West Virginia Chapter
National Hemophilia Foundation

WINTER E-NEWSLETTER 2021

In this newsletter you'll find:

- The 2022 Calendar of Events
- Scholarship Opportunities
- Holiday Party Recap
- Info and RSVP details for the Annual Meeting
- Chapter Chats
- New von Willebrand Disease Guidelines

We are looking forward to in-person events for 2022!

March 1-2, 2022: Virtual Washington Days

- NHF will host a training and then a day of congressional visits to advocate on topics important to the community.

April 9-10, 2022: Annual Education Retreat, Roanoke, WV

- A weekend of bonding, networking, and education for the community, and our first major LIVE event.

June 6-10, 2022: Camp Winaca HemoVon, Marlinton, WV

- 5-day residential camp for kids ages 7-17 to positively impact and enrich the lives of children and teens diagnosed with cancer or a bleeding disorder.

June 10-12, 2022: Family Camp, Marlinton, WV

- A fun 3-day camp that promotes personal growth, self-worth, and self-reliance for the entire family.

July 10-17, 2022, Camp BleedSTEM, Morgantown, WV

- A camp for students entering 9th-12th grade who are interested in STEM careers.

August TBD: Chapter Meet & Greet Potluck, Nicholas County, WV

- Food and fun while families get to meet each other, share stories, and socialize.

September 17, 2022: WVNHF Unite Walk, Charleston, WV

- Show support for the community at the signature fundraising and awareness event.

October 1, 2022: Spokes Men for Bleeders, Harpers Ferry, WV

- An awareness and fundraising effort with a 100-mile bike ride followed by a finish line party.

December TBD: Holiday Party, Wood County, WV

- Fun crafts and snacks with a gingerbread house decorating competition.

Check out our Events Calendar or Facebook for up-to-date info and registrations for events.

Tired of Searching for Scholarships?

Check out what The Greater Kanawha Valley Foundation (TGKVF) has to offer.

Not only is this community partner helping to fund our Dental Program, they also help students follow their educational dreams and prepare for their future careers. TGKVF administers more than 500 funds and over 100 of those are designated for statewide scholarships.

They have opportunities based on what high school a student attends or college they plan to go to, GPA, area of study, or even which church they attend.

The application deadline is February 1st, so make sure you act fast!

Click Here for Info

Holiday Party Recap

Just last week we had our first Annual Holiday Party. Since it was virtual, everyone was sent a box of goodies, including craft supplies, snacks, and ornaments to paint. We made snowmen while we talked about our holiday plans. Hard work paid off for two of our scavenger hunt participants with Amazon gift cards. It was a really nice way to wrap up the new year.

RSVP for the Annual Meeting

Annual Meeting, Education Weekend, Annual Retreat? Whatever you call it, it's back!

April 9-10 at Stonewall Resort, Roanoke, WV

Registration closes February 28th

Although we will be adhering to NHF's event guidelines, barring anything crazy from happening, this event WILL BE IN-PERSON. We'll have education sessions, networking with other community members from throughout the state, and plenty of time to hang out and enjoy the resort.

If you plan to enjoy this weekend with us, make sure you check out NHF's live event policy, and register soon.

Register Here

Chapter Chats

Hi, I'm Chelsea, the Program Manager for the chapter. I'm the one working in the background, planning events, writing grant reports, and checking the mail!

I'm still pretty new to the bleeding disorders community and I'd love to get to know you and hear your story. In 2022, I'd like to travel around West Virginia and meet up with as many people as I can.

The more I know, the better I and the chapter can work to meet your needs. If you want to schedule a time to talk-on the phone, over zoom, or in real life, please let me know. I can't wait to meet you!

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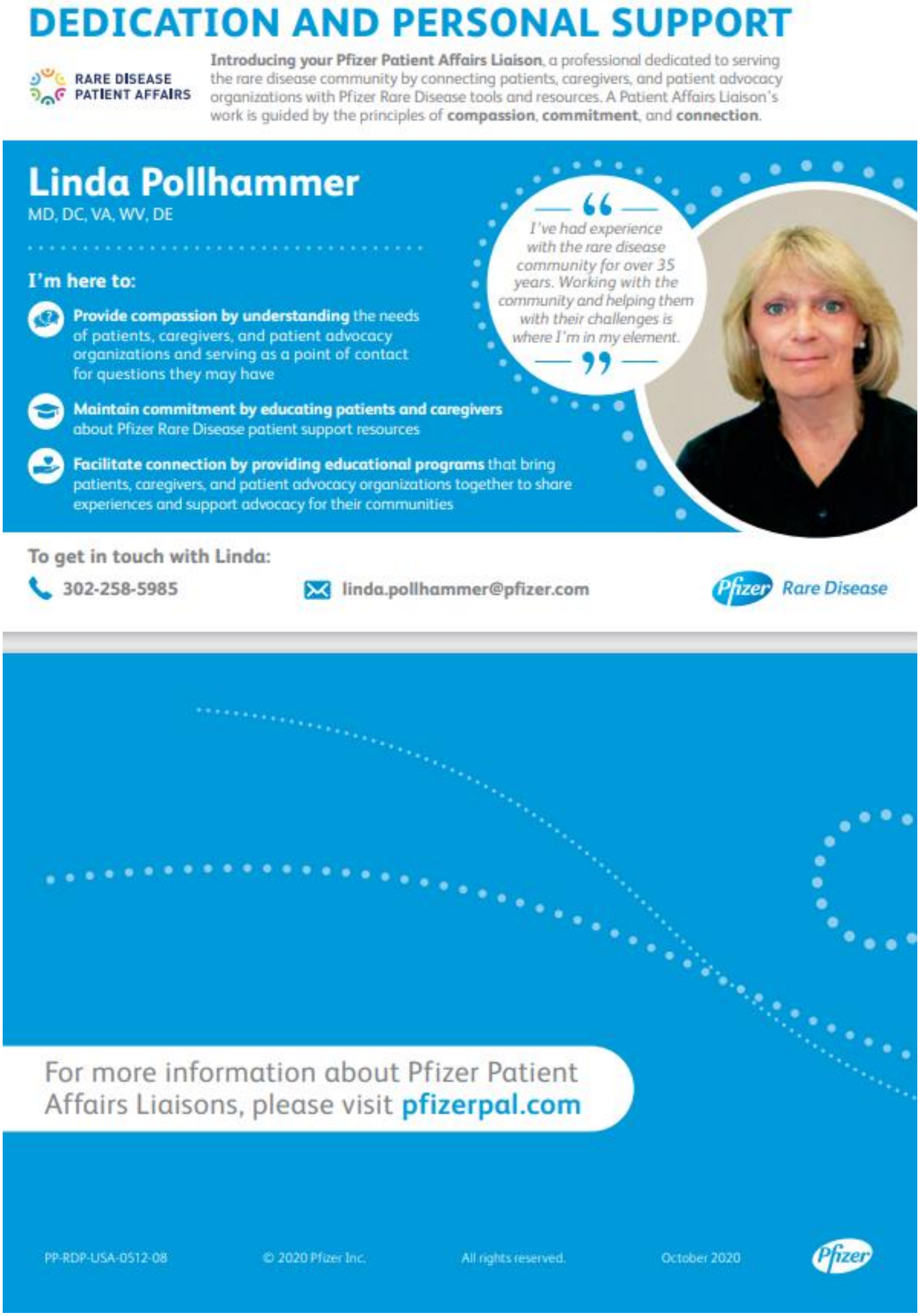

DEDICATION AND PERSONAL SUPPORT

Introducing your Pfizer Patient Affairs Liaison, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison's work is guided by the principles of **compassion**, **commitment**, and **connection**.

Linda Pollhammer

MD, DC, VA, WV, DE

> *I've had experience with the rare disease community for over 35 years. Working with the community and helping them with their challenges is where I'm in my element.*

I'm here to:

- **Provide compassion by understanding** the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have
- **Maintain commitment by educating patients and caregivers** about Pfizer Rare Disease patient support resources
- **Facilitate connection by providing educational programs** that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

To get in touch with Linda:

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For more information about Pfizer Patient Affairs Liaisons, please visit **pfizerpal.com**

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Have You Seen the New von Willebrand Disease Guidelines?

WD affects approximately 1% of the world's population, and it is the most common bleeding disorder. Although VWD occurs among men and women equally, women are more likely to notice the symptoms because of heavy or abnormal bleeding during their menstrual periods and after childbirth. This inherited condition results in the decreased production, absence, or abnormal function of the clotting protein von Willebrand factor.

This year brought new guidelines on the diagnosis and treatment of WVD, thanks to two expert panels made up of 32 individuals, including U.S.-based and international hematologists, individuals living with VWD, and scientists.

The guidelines include a combined 19 recommendations such as:

- making suggestions to classify VWD to be more inclusive of patients who experience bleeding, but whose blood work does not meet currently accepted thresholds for diagnosis, and
- recommending that VWD patients who suffer from frequent, severe bleeding should receive routine VWD prophylaxis – an injectable concentrate of clotting protein – several times a week.

Click Here for Info