News and Stories - Summer 2021

Marcie Peaco Annual Memorial Invitational

A little over 2 years ago, Marcie Peaco lost her battle with amyloidosis. Marcie was a very loving and devoted wife to Ray Peaco, the SV Track and Field Head Coach and mother to daughters Megan and Morgan.

She was an avid volunteer, an administrative assistant to the SV school district and a huge part of the Seneca Valley family and the track and field program. She had a heart of gold and always put others before herself. She is truly missed by those that knew her. This memorial invitational will continue in her memory.

The meet not only helped to create awareness, gave the team the opportunity to share educational materials, but also raised funds to help us to continue our mission to support amyloidosis patients and their families, continue research and ultimately find a cure.

We thank the Seneca Valley Track and Field Team and the SV community for a $2,000 donation in memory of Marcie. **AF**

(Pictures continued on page 2)

ANDROMEDA Results Published in The New England Journal of Medicine

By: Jeffrey Zonder, MD

Light chain (AL) amyloidosis is a systemic form of amyloidosis in which clonal plasma cells in the bone marrow make abnormally folded antibody fragments called light chains. The abnormal light chains aggregate into organ-damaging protein deposits.

The goal of therapy is to lower the blood levels of the abnormal light chains, usually by targeting the plasma cells with chemotherapy regimens like CyBorD (cyclophosphamide, bortezomib, dexamethasone), or with antibodies like daratumumab (Dara) or isatuximab. The FDA granted approval to to the combination of CyBorD+Dara based on the positive results of the ANDROMEDA Trial (N Engl J Med. 2021 Jul 1;385(1):46-58). ANDROMEDA was a Phase 3 trial in which 388 patients with newly diagnosed light chain (AL) amyloidosis were randomized to receive either six cycles (Continued on pg. 7)

Marcie Peaco

(Continued from page 1)

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
- Caregiver/Patient Binder
- Fundraising Toolkits

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President's Corner

Mary E. O'Donnell

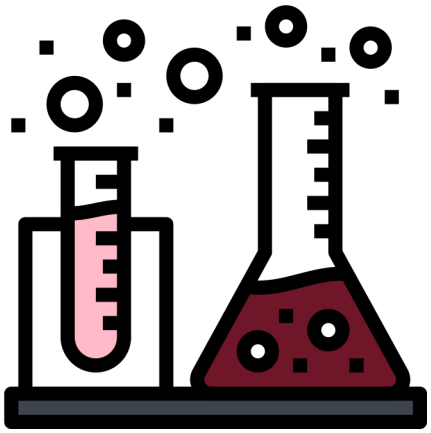
Since the Amyloidosis Foundation opened its doors in 2003, we, as a community, have endured many ordeals but there have also been several accomplishments in the world of amyloidosis. Since 2018, there have been 3 FDA drug approvals and just 3 months ago, a different standard of care for newly diagnosed AL patients.

As we near the end of Summer, I want to thank all of our partners—especially our donors and our staff—for responding to this year with tremendous courage and heart.

We can take the lessons we've learned so far—and the hope this season inevitably inspires us into the days ahead. I believe that by continuing to listen, support and work side-by-side, we will survive any test of our resolve and our humanity—and we will emerge much stronger for having done it together.

Warm regards to you and your loved ones,

Mary



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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

HealthWell Foundation Launches Enhanced Fund Tracking Tool

The HealthWell Foundation®, an independent non-profit that provides a financial lifeline for inadequately insured Americans, is excited to announce that it has recently launched an updated version of its disease fund tracking tool, Real-Time Fund Alerts.

Through the enhanced portal, anyone can register and receive instant email notifications to track the status of HealthWell's diverse portfolio of disease funds in real-time.

Registering for fund alerts is a fast and easy three-step process:

⇒ Simply select Real-Time Fund Alerts from the dropdown Portal button at HealthWell-Foundation.org.

⇒ Create an account with just your name and email address.

⇒ Once you are logged in, click "Get Fund Alerts" and select the funds you would like to monitor in real-time.

If the status of a fund changes, you will receive an instant notification through the email address you provided during registration. In addition, you can change the funds you would like to monitor by selecting additional funds or removing a currently selected fund at any time.

HEALTHWELL FOUNDATION®

When health insurance is not enough.®

"We are always identifying new ways to make the HealthWell experience as user-friendly as possible and making our Real-Time Fund Alerts available to the general public has been an operational goal of the Foundation," said Fred Larbi, Director of Operations at HealthWell.

"By offering this valuable resource to anyone who is interested in tracking the status of our funds, we have streamlined the process and eliminated the need to continuously check our disease funds listing to determine the status of a fund.

The enhanced design now allows anyone to select the funds for which they would like to receive status updates. For example, if a fund selected is currently closed, the user will receive instant notification if the fund reopens or vice versa."

stakeholders and to further streamline the online user experience for everyone interested in monitoring the status of HealthWell's funds.

Offering this feature to the general public continues to demonstrate our commitment to transparency by allowing everyone equal access to real-time information on fund status changes," said Krista Zodet, HealthWell Foundation President.

"The enhanced portal was created for anyone interested in tracking HealthWell funds. The portal offers a simple and easy way for our alliance partners, patients, families, donors, health care professionals and others to now monitor our funds in real-time."

Visit the Real-Time Fund Alerts Portal today to register.: https://healthwellfoundation.secure.force.com/guests

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Rare Disease Week 2021

One of our staff members participated in Rare Disease Week on Capitol Hill virtually. She attended a Congressional Caucus Briefing, a Legislative Conference and had meetings with members of Congress and Senators to discuss copay accumulators and PBM's (Pharmacy Benefit Managers).

PBM's are the middle man between insurers, drug makers and pharmacies. Pharmacists have "gag" clauses so they can't bring up that you may be able to get your Rx cheaper by NOT using your insurance.

In most states, this new health insurance trend of copay accumulators is jeopardizing access to copay assistance that counts toward out of pocket spending. All copays need to count for amyloidosis families.

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Have questions about public policy or regulatory science?

Contact: kathi@amyloidosis.org

Support The AF While You Shop!

There are many ways to support the Amyloidosis Foundation while you shop!

Every little bit adds up:

Amazon Smile- **http://amzn.to/1pWN2E3**

iGive.com- **iGive.com/pSpIPJr**

ShopWithScrip (RaiseRight) App- order online or call our office at **248.922.9610** for the access code.

Kroger Community Rewards- **Organization Number: HS565**

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ShopWithScrip

2nd Annual Virtual 'Run For Your Life' 5K/10K

Thank you to the 350+ runners, walkers and rollers we had for this event!

The participants could walk, run or bike at their leisure to help raise awareness of amyloidosis, in their local community.

Many encouraged family and friends to register and participate. The event was to be completed anytime between May 1, 2021 and July 31, 2021.

Below are some of the pictures that were shared with us. This event raised over $15,000 and will go toward research, education and awareness.

We truly appreciate the wonderful support we have received.

AF

ANDROMEDA

(Continued from page 1)

of CyBorD+Dara followed by up to 24 more cycles of Dara maintenance, or six cycles of CyBorD without any Dara during or after.

The main goal of the study was to compare the likelihood of reaching a complete hematologic response (CHR) using each of these strategies. Put simply, achieving CHR means the abnormal light chain concentration in the blood is reduced into the normal range, and any other abnormal protein markers produced by the abnormal plasma cells also disappear from the blood or urine.

Patients treated with CyBorD+Dara had almost 3x the likelihood of reaching a CHR compared to those who only got CyBorD: 53% vs 18%. This in turn translated into a better chance of improvement in the function of organs affected by the amyloid deposits.

For example, after 6 months of therapy, cardiac improvement was observed in 41% of patients with amyloid affecting the heart who were treated with CyBorD+Dara, versus 22% of patients treated with CyBorD only.

The story was the same in patients with amyloid affecting the kidneys: 53% of

of patients getting CyBorD+Dara had improvement in kidney function, compared to only 24% who got CyBorD alone.

The addition of Dara did increase the likelihood of certain undesirable events like low blood counts and infections, but this is not surprising since this was also seen when Dara was added to chemotherapy for another plasma cell disease, multiple myeloma.

Overall, adding Dara to CyBorD did not affect the likelihood of survival one way or the other during the first 60 days of treatment. It is hoped that the higher rates of early CHR and organ function improvement will eventually translate into superior survival with longer follow-up. Even as we wait to see whether this turns out to be the case, it is clear the ANDROMEDA Trial should be viewed as a major success, as it led to CyBorD+Dara becoming the first regimen to receive FDA approval for the treatment of AL amyloidosis.

Dr. Jeffrey A. Zonder is a hematologist in Detroit, Michigan and is affiliated with multiple hospitals in the area, including DMC Harper University Hospital and Karmanos Cancer Center. He received his medical degree from Wayne State University School of Medicine and has been in practice for more than 20 years.

MULTIDISCIPLINARY TEAM-Hematology Oncology Multiple Myeloma and Amyloidosis Program **AF**

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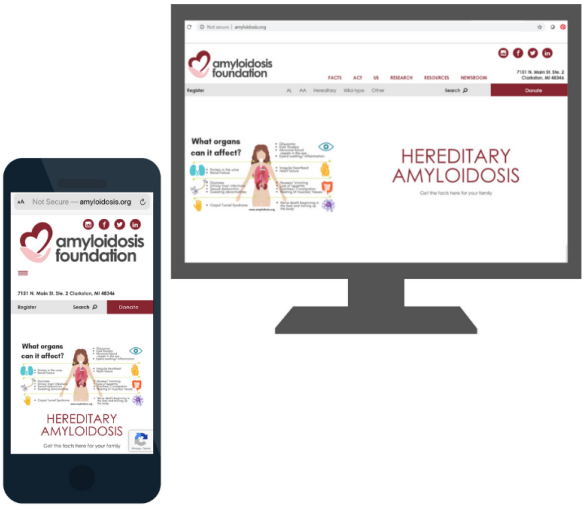

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