VF Partners with ACR on Guidelines for Systemic Vasculitis

Once Approved, Recommendations to be Published, Distributed Worldwide

By Nina Silberstein

The Vasculitis Foundation (VF) and the American College of Rheumatology (ACR) have formed a first-ever partnership to distribute a set of guidelines for the treatment of systemic vasculitis in rheumatology patients.

The draft recommendations were presented in November at the annual meeting of the ACR and the Association of Rheumatology Professionals (ARP). Once complete, the guidelines will be published in medical journals and distributed worldwide. This is the first time the ACR has provided guidance on how to manage systemic vasculitis in rheumatology patients, and the first time the VF and the ACR have partnered on this type of effort. This partnership was generously underwritten by The DePaolis Family.

“I think that both organizations have been excellent at advocating for patients and providing resources and support for both patients and the providers taking care of them,” said Anisha Dua, MD, MPH, assistant program director, Department of Medicine-Rheumatology at Northwestern University. “The collaboration between these organizations is very exciting and will only strengthen the final guidelines that we recommend.”

Joyce Kullman, executive director of the VF, is also excited about the collaboration. “Partnering with the ACR to distribute the guidelines will improve understanding of vasculitis in the rheumatology community,” she said, “and help other specialists such as pulmonologists, nephrologists, dermatologists, and otolaryngologists who treat vasculitis patients.

Young Adults Take Home Best Short Video at Philly Awards Ceremony

By Nina Silberstein

The message in an award-winning video created by young people living with vasculitis is simple, yet powerful: You can chase your dreams, no matter the circumstances.

“Young Adults with Vasculitis Look to the Future,” a montage of video clips created by 12 young vasculitis patients, won Best Short Video in the 2019 Nonprofit Connect Philly Awards this past November. The event, held at The Vox Theatre in Kansas City, Kansas, celebrated outstanding achievements in nonprofit marketing and communications.
I’ve been privileged to meet and work with many wonderful and interesting people over the years. Unfortunately, in December we lost two of our friends and volunteers.

Meaghan Carpenter passed away unexpectedly on December 9 at the age of 27. We met Meaghan when she was just 15 at the 2008 International Symposium, shortly after she was diagnosed with Churg-Strauss syndrome, now eosinophilic granulomatosis with polyangiitis (EGPA). Meaghan never let vasculitis stop her. She was a National Merit Scholar and earned a Master of Library and Information Sciences degree from the University of Illinois. She was creative, funny, and compassionate. As a leader of our Young Adults Group, she often shared her personal experiences and professional research skills to help other patients learn about the disease. In 2017 she shared:

“I dream that we’ll reach a point where complete remission is a guarantee. That newly diagnosed patients won’t have to be scared but will know that their bodies can’t stop them from living full lives and achieving their goals. The VF’s research efforts and the community of support they provide have helped me to have hope for my future. I dream of a day when everyone can feel the same.”

I hope you will read her obituary, which celebrates her amazing, but short life: bit.ly/36r6HSX.

We met Sam and Helen Dodge at the 2019 International Vasculitis Symposium and featured their story about his microscopic polyangiitis (MPA) diagnosis in our November/December newsletter. As a member of the VF Facebook group, he offered support and encouragement to other patients battling vasculitis. He and Helen generously agreed to be part of our recent Join Our Journey campaign, and we have all been touched by their kindness and concern for others. Sadly, he passed away on December 28, from complications of vasculitis. I hope you will visit his website to read about his collection of antique motion picture studio cameras and the story of his cross-country trip in a biplane: www.samdodge.com/.

Many thanks to all of you who generously supported our 2019 Join Our Journey campaign. We have many ambitious programs planned for 2020 and we cannot be successful without your support.

Sincerely,

Joyce A. Kullman
Executive Director
Joyce Kullman, executive director of the VF, said the goal was a video created by young adults for young adult patients, as part of Vasculitis Awareness Month. The VF asked the group to create the video, and they took it from there.

“Joyce, Ben, and the other young adults featured in the video have heightened awareness and provided inspiration to many.”

—Jacquelyn Eidson

Ben was diagnosed in 2014 with eosinophilic granulomatosis with polyangiitis (EGPA) and is a VF Young Adults Group leader. "We knew going in we wanted to create a message that would be powerful and concise, while at the same time, include enough young adults to really drive home the point of the awareness campaign." The video participants included 12 young adults with vasculitis, ranging in age from 16 to 35, from different backgrounds, locations, and experiences.

“I thought doing a video that reflected our goals as a group, and also allowed each individual to share their own aspirations, would help tie everything we wanted to get across together," said Ben Wilson, a 26-year-old sports broadcaster, who served as executive producer and post-production editor of the video.

Sadly, one of the video participants, Meaghan Carpenter, passed away suddenly December 9 at age 27 (see sidebar).

“Our Young Adults Group has come a long way over the past few years, and a big reason is because we’ve changed the narrative about vasculitis only being a disease that is present in middle age and the elderly," Ben said. As more people realize how much the disease impacts young adults, the push for earlier diagnosis and the introduction of better treatments with fewer side effects should only increase.

View the award-winning video here: bit.ly/2ZHWwGV.

Philly Awards, cont.

Attending her first event as a new VF board member, Jacquelyn Eidson thought the Philly Awards was a fantastic night of celebrating the nonprofit community. "Ben and the other young adults featured in the video have heightened awareness and provided inspiration to many," she said. "It was wonderful to see their important work recognized."

A Tribute to Meaghan Carpenter

“I have to mention Meaghan Carpenter, one of the participants in our video. Meaghan tragically passed away recently, and all of us within the community are still in mourning. I can’t say enough about the impact Meaghan had on all of us—from her countless fundraising efforts, advice for the recently diagnosed, and constant push for self-advocacy, she was the model example of a patient who refused to be defined by her disease.

Meaghan was never afraid to speak her mind and challenge doctors who she felt were unaware of the many intricacies of vasculitis. Despite going through so much as an EGPA patient, Meaghan always had a smile on her face and uplifted everyone around her.

We had such a great time hanging out this summer in Rochester, Minnesota, at the 2019 International Vasculitis Symposium, and I know Meaghan couldn’t wait to help with all of our endeavors in 2020. I think anyone who ever got to know Meaghan, or even had an interaction with her, would agree with everything I just said.”

—Ben Wilson, Young Adults Group leader

VF Executive Director Joyce Kullman, Ben Wilson, and Kaley Beins at the 2019 Philly Awards in November.

VF News
Thank You for Helping Us Exceed Our Goal for Join Our Journey!

Together, we did it! Our three-month Join Our Journey campaign for better treatments ended December 31, and the numbers are in: 1,155 donors rallied to help us raise $272,906—sending us above and beyond our goal for the campaign. That’s a 21 percent increase in dollars raised over 2018.

The numbers are important. They mean we can fund research fellowships, provide world-class regional conferences—with some already in the works—and translate our educational materials into other languages to disseminate around the globe, among other important initiatives.

But the volunteer effort tells an equally important story. Dedicated volunteers set up their own online fundraisers on behalf of the VF through Facebook and MobileCause. Patients shared their vasculitis journeys to shed light on the need for better treatments, while others worked hard behind the scenes.

“The 2019 Join Our Journey campaign was a great success,” said Beth Westbrook, VF senior director of outreach. “In addition to raising more revenue than in years past, the campaign reached more people, raising awareness and underlining the need for funding for critical VF programs.

“On behalf of the board, staff, and the volunteers—thank you,” she said. “You made a positive impact on the journey for someone living with vasculitis,” she added. (See related article on p. 11.)

The Time has Arrived! Make Your Nominations for V-RED by March 15

Do you know a medical professional who deserves recognition for making an early vasculitis diagnosis? The deadline for the VF’s 2020 Recognizing Excellence in Diagnostics (V-RED) awards program is almost here. We’re accepting applications until March 15, from patients worldwide who want to nominate a medical professional for making a critical, early diagnosis of vasculitis.

Now in its seventh year, the V-RED program recognizes medical professionals in a broad range of clinical specialties. It also helps spread awareness throughout the medical community, putting vasculitis on the radar of colleagues, patients, and specialty medical associations. Over the past seven years, 270 health care professionals have been nominated by their patients.

Karen Hirsch, past-president of the VF Board of Directors, created the award after her son, Michael, received an early diagnosis of granulomatosis with polyangiitis (GPA, formerly Wegener’s) in 2011 by Juanita Mora, MD, an allergist/immunologist at the Chicago Allergy Center. The early diagnosis was critical and lifesaving in the preservation of Michael’s healthy organs and getting him into remission.

The winners will be announced in May during Vasculitis Awareness Month. For more information on the V-RED award program or to nominate someone, please visit: www.vasculitisfoundation.org/2020-v-red-program/.

Every nominator will receive an awareness T-shirt and every nominee will receive a certificate of appreciation.

Saying Goodbye to Sam Dodge

Over the past six months, many of you met Sam and Helen Dodge as they shared their journey with his diagnosis of microscopic polyangiitis (MPA) in October 2018. You may have read his story in the November-December VF newsletter and/or watched their video on the VF website. Sadly, Sam passed away on Saturday, December 28, surrounded by family, after an ongoing battle with health complications from vasculitis.

Sam and Helen attended the 2019 International Vasculitis Symposium and quickly captured our hearts with their positive attitude toward life and living. Sam joined our Facebook forum and jumped in to offer support and encouragement to other patients battling vasculitis. We have all been touched by their kindness and concern for others in the vasculitis community. Sam marveled at the tenacity of everyone dealing with vasculitis.

We are all saddened by his death and offer our heartfelt condolences to Helen and their sons and family.

You can watch their video and read their story here: bit.ly/2QYRemD.
Podcast Series Offers Insights on What It’s Like to Live with Vasculitis

By Nina Silberstein

Although being diagnosed with vasculitis can feel scary at times, one thing that can help you manage the disease and come to terms with it is talking to other patients. VF Board Member Sara Baird Amodio, MSW, EdD, was diagnosed with eosinophilic granulomatosis with polyangiitis (EGPA, formerly Churg-Strauss syndrome) in 2015. She wanted to reach out to all those affected by the disease through a podcast series titled, “The Ride by Vasculitis Journey.”

The series, which Dr. Amodio started a few months ago, is available through Apple Podcasts and Spotify®. It’s an offshoot of her Facebook site, Vasculitis Journey. Her aim is to do interviews and “field trips” around vasculitis topics. “I’ve done episodes about prednisone, sinus involvement, and most recently, blood draws,” Dr. Amodio explained. “I’ve tried to infuse humor into the podcast, because sometimes you just have to laugh at it all,” she said.

Caregivers and medical professionals can benefit by listening to the podcasts as well. “Vasculitis can be a lonely disease for caregivers, too,” she said.

Dr. Amodio plans to discuss mental health, mobility/neuropathy issues, family members’ reactions to the disease and practical tips for getting infusions. All listenership profits will go to the VF. “You listen, you donate,” she said. “It’s just my little way of giving back.”

VF Webinar: Vasculitis 101 — What You Need to Know!

The VF is presenting a new webinar Thursday, February 27, from 4 to 5 pm EST titled, "Vasculitis 101: What You Need to Know."

In this live, one-hour webinar, Kenneth Warrington, MD, will present an overview about what you need to know about the symptoms, diagnosis, treatment, and management of vasculitis.

Among the topics that will be discussed:
- What are some of the symptoms associated with vasculitis?
- What are the different types and classifications of vasculitis?
- What tests are commonly used to make a diagnosis?
- How is vasculitis treated?
- What strategies are used in the management of vasculitis?

Whether you are newly diagnosed or want to refresh your understanding with the latest information, this webinar will tell you what you need to know so you can make the best decisions about your illness.

To register for the webinar, please visit: bit.ly/2uxTeKJ.

VF Partners with ACR, cont.

Covering a wide variety of large-vessel, medium-vessel and ANCA-related conditions, the guidelines provide recommendations on everything from diagnostic tests such as serology, imaging and biopsy, to remission induction, maintenance therapies, managing refractory disease and surgery.

The manuscripts containing the full list of recommendations and supporting evidence are currently under review and are anticipated to be published by summer of 2020.

“We hope that these recommendations will assist rheumatologists with managing some of the classic systemic vasculitis conditions they may encounter in clinical practice,” said Sharon Chung, MD, lead investigator on the guidelines.

Different forms of vasculitis can have similar symptoms and treatment regimens; however, each disease is distinct. Many vasculitis patients experience a journey of trial and error in finding the right treatment with the fewest side effects.

“VPPRN Presents Study Findings at ACR

The Vasculitis Patient-Powered Research Network (VPPRN) shared its own research findings at the ACR/ARP annual meeting. The study, “Accuracy of Self-Reported Diagnosis of Antineutrophil Cytoplasmic Antibody-Associated Vasculitis (AAV),” was conducted to determine the accuracy of self-reported diagnosis. The data provided by patients in the VPPRN were compared with standard classification criteria for vasculitis, the 1990 ACR annual meeting and/or the 2012 Chapel Hill Consensus Conference. Read the results of the study at bit.ly/2s8tYKc.
Brandon Hudgins Sets His Sights on U.S. Olympic Team Trials in 2020

By Nina Silberstein

Most days, professional distance runner Brandon Hudgins wakes up with a burning desire to reach the goals he’s dreamed of since he was 15 years old. But there have been days when the obstacles seemed insurmountable. At one point, in 2013, he quit running entirely and threw his gear in the trash.

He couldn’t handle the mental toll of another setback, and every time he went through a rough patch, he had to remind himself that he chose his path. No one was making him run.

At 33, Brandon is an accomplished athlete, running coach and author, who was diagnosed with granulomatosis with polyangiitis (GPA) in 2008.

Now he has his sights on the 2020 U.S. Olympic Team Trials for Track & Field, June 19-28, in Eugene, Oregon. Brandon already has a long list of accomplishments to prove that he hasn’t let his illness get in his way.

He’s an ambassador for the VF, founder of the Victory over Vasculitis campaign, made it to the Olympic Trials in 2016, and was named a 2017 NORD® Rare Impact Honoree for his volunteer work in the vasculitis community.

Brandon has had three relapses since his diagnosis; his third and most serious relapse occurred in late 2016 and lasted almost two years. He had 10 Rituxan® infusions, spent nine months on high doses of prednisone and nearly lost his kidneys. With treatment, his kidneys were saved, and in early 2018 with a clean bill of health, he slowly started training hard again.

Following some extensive blood work in 2019, Brandon found out he was battling a rare form of anemia. After getting his iron levels restored, and his body responding to training, he had several good races where he started to feel like his old self. He finished the season with a 4:03 mile against a very good field of professional runners.

Brandon is now in remission and his goal for 2020 is to race the 1500m at the June Olympic Team Trials at the University of Oregon. A normal training week for Brandon is 80-95 miles divided up into 11-12 runs. Four to five days a week he runs twice a day; Saturdays are for a light recovery jog and Sundays are long runs between 15-19 miles. Included are two weightlifting and physical therapy sessions at the gym. Brandon currently coaches in person and online, and works part time at a running store.

“Each year, I try to live a healthier and more balanced life. For 2019, I can certainly say that I achieved that goal,” he said.

Brandon is currently setting up his racing schedule for 2020. He’ll be running a brief indoor track season, which starts in late January, then another one to two races in February before shifting the focus to outdoor track. His outdoor racing starts in April and he will have to qualify at 3:37.50 for 1500m by June 7.

The Olympic Team Trials for Track & Field include three rounds: The first will be three heats of 10 people; 24 will advance to the semi-finals; 12 will make the final and then the top three winners will make the team and represent the United States at the 2020 Summer Olympic Games in Tokyo, Japan, in late July.

The easiest way to support and follow Brandon on his journey to the Olympics is on social media. He does his best to post regularly and enjoys shedding light on what his lifestyle and training are like. “Some of my races are televised or streamed online, and I try to let everyone know when and where they can watch. If I’m in your city, come out and yell!” he said.

“We look forward to cheering Brandon as he chases his Olympic dream,” said Joyce Kullman, executive director of the VF. “Many of us in the vasculitis community have benefited from his optimism, enthusiasm and advice to set dreams and to never give up, no matter what challenges we face.”

Learn More About Brandon Hudgins

As VF ambassador, Brandon is a mentor to other patients with vasculitis, encouraging them to stay active and live life to the fullest. See Brandon and college student Katrina Bargender discuss being active with vasculitis and how they motivate each other at: bit.ly/35LvEan. The video is part of the VF’s Vasculitis Voices series, recorded at the 2019 International Vasculitis Symposium last July.

• Follow Brandon on social media at bit.ly/30cwj3y.
• Learn more about Brandon’s book: “Going the Distance: The Journey of a Vasculitis Patient on the Road to Olympic Glory” at bit.ly/2R7be6q.
• Learn more about Victory Over Vasculitis at bit.ly/37YCkmV.
What Story Does Your Skin Tell?  
New Study to Look at Impact of Skin Involvement in Vasculitis

By Kalen Young, MA

The impact of vasculitis on physical and mental health can be significant. Many patients with vasculitis not only have debilitating pain, but are also dealing with the mental and social ramifications of the disease.

In particular, cutaneous (skin) involvement caused by vasculitis can cause rash and lesions, which can be painful, burning, itchy, and visible to others. The effects on quality of life and well-being can be serious, and are poorly understood by direct care providers.

In fact, the impact of skin involvement on patients with vasculitis has never been studied systematically. Currently, there is no validated patient-reported measurement of disease activity or quality of life effects specifically for vasculitis.

To better understand these impacts, Robert Micheletti, MD, assistant professor of dermatology at the Hospital of the University of Pennsylvania, in partnership with the Vasculitis Patient-Powered Research Network (VPPRN), launched the VascSkin Study in 2019.

Dr. Micheletti and the VPPRN are interested in quantifying the contribution of skin disease to overall disease impact and hope to discover an important area of unmet clinical need and a target for future investigation and intervention. This work may also inform similar efforts in other rare disorders which affect the skin.

The VascSkin Study is a patient-reported quality of life survey for patients with skin involvement. The goal of the VascSkin Study is to help researchers better understand specifically the impact that vasculitis skin disease has on patients. This information will help form the basis for a patient-reported outcome tool measuring response in clinical studies, to help improve the lives of patients.

The VascSkin Study is currently enrolling participants. If you are a patient with vasculitis and have cutaneous manifestations and would like to participate in this study, please contact Kalen Young, director of research affairs for the VPPRN, at: kyoung@vasculitisfoundation.org.

Clinical Study: Safety and Efficacy Study of IFX-1 as Add-on to Standard of Care in Subjects with GPA and MPA

Now Enrolling Patients

Primary Objective:
To investigate the safety and tolerability of two dose regimens of IFX-1 as add-on to standard of care (SOC) in subjects with granulomatosis with polyangiitis (GPA) and microscopic polyangiitis (MPA) compared with placebo.

» Ages Eligible for Study: 18 Years and Older
» Sexes Eligible for Study: All

Inclusion Criteria:
» Diagnosis of GPA or MPA according to the definitions of the Chapel Hill Consensus Conference
» Have at least one “major” item, or at least three other items, or at least two renal items on the Birmingham Vasculitis Activity Score (BVAS) Version 3.0
» New or relapsed GPA or MPA that require treatment with CYC or RTX plus GCs

For the full study description, design, full inclusion and exclusion criteria, and enrolling sites around the United States, please visit: bit.ly/30593Ev.

If you do not have internet access, please contact the VF office for a study flyer: 800.277.9474.
Positive Topline Data Announced from Pivotal Phase III ADVOCATE Trial

On November 25, ChemoCentryx, Inc. and Vifor Fresenius Medical Care Renal Pharma (VFMCRP) announced positive topline data from the pivotal Phase III ADVOCATE trial of avacopan, an orally administered selective complement 5a receptor inhibitor, for the treatment of patients with antineutrophil cytoplasmic antibody-associated vasculitis (ANCA-associated vasculitis, or ANCA vasculitis).

This global study, in which a total of 331 patients with acute ANCA vasculitis were enrolled, met both primary endpoints of clinical remission at weeks 26 and 52 with statistical superiority of avacopan over standard of care (SOC) at 52 weeks.

Subjects who received avacopan experienced additional benefits compared to those in the glucocorticoid SOC control group. These benefits, assessed as pre-specified secondary endpoints, included:

» Significantly reduced glucocorticoid toxicity
» Significantly improved kidney function compared to glucocorticoid-containing SOC
» Improved health-related quality of life measures compared to SOC

A full analysis of the data is underway and expanded results are expected to be announced in the coming weeks.

“These results exceed our expectations,” said Thomas J. Schall, PhD, president and chief executive officer of ChemoCentryx. “Today we mark the dawn of a new and historic period in the lives of ANCA vasculitis patients. This day we have for the first time demonstrated that a highly targeted therapy aimed at the very center of the ANCA disease process is superior to the traditional approach of broad immune suppression therapy; a therapy which the present findings may make obsolete,” he said.

“Until now ANCA vasculitis patients have had to endure regimens that contain chronic high doses of steroids and all their noxious effects, but with today’s data it is clear that the time of making patients sick with steroid therapy in an attempt to make their acute vasculitis better may at last be over. Working with our partner, VFMCRP, we plan to make regulatory submissions for full marketing approval to both the European Medicines Agency and the U.S. Food and Drug Administration in 2020,” he added.

ANCA vasculitis is a systemic disease characterized by inflammation and destruction of small blood vessels, potentially leading to organ damage and failure, with the kidney as the major target.

To read the full press release, please visit: bit.ly/37GhV5V.

My Journey – A Resource for Patients

By Nina Silberstein

When VF Board President Suzanne DePaolis was diagnosed with eosinophilic granulomatosis with polyangiitis (EGPA) in 2007, she had notebooks filled with information about her symptoms and lab tests. It helped her track, for example, that whenever she came off prednisone for her asthma, odd things would happen to the rest of her body.

In 2018, Suzanne had a fever of an unknown origin. “I went back to documenting everything and realized I had started a new medication just before the symptoms began,” she said. “Without having records of the start/stop dates of medications, along with the journal of my symptoms, it might have taken longer to figure this out.”

With the goal of helping others, Suzanne created, “My Journey – A Resource for Patients.” It’s an easy-to-use tool tailored to vasculitis patients for keeping information all in one place for managing their illness. This project was funded by GSK.

Suzanne thought patients would know best what they wanted/needed to document, so drawing from her own experience and talking to others through social media, the journal was born. “I wanted to make it easy,” Suzanne said. “We struggle so much with everything, so making something easy is always a plus.” The journal is also a living document—more pages can be added if enough patients make a request.

Suzanne added that without the help of Beth Westbrook, VF senior director of outreach, the journal would have never happened. “Her belief in my vision and motivation to obtain funding made this project a reality.”

The journal is available for download on the VF website at: bit.ly/2FdSooA.
Dr. Velma Mockett: Turning Pain into Passion and Purpose

By Nina Silberstein

Patients with vasculitis and their families may find it helpful to talk to a counselor or therapist to sort out the variety of feelings that can come with a diagnosis. Some may have a hard time accepting the disease; others may feel anxiety, anger, fear, sadness or even guilt about being sick because of the stress it can put on all those affected.

But when people like mental health expert Velma Mockett, PhD, are diagnosed themselves, who do they turn to? How do they manage and cope with a chronic illness?

Dr. Mockett can look at her situation from both a clinician and patient perspective. She’s been a practicing mental health consultant/specialist for 15 years, counseling patients with anxiety, depression, grief and loss with chronic illness, trauma and addiction. Dr. Mockett also helps companies implement mental health training in the workplace and has presented workshops on a variety of topics. She lives in Calgary, Alberta.

And she is a patient with vasculitis herself. During the nearly five years it took to get a vasculitis diagnosis, Dr. Mockett had multiple medical conditions at the same time. Her symptoms included rashes and bruises on her skin; fever, fatigue and mouth pain. “Nobody could figure out what was wrong,” she said. Her rheumatologist suspected her condition was autoimmune related. After multiple biopsies and visits with other specialists, Dr. Mockett was finally diagnosed with small blood vessel vasculitis in 2015. Treatment for her today includes 10 to 15 different medications, including prednisone and methotrexate, to combat her numerous conditions.

Following her diagnosis, Dr. Mockett felt bogged down with specialist appointments, managing medication/treatment options, controlling her energy, and canceling or postponing other commitments. Combined with work responsibilities, she was too exhausted at the end of the day to think about anything else other than rest.

She wanted to understand the emotions she was feeling, and with the encouragement of a social worker, she began journaling her experience. “Writing gave me the liberty to explore both from the outside and inside when I found it hard to express what I was thinking and feeling,” she said.

Dr. Mockett titled her journal, “Project R: A Loss and Grief Journal for Individuals with Auto-Immune Disease/Chronic Illness.” The R means reset—a reset of her life and her expectations. “But it can also mean renewal, rebirth, revival, re-engage or renew,” she added. “Loss and grief are normal parts of an illness journey that touch all of us who have been impacted by autoimmune/chronic illness,” she said. Dr. Mockett defines her loss as a diminishing of her health, decrease in activities, reduction in capabilities and quality of life.

Dr. Mockett has created a workbook that invites patients to reflect on where they are in their illness journey and express how they’re feeling with questions such as: Are you having trouble accepting the disease? Are you confused, angry and/or fearful about being ill? Do you want your old life back?

Also included is an overview of loss, grief and mourning, common thinking patterns, how to reflect on behaviors, and more. Dr. Mockett hopes that talking about loss and grief will move diseases like vasculitis out of a medical context only and into psychological, spiritual, and social realms—with the possibility for greater meaning and hope.

“The goal isn’t only to listen to your body and mind, or to learn to accept losses and limitations, but also to transform the experience into something livable and bearable. It’s important to learn to accept the loss and integrate it into your life,” she said.

Dr. Velma Mockett: Turning Pain into Passion and Purpose

Calgary Support Group in the Works

Dr. Mockett is working with leading rheumatologist, Dr. Aurore Fifi-Mah, in Calgary to establish a vasculitis support group for patients and their families. The hope is to offer a forum where members can talk about vasculitis and tap into the mental health aspects, access educational resources/materials, participate in research efforts and promote awareness of the disease. Meetings are slated to begin in early 2020.

To obtain a copy of “Project R: A Loss and Grief Journal for Individuals with Auto-Immune Disease/Chronic Illness,” email Dr. Mockett at info@blinkmentalhealth.com.
"This night was not something they had to do but everyone was all in," Sam added. "Not only did we raise the money for the VF but I had multiple questions asked about GPA—not only from my team but people on campus!"

Playing for a Cause: Annual Awareness Night Volleyball Game Raises Funds for the VF

By Nina Silberstein

The University of Wisconsin's Oshkosh Titans Women's Volleyball Team played its annual "Awareness Night" game this past October in support of the VF and Sue Silbernagel, who was diagnosed with granulomatosis with polyangiitis (GPA) in 2008. Sue’s daughter, Sam, is a member of the team.

"The awareness night was so special, not only to my mom and me, but our entire family," Sam said. "The UW-Oshkosh volleyball program is full of some of the most selfless, loving people I know. Having them stand behind my mom and me was a very impactful moment. You could physically see a group of people standing behind us that have our back no matter the difficulty my family will face with my mom's health."

Assistant volleyball coach Braeden Melton worked with the VF to create an online fundraiser on MobileCause, which ran until November 1, and raised $1,075.

"Partnering with the VF this season presented us with a new way to host our Awareness Night because someone on our team was currently being affected by what we were playing for," Braeden said. "In the past that has not been the case, so this season felt personal not only for Sam and her family, but the whole program because we really knew who we were playing for—Sue."

To learn more about Sue's story, watch her compelling video on the VF website: [bit.ly/2FlJmpw](http://bit.ly/2FlJmpw).
Join Our Journey Ends on High Note: We Exceeded Our Campaign Goal!

By Beth Westbrook

Last year was full of happy moments, grateful thanks, sad goodbyes and a few surprises sprinkled in between. When it comes to raising money to facilitate programming, those phrases certainly apply.

As we begin 2020, the numbers are in for our Annual Appeal 2019/Join Our Journey campaign for better treatments, and we couldn’t be more grateful to our generous community. We’re proud to say that 1,155 donors came together to help us raise $272,906 during the three-month campaign—surpassing our goal for Join Our Journey! That’s a 21 percent increase in dollars raised over 2018.

Every year, #GivingTuesday—held the Tuesday after Thanksgiving—coincides with our Annual Appeal campaign. This past #GivingTuesday was catapulted into significantly higher revenue under the leadership of Suzanne DePaolis, chair of the VF’s #GivingTuesday event. Along with Suzanne, seven volunteer ambassadors sent out messages of hope and asked for support. Together, we raised over $61,000, met our Matching Gift Challenge, and set a new record for giving on #GivingTuesday.

Volunteers contributed to Join Our Journey in other ways, too. Many of our patients stepped up and shared their sometimes heart-wrenching vasculitis journeys so that our giving community could understand why better treatments are so critically needed.

During the campaign, we had to say a sad goodbye to two of our friends and volunteers, Meaghan Carpenter and Sam Dodge. Their journeys may have come to an end but their legacies will live on. Both Sam and Meaghan inspired others to live life to the fullest, despite their disease. Our deepest sympathies to both families, and our grateful thanks for all they did to improve the journey for other vasculitis patients.

As a result of your support, we can fund research fellowships, provide world-class regional conferences and offer so many other critical programs. Thank you for your commitment to the vasculitis community.

May 2020 be the year of new discoveries and positive outcomes for all!

Be well,

Beth Westbrook
Senior Director of Outreach

Behcet’s Summit Focuses on Patients

More than 100 patients and family members attended the 2019 Behcet’s Disease Patient Summit, co-hosted by the Vasculitis Foundation and the American Behcet’s Disease Association (ABDA), with sponsorship from Celgene. The event was held November 9 in Atlanta, Georgia, and drew another 100 people participating via livestream.

The half-day summit included educational sessions exploring the experiences of people living with Behcet’s disease. Andrew J. Sulich, MD, Shores Rheumatology, PC, Saint Clair Shores, Michigan, provided an overview of Behcet’s and an overview of Otezla®, which was approved by the FDA in July 2019 for the treatment of oral lesions caused by Behcet’s.

Dr. Sulich was joined by Glenn Parris, MD, rheumatologist, Lawrenceville, Georgia, and Robert Micheletti, MD, assistant professor of dermatology, Hospital of the University of Pennsylvania, for a moderated session, “Physician Perspective: Coordinating Behcet’s Disease Care.”

“Patient Perspective: Living with Behcet’s Disease” featured patients Ashley Pelletier, Alisa Erkes, and Alisa’s husband, Nicholas Kaiser, who discussed coping with Behcet’s. Sarah Schuster, editorial director at The Mighty, an online community for people with health challenges and disabilities, led the final session on journaling.

A video recording of the summit will be available later this year via the VF website.
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VF Calendar of Events • 2020

vasculitisfoundation.org/events/

Thursday, February 27, 2020
VF Webinar: Vasculitis 101 – What You Need To Know
3 pm – 4 pm CST
bit.ly/36NBidz

Friday, February 28, 2020
Rare Disease Day® at NIH
» Sponsored by NCATS & NIH Clinical Center, Natcher Conference Center, Building 45
NIH main campus, Bethesda, Maryland
» 8:30 am – 4:30 pm EST
» Event is free and open to the public
» Live stream will be available
» ncatst.nih.gov/news/events/rdd

Saturday, February 29, 2020
Rare Disease Day (NORD®)
Sponsored by the National Organization for Rare Disorders (NORD). Awareness events take place across the country and globally.
rarediseases.org/rare-disease-day/

Saturday, April 11, 2020
Kansas City Chapter Meeting
University of Kansas (KU) Edwards Campus, Best Building
12600 Quivira Road, Overland Park, Kansas
1 pm – 3 pm CDT
dhale3@kc.rr.com
913-558-4713

Saturday, April 18, 2020
Greater Washington, DC Area Regional Conference
Location to be announced
go.shr.lc/2tbtZh5

May 1 31, 2020
Vasculitis Awareness Month
(Stay tuned for details)

Saturday, August 8, 2020
2020 VF - KU Patient & Family Regional Conference
KU Edwards Campus
Best Building, 12600 Quivira Road, Overland Park, Kansas
go.shr.lc/2tbtZh5