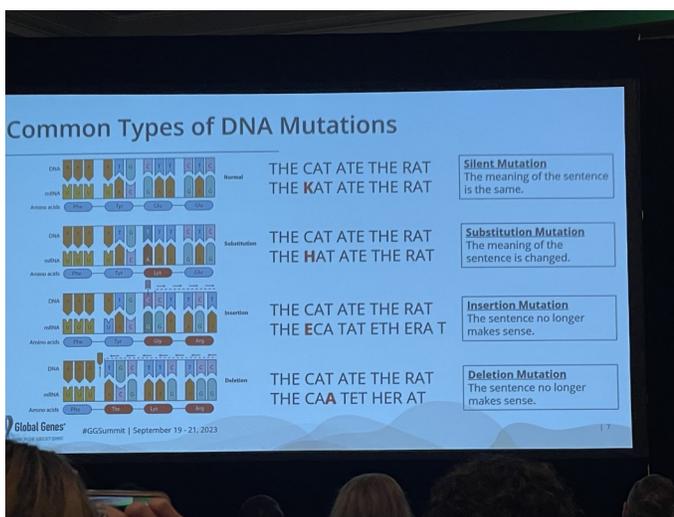
(Continued from page 4)

biologics, empowering the rare individual on communicating with health care providers (HCP's), RNA therapies, and new models for trial participation.

Day 3 of the Summit started with a members only Corporate Alliance Leadership/ Global Advocacy Alliance Leadership Networking breakfast session at 7:30 am followed by an opening plenary on 'Emerging Opportunities to Accelerate Research Through Disease Community Collaborations'. They then broke out into tracks on managing life without a diagnosis, community building, studies and regulatory strategies, and gene replacement and gene editing therapies.

The next session started with learning to live well in your new reality and navigating the diagnostic journey, navigating international research, data sharing, legislative action (policy issues), the cost of delayed diagnosis, mental health, engaging the FDA, and a closing plenary about working together to strengthen our future.

Attending conferences has many benefits as it allows us to meet with leaders and industry experts in the rare disease field and learn from their expertise, hear about the latest research, and learn how others are breaking down disparities in the medical space. We will continue to work tirelessly to become more knowledgeable to better serve the amyloidosis community.



AF



## Did You Miss Our Webinar?



The recording is now available!!!

Type the link below in your browser 

<https://youtu.be/R5qaREBCbe8>

**AF**

## Good News From Attralus, Inc.

124I-Evuzamitide (AT-01), a Novel Amyloid-Specific PET Imaging Agent, was a hot topic at the 28th Annual Scientific Session of the American Society of Nuclear Cardiology.

Here are key takeaways:

- AT-01 is a first-in-class pan-amyloid imaging agent capable of detecting diverse types of systemic amyloidosis in multiple organs.
- AT-01 demonstrated to be highly accurate, with 100% sensitivity for detection of cardiac amyloid, across three independent investigator-initiated studies.
- Attralus-Sponsored Test-Retest repeatability study demonstrates excellent repeatability and supports the potential use of AT-01 imaging to monitor disease progression in patients with cardiac amyloidosis.
- AT-01 may be more sensitive than 99m-Tc pyrophosphate bone scintigraphy (Tc99m-PYP) for detecting transthyretin cardiac amyloidosis in patients with hereditary ATTR-CA.
- AT-01 uptake in cardiac amyloidosis shows moderate and statistically significant correlations with traditional measures of cardiac structure and function.
- AT-01 has the potential to play a valuable role for diagnosing cardiac amyloidosis and for monitoring changes in organ-specific amyloid load. **AF**



## AF VIRTUAL Run-Walk-Roll-Bike Was A HIT!

Thank you to all that participated in our annual event! We raised over \$ 14 K to go toward amyloidosis research. This is an important way for us to bring awareness as well as raise funds. We appreciate each and every one of you that took part and hope you wear your t-shirts proudly to draw attention to amyloidosis!

**AF**





7151 N. Main St.  
Ste. 2  
Clarkston, MI 48346

NONPROFIT ORG  
U.S. POSTAGE  
PAID  
ROYAL OAK, MI  
PERMIT NO 964



*Be you  
Do you  
For you*



Scan this code with the camera on your mobile device and get directed to our webpage!

