The VF Newsletter has come a long way over the last 20 years. Now, we’re taking it to a whole new level.

We want our bi-monthly newsletter to meet the needs and expectations of our readers. We can only do that through your feedback. Your ideas and suggestions will help us improve this popular publication.

Please take a few minutes to complete our short, online survey. We value your feedback because it tells us what we’re doing right, what we need to change, and how to make it a resource that helps you understand and manage vasculitis.

Click on the link below, take the survey, and help us turn the newsletter into a more powerful, popular resource. Thank you.

Take me to the VF Newsletter Survey
VF Research Committee Paving the Way For a New Generation of Investigators

By Nina Silberstein

The promise of better treatments for vasculitis has special meaning for Jason Springer, MD, MS, chair of the VF Research Committee and member of the Board of Directors. Before he ever started medical training, Dr. Springer’s father was diagnosed with vasculitis, a disease he had never heard of before. Despite treatment, his father passed away six months after his diagnosis.

“I am always amazed to think of the progress that has been made and the future ahead for the treatment of vasculitis,” said Dr. Springer, director of the University of Kansas Vasculitis Center and Assistant Professor in Allergy, Clinical Immunology and Rheumatology at the university’s medical center. “To think that some forms of vasculitis that used to be almost universally fatal are now treatable and can be managed as chronic diseases.”

As the VF prepares to launch its Annual Appeal 2019 on October 1, we conducted a Q&A with Dr. Springer about the challenges with today’s treatments for vasculitis, current
Dear Friends,

Living with vasculitis can be an isolating experience. Take the story of Dedra DeMarco and Devri Velazquez, two vibrant young women who share something in common: They both have Takayasu’s arteritis.

Dedra was diagnosed last December during late pregnancy and underwent an emergency C-section to save her baby and stabilize her own medical condition. Devri was diagnosed during college in 2011—she is a prolific blogger who faces challenges of supporting herself in New York City, due to the ramifications of her disease.

Neither of them knew anyone else with Takayasu’s until they met at the International Vasculitis Symposium July 19-21 in Minneapolis, where they formed a fast bond. “I met so many wonderful, compassionate, and optimistic people who really understood my journey, and that really lifted my spirits to know I’m not alone in this!” said Dedra.

Similar stories of connection played out all weekend long, as more than 300 patients, family members, medical experts and researchers gathered for education, fellowship and entertainment. We thank everyone who helped make this Symposium a resounding success!

On October 1, we launch our Annual Appeal—the second pillar of our Join Our Journey campaign, focusing on better treatments. Progress is being made on the treatment front. The Food and Drug Administration (FDA) recently approved Otezla® (apremilast), for the treatment of adult patients with oral ulcers associated with Behcet’s disease. While this is exciting news, we know we have to work harder to get better treatments for our patients with all types of vasculitis. And research takes funding.

Please help us to support research during our Annual Appeal. Our fundraising web page will be fully launched October 1. Please visit https://bit.ly/2YATHFh to learn more and donate. Thank you!

Sincerely,

Joyce A. Kullman
Executive Director

Mission Statement

Building upon the collective strength of the vasculitis community, the Foundation supports, inspires, and empowers individuals with vasculitis and their families through a wide range of education, research, clinical, and awareness initiatives.

The Vasculitis Foundation is grateful to authors who have shared their personal experiences with vasculitis in the newsletter. These contributions are personal reflections of the writer and do not represent medical scientific statements. VF’s materials are not intended to replace the counsel of a physician.
VF Newsletter Survey Deadline Extended: We Need Your Feedback!

Are you an avid reader of the VF newsletter? Or even an occasional reader? If so, we want your opinion!

More than two decades after our first edition, the newsletter remains an important membership benefit that we continually strive to improve. To that end, we are conducting a readership survey, and we hope you will participate. Visit https://www.research.net/r/VFNL2019. Responses are due October 14.

Your feedback will help us improve our newsletter and ensure that you are getting the information you need and want, in the format you prefer. Thank you!

Retiring Board Member Greg Lesko Recognized for Service to the VF

Greg Lesko and his wife, Lynn, lost their son, Mark, in March 2009 to granulomatosis with polyangiitis (GPA), formerly Wegener’s granulomatosis. Over the years, he and Lynn have hosted informational tables at local health fairs and other venues to raise awareness of GPA, vasculitis and the VF. Greg joined the VF Board of Directors in 2011 to expand efforts to raise awareness of vasculitis on a global basis. Greg served on the VF Support and Education Committee, as well as the Vasculitis Awareness Month committee.

In a touching 2009 video called “Mark Lesko’s Story - Wegener’s Granulomatosis,” Greg talks about his son’s journey with Wegener’s, the importance of early diagnosis, and more. View the video at the following link: https://www.youtube.com/watch?v=l7s6GXVn7Yw.

As Greg’s service on the board comes to an end, we thank him for all of his contributions to the VF and vasculitis community.

New VF Board Member Jacquelyn Eidson Hopes to Advocate for Rural Patients

By Nina Silberstein

Jacquelyn (Jacque) Eidson wanted to serve on the VF Board of Directors because she knows firsthand the impact that vasculitis has on patients, and those who love them. Jacque’s father-in-law was diagnosed with vasculitis nearly 15 years ago and she believes his medical journey was much different from patients who live in larger metropolitan areas.

Jacque’s father-in-law lives in a rural community of about 12,000 people in mid-Missouri. He had been experiencing symptoms for a couple of years, and although the local hospital offered excellent care, he had to travel nearly two hours to larger hospitals on his path to diagnosis. In addition to local care, he is now under the care of the University of Kansas Medical Center. Not long after his vasculitis diagnosis, he was also diagnosed with inclusion-body myositis, a debilitating, inflammatory muscle disease. He is also battling lymphoma for the second time. “Needless to say,” Jacque said, “it has been a difficult 13 years.”

After her father-in-law was diagnosed with vasculitis in 2006, Jacque and her family left Kansas City and moved to their rural hometown to be closer to him, and stayed there until 2018. Jacque served on the board of the local hospital. She has volunteered on local, state and national levels.

Jacque has over 20 years’ experience in business development, compliance and higher education, and holds a master’s in business administration and a bachelor’s in accounting. She has been married for 21 years, has four children, and resides in Kansas City. She is currently finishing her final year of a PhD program in organizational psychology at Grand Canyon University. In addition, she is an adjunct professor of business at Missouri Valley College. Jacque hopes to leverage her business education and background to assist with the financial aspects of the VF.

For patients in small communities, finding a specialist is often a detour to a larger city or university medical center. Jacque says her father-in-law’s arduous journey played a role in her decision to serve on the board. “I feel passionate about providing a voice to those in rural communities,” she says, “and I don't want them to be overlooked.”
Symposium Delivers Education, Camaraderie and Hope

“The Symposium was a wonderful event for me as a recently diagnosed vasculitis patient. We were educated by dedicated physicians, able to share experiences and insights with other patients, and receive hope and support from many people who care.”

—Ilse Deel

These words from Ilse Deel reflect a sentiment echoed by many of the 325 attendees at the 2019 International Vasculitis Symposium, held at the Hyatt Regency in Bloomington, Minnesota, July 19-21.


Our thanks to the following photographers: Kayleigh McKee/Encore, Diane Shaw and Ed Becker.
Sara Baird Amodio, MSW, VF Board of Directors, delivered an inspiring keynote address describing her experience with vasculitis, and how it changed her life.

VF Board President Suzanne DePaolis unveiled the new VF Medical Journal, to help patients track symptoms, medications and doctor appointment summaries.

Peter Merkel, MD, drew a lot of laughter hosting a lively game of Family Feud with Symposium attendees.

Peter Grayson, MD, presented a special plaque recognizing the VF Board service of the late Chris Cox Marinelli, MD, to Chris’s husband, William, and daughter, Kathy. Dr. Grayson also announced a new Young Investigator Award created in memory of Chris.

Allison (Lint) Ross received the 2019 Raising Vasculitis Awareness Star Award from Board Member Karen Hirsch.

Judy Kullman accepted The Caring Family Award Glennon and Arlene Kullman Family from Diane Shaw.

These medical experts were among about 50 distinguished speakers featured at the Symposium.
Support to Fund Critical Research, cont.

next year, is that the VF can play a role in this area, but we need support from the patient community.”

Westbrook said the bar has been raised on this year’s fundraising goal. Last year, Join Our Journey brought in $217,000. She hopes to surpass that amount by 15 percent, which translates into approximately $250,000 from October through December.

This year, the VF is once again using Mobile Cause, an online fundraising platform, so that people can set up their own grassroots Annual Appeal fundraising sites. About a dozen people used it in 2018, and Westbrook hopes a lot more will take advantage of this effective peer-to-peer tool for this year’s campaign.

While fundraising is a central part of any Annual Appeal campaign it’s essential not to lose sight of the bigger picture, said Joyce Kullman, executive director of the VF. “One of the things we hear from patients with vasculitis is the negative impact of treatment like steroid therapy. The side effects can be devastating. That’s why we are supporting research efforts to reduce reliance on such drugs. When you support the VF during Annual Appeal, you are also supporting these initiatives.”

The VF is creating a new Annual Appeal 2019 web page that will have video interviews with patients and doctors about the need for developing better treatments. The web page, which fully launches October 1, has a link to quickly and easily set up an individual Annual Appeal campaign through Mobile Cause.

To learn more, or to support the campaign, please visit: https://bit.ly/2YATHFh.

Q&A: Dr. Springer, cont.

research being done to find better treatment options, and the VF’s role in supporting vasculitis research.

**VF: What is the role of the VF Research Committee?**

**JS:** The purpose of the committee is to promote research that has the potential to improve the quality of life for patients and families, with the ultimate goal of finding the causes and cure for the various forms of vasculitis. We critically evaluate research proposals, seeking expert opinion when necessary and ultimately provide recommendations to the board for grant applications submitted to the VF.

**VF: What is the Research Committee currently focused on?**

**JS:** We recognize the importance of supporting junior investigators in developing a career focused on vasculitis research. New this year will be a “Young Investigator Award” in memory of Dr. Christine Cox-Marinelli. Chris was a strong advocate for promoting the development of junior investigators toward a career in vasculitis. In addition, we hope to further develop the structure of the VF fellowship program, which provides trainees with both clinical and research experience in vasculitis.

“We are in an exciting era with the potential to dramatically improve the quality of our treatments.”

—Dr. Jason Springer

**VF: What does “better treatment” look like for patients?**

**JS:** Multiple studies are under way to look at means to reduce or eliminate glucocorticoids (ie, steroids)—medications that can have numerous unwanted side effects. In the last decade, we have seen FDA approval of multiple pharmaceutical drugs for systemic vasculitis (eg, rituximab, mepolizumab, tocilizumab, apremilast). Approval of these medications has raised the enthusiasm of researchers and pharmaceutical companies to continue to look for new, better treatment options. We are in an exciting era with the potential to dramatically improve the quality of our treatments. This opens a new frontier in which we think beyond the mindset that steroids are a necessary part of the treatment of vasculitis.

Continued on page 7
Q&A: Dr. Springer, cont.

VF: What are the main challenges with treatment today?
JS: Patients still deal with a plethora of medication side effects. Infection remains a major concern with almost all the current medications we use for vasculitis.

Another major challenge is the late diagnosis of some patients. While early signs of the disease can precede the diagnosis by years, the rarity of the diseases means many physicians are not familiar with them. Earlier diagnosis and treatment can help to prevent organ damage.

VF: What are the most important research studies taking place now or coming down the pipeline?
JS: One example is a study the VF helped fund, called, “Diagnostic and Classification Criteria for Vasculitis” or DCVAS. To my knowledge, this is the largest vasculitis study to date. It includes a total of 6,991 patients from 136 sites in 32 countries. One focus of the study is to give physicians better tools to diagnose vasculitis—hopefully leading to a shorter time to diagnosis and initiation of appropriate therapy for the patient.

VF: What are the main challenges for vasculitis research?
JS: These are rare diseases which can make it difficult to get enough participants to complete these studies. However, more vasculitis centers are collaborating, such as the Vasculitis Clinical Research Consortium (VCRC), to increase the number of participants. The Vasculitis Patient-Powered Research Network (VPPRN), a partnership of the VCRC and the VF, also offers a powerful tool to enhance participation in research. Through the VPPRN’s convenient online portal, patients and families can provide researchers a wealth of information through the surveys they complete—without having to live near a vasculitis center.

VF: Do you foresee funding for research getting better?
JS: One of the challenges for investigators is that there are few funding opportunities for vasculitis research. This can be especially challenging for junior investigators who have a lot of potential, but have a difficult time competing with more senior investigators for funding. The VF research grants serve an important role in providing the support vasculitis researchers need to get a project off the ground.

VF: What would the VF Research Committee do with a $5 million endowment?
JS: Wow! For one, we could develop different funding structures based on the level of the researcher. For instance, there are more established vasculitis researchers who have gathered a large amount of preliminary data and need more substantial funding. These projects can lead to breakthroughs.

In addition, it’s important to continue to support new vasculitis fellowships. The vasculitis fellowship has been a good investment for the VF, as these fellows go on to be good clinical vasculitis specialists, and many times open vasculitis centers and continue their vasculitis research throughout their career. I also feel it would be important to provide continued support for the VPPRN.

VF: What can the vasculitis community do to help?
JS: The vasculitis community has been so generous with their donations for vasculitis research that we have reached several milestones, including funding our 50th research study. I would like to see this reach 100. Patient and family participation in research studies, such as offered through the VPPRN, is also critical.

To learn more about research opportunities, patients can visit www.vasculitisfoundation.org/research/vpprn/.

VF: Is there anything else you’d like to say about the VF?
JS: I have been on the board for four years now. It has been my privilege to see the VF, and the VF-supported research, grow during that time. Our research committee receives excellent grant applications from all over the world, many with the potential to make a significant impact on the lives of vasculitis patients. We are one of the largest private funders of vasculitis research.

I believe the vasculitis research community views the VF as a leader in research support, and we should continue to work toward our goal of finding the causes and cures for these devastating diseases.

“Our research committee receives grant applications from all over the world, many with the potential to make a significant impact on the lives of vasculitis patients.”

—Dr. Jason Springer
FDA Approves Otezla® for the Treatment of Oral Ulcers in Behcet’s Disease

Celgene Corporation announced on July 19 that the U.S. Food and Drug Administration (FDA) has approved Otezla® (apremilast) 30 mg twice daily (BID) for the treatment of adult patients with oral ulcers associated with Behcet’s disease. Otezla, an oral, selective inhibitor of phosphodiesterase 4 (PDE4), is the first and only approved treatment option for oral ulcers associated with Behcet’s disease, a rare, chronic, multisystem inflammatory disease that is difficult to treat.

“Oral ulcers are a recurring and debilitating manifestation that affects nearly everyone living with Behcet’s disease, and have an important negative impact on the quality of life for these patients,” said Yusuf Yazici, MD, clinical associate professor, Department of Medicine, New York University Langone Health. “In the clinical trial, Otezla demonstrated improvements in measures of oral ulcers at week 12. Otezla has the potential to be a needed treatment option for U.S. patients and their physicians, who previously had limited options available.”

Behcet’s disease, also known as Behcet’s syndrome, affects approximately 5 in 100,000 people in the U.S. Oral ulcers, the most common manifestation of Behcet’s Disease occurring in more than 98 percent of patients, can be painful, disabling and negatively affect quality of life.

“We are excited to provide the first and only FDA-approved treatment for oral ulcers associated with Behcet’s disease,” said Terrie Curran, president, Celgene Inflammation & Immunology. “This approval is a reflection of Celgene’s commitment to research in areas of high unmet need, including rare diseases such as Behcet’s disease. We remain dedicated to further studying Otezla and its role in inflammatory conditions.”

To read the full press release, please visit: https://bit.ly/2Mhl6cX.

Support the Vasculitis Foundation through Your United Way Campaign

More than a donation. It’s an investment.
Your United Way donation is an investment in the VF. It helps us to fulfill our mission of providing patient education and support throughout the world.

It’s also a way to help the VF with funding more research so that we can develop new diagnostic tools, less invasive treatments, and possibly a cure for the disease.

It’s simple to designate the Vasculitis Foundation as your recipient for United Way funds.

If your agency is not listed, simply complete the appropriate form (provided by your employer or local United Way) with the following information:

- Vasculitis Foundation
- www.VasculitisFoundation.org
- PO Box 28660, Kansas City, MO 64188
- 1.816.436.8211 or 1.800.277.9474
- EIN #: 43-1492959

Visit the VF United Way web page to learn more about how your donation advance the support of patients and research: https://bit.ly/33wkczw.
Support Groups, Family Help Ease Long Journey with Rare Urticarial Vasculitis

By Nina Silberstein

For Richard Kujawa, attending the 2019 International Vasculitis Symposium in Bloomington, Minnesota, during July was a chance to learn more about urticarial vasculitis, the rare disease he was diagnosed with in recent years. But he got something else he wasn’t expecting: a connection with someone who has the same disease.

Richard, 72, was sitting in a classroom at his first-ever vasculitis symposium when another attendee tapped him on the shoulder and said to him, “We got the same stuff.”

Urticarial vasculitis is among the rarest forms of vasculitis that primarily affects the small blood vessels of the skin, causing red patches, hives, and skin discoloration. The two started talking and discovered they had things in common besides urticarial vasculitis. “She’s Polish, as I am. She likes pierogis, which I do,” he said, with a laugh.

For many people attending Symposium, it can be powerful to hear the experiences of others and make connections with people who can relate to their medical condition.

Richard’s road to a diagnosis took many years, starting in 2012 at the Mayo Clinic in Minnesota. “My first indication was red, itchy spots all over my body,” Richard explained. “They took pictures. I was a Dalmatian with red spots.”

Richard was prescribed a variety of drugs but nothing seemed to work. “Having one of the oddball versions of vasculitis probably makes things more difficult,” he said.

In 2013, Richard had his right hip replaced and developed an infection, for which he was treated. Then came a two-year remission. “I didn’t have any problems of vasculitis at all. Then it started back up again,” he said.

Richard was formally diagnosed with urticarial vasculitis in the last couple of years. Currently, he is taking prednisone and methotrexate, both of which address inflammation. When he has a flare-up, he has red bumps, spots and lumps all over his body.

“Depending on how bad it is, the doctor will bump up the prednisone dosage so it usually takes a week for it to go away,” he said. But in the meantime, he’s itching and scratching and it’s very uncomfortable.

Fortunately, the only side effects that he notices from the medications are fatigue and wanting to nap. “I've heard a lot of complaints about prednisone but it seems to work the opposite for me," he said. His doctor postponed starting him on the biologic drug Rituxan® because of a second hip replacement he had in March.

Richard is grateful for the support of his family, especially his wife of 37 years, Peri. They live in Andover, Minnesota, and have two grown children, 48 and 34. He is retired from working in the IT field.

“The many appointments to try and figure out a cure/remission have been made somewhat easier for me by my wife,” he said.

Richard thanks the internet for helping him find a vasculitis support group, which put him in touch with another support group at the University of Minnesota. There’s comfort in knowing that there are places where others understand your diagnosis, have the same concerns and know what it’s like to live with the same rare disease.

His hope for the future: "I guess the one thing that bothers me the most is they tell me there’s no cure. So, OK, now what? I’d like them to find a cure," he said. "Obviously, that’s not going to happen overnight. Maybe sometime in the next 10 years. I hope they don’t give up.”

“I’d like them to find a cure. Obviously, that’s not going to happen overnight. I hope they don’t give up.”

—Richard Kujawa
VF Launches Annual Appeal Campaign: Help Us Support Vasculitis Research

By Beth Westbrook

The VF Annual Appeal 2019 fundraiser is upon us. Starting October 1, as we launch the second pillar of the Join Our Journey campaign—Better Treatments, our board of directors, staff and volunteers will be raising money to deliver on an important part of our mission—funding research.

Ever-present in our minds and our hearts is the need to help people living with vasculitis. It is not enough to hope someone else will give; it is important to look within ourselves to see how we can help.

I am often asked why I became a fundraiser. I certainly didn’t seek out this career. After my daughter, Katie, died from cancer, I was offered a job fundraising for a children’s hospital. At the time, I was a middle school teacher. “The only thing I know about fundraising is selling candy bars and wrapping paper,” I told the woman interviewing me. She reassured me they could teach me the mechanics of fundraising, but I had the one quality no one can teach you—the passion to make life better!

She was right. When I told my story and asked people to help make life better, I was able to raise money for research. Over time, it got easier to ask friends and family to help. I knew I was not asking people to help me, I was asking them to help people I cared about.

Thanks to research studies, there have been beneficial gains in vasculitis treatment in recent years, and there are promising, new treatments on the horizon. The challenge is getting there. It will take more than hope to achieve the goal of better treatments; it takes money to fund research.

And here is a fundraising secret: When many people give modest donations, the result is higher, more sustainable funding for the long haul. When an organization relies on a few donors giving larger amounts, the weight of the mission rests on the shoulders of a few people.

Please consider joining our journey this year! In addition to the focus on better treatments, the VF will begin planning for a summit of stakeholders to discuss the challenges and barriers to research for the rarest forms of vasculitis.

Along with my passion for helping others, I carry a deep love of baseball. One of my heroes is Roberto Clemente. I had the pleasure of working for the Pittsburgh Pirates at their Spring Training facilities in Florida. Every day when players go out to the practice field, they walk under a famous Clemente quote. I leave you with his words and our deepest gratitude for your support of the vasculitis community:

“Any time you have an opportunity to make a difference in this world and you don’t, then you are wasting your time on Earth.”

Please visit our fundraising web page, which will be fully launched October 1, at https://bit.ly/2YATHFh.

Thank you for joining our journey.

Beth

Victory Over Vasculitis Campaign Renewed with New Focus, Logo

In 2016, the VF created a new campaign called, “Victory Over Vasculitis.” It was championed by professional runner, Brandon Hudgins, whose inspiring story of making it to the 2016 Olympic Trials despite his vasculitis encouraged other patients to pursue their own goals. Three years later, the Victory Over Vasculitis campaign has been given a reboot, and a new Victory Over Vasculitis logo has been created.

“Although I didn’t make the Olympic team, the campaign charged people up to go after their own goals,” said Brandon. “We decided to do a reset to get more people involved. It’s not as much about my own goals, but helping patients define their own victory, and to achieve it.”

Brandon will also be raising awareness about vasculitis through his interviews, and weekly Facebook Live broadcasts. You can join the Victory Over Vasculitis Facebook Group at: https://bit.ly/2DU2Yjn.
Positivity, Perseverance Inspires Other Young Adults in Vasculitis Community

By Ben Wilson

This summer’s International Vasculitis Symposium in Bloomington, Minnesota, marked another successful gathering of young adults and continued the growth of our community. While it was great to see old friends again, I was reminded of how this disease continues to impact new people every year, and how scary and daunting it can feel as a patient in those first few months after diagnosis.

That’s why I wanted to share the story of Jenna Curl in this edition’s young adult patient profile. Jenna is one of the newest members of our community after being diagnosed with Takayasu’s arteritis this April, but her positive attitude and determination to fight back against the disease has been incredibly inspiring.

There’s certainly no good time to be diagnosed with vasculitis, but you could make a pretty compelling case that your senior year in high school is the absolute worst time for it. This is what happened to Jenna, an 18-year-old from the Tampa, Florida, area who developed high blood pressure and shortness of breath for two years leading up to her diagnosis. She was a standout cheerleader at her high school—a four-year member of the varsity squad, in fact—but said her diagnosis took a toll on her, both physically and emotionally.

She couldn’t go back to school after being diagnosed and starting treatment, and even had to give up her top college choices because her doctors wanted her to stay close to home for school. It meant big universities like Alabama or Florida State that Jenna had dreamed of were now out of the question. But Jenna refused to give in to her disease, and instead developed an outlook that many teenagers—or even adults—might struggle to embrace.

Shortly after her diagnosis, Jenna enrolled at Florida Gulf Coast University, located about two hours from home. “I was upset at first, but at the same time I knew it was the best decision for me,” she said.

Not only did she find a school that fit with her doctor’s requests, but also realized she had a growing passion for medicine and the desire to help others. “Being diagnosed has made me want to help other people,” Jenna said. “Getting a different outlook as a patient really changed things for me.”

While most people would focus on themselves and their own struggles, Jenna went the other way, instead working to educate herself so that she can have an impact on patients in the future. It all comes back to her mentality, which she plans to carry into her college journey.

“For me, I just get up and don’t let it beat me down,” she explained. “I know I’m going to have that same mindset in college and be an advocate for myself.” Fortunately, Jenna’s health status is showing improvement as she gets ready for her freshman year. Tests this summer showed her overall inflammation has gone down, and she is excited to be on her own and experience college life.

For all of us who know what it’s like to deal with the pain of our disease and the subsequent treatment it requires, it’s impossible not to admire Jenna and the path she has taken over the past few months.

Jenna’s end-goal is not just to overcome her disease, but to become a nurse practitioner and have the same sort of impact as her mom, who also works in the medical field. This type of thinking and perseverance is what gives people hope, and it’s why we’re proud to include Jenna in our family of young adults fighting against this disease as one collective group.

Ben Wilson is a sports broadcaster and works with the VF’s young adult patient community.

“Being diagnosed has made me want to help other people. Getting a different outlook as a patient really changed things for me.”

~ Jenna Curl
The Keesha Vessell Walk: Raising Awareness One Step at a Time

By Nina Silberstein

When someone close to us passes away, it’s natural to want to find distractions to get through the pain and loss. For people like Diann Alford and her family, though, it’s not the pain and suffering they focus on. Their goal has been to raise awareness of vasculitis by honoring their loved one’s wishes.

Diann’s oldest daughter, Keesha Vessell, was diagnosed with granulomatosis with polyangiitis (GPA, formerly Wegener’s) in August 2005. It’s a rare disease and type of vasculitis that affects many different organs and systems of the body. It primarily attacks the respiratory system (sinuses, nose, windpipe, lungs) and the kidneys, and one of the main characteristics of the disease is an inflammation of the blood vessels. Keesha managed to survive a medically induced coma, a myriad of tests and medications, a feeding tube and ventilator-assisted breathing for five months before her death in January 2006.

Diann and her three other daughters decided to create a walk to honor Keesha’s wishes: “All I want to do when I get better is give glory to God and make people aware of this disease.” Thus, the Keesha Vessell Vasculitis Walk was born. This year’s walk is Saturday, September 21. See additional details in the Events Calendar on page 16.

Since 2006, the walk has been held at Veteran’s Memorial Park in Newnan, Georgia, in September—Keesha’s birth month. “The whole family participates each year,” Diann said. “Newnan is small enough that most people know where the Veteran’s Park is and it can easily be found by others.” The 2-mile walk through town gave them the safest route with the most visibility. To date, the walk has raised about $33,000. Sixty-seven people participated the first year and it has grown to as many as 119 walkers. The average is around 90 to 110 participants. “The first year our 2-mile walk wound up being 5 miles,” Diann said. “Not really sure how I measured so badly but I took a lot of kidding about that and still do. Makes for a good laugh and we got a great workout!”

For Diann, the best feeling about organizing this event has been the kind words she has received from people over the years who have loved ones with vasculitis, or those who have vasculitis themselves. Their words encourage her. “It’s so hard each year emotionally to gear up for it,” she said. “I pray for strength to do it again. And so much thanks to all who send money, who walk, who encourage. It would not happen without those people.”
The Vasculitis Clinical Research Consortium (VCRC) is the major clinical research infrastructure in North America dedicated to the study of vasculitis. The VCRC has grown to include 18 academic medical centers in the United States and Canada conducting investigator-initiated clinical and translational research. The VCRC also partners with 50 other centers worldwide for the conduct of clinical trials.

The VCRC conducts observational cohort studies, biomarker development, studies of genetics and genomics, clinical outcomes research, studies using an online patient registry, pilot clinical projects, and multicentered, randomized clinical trials. Core components of the VCRC include the VCRC Clinical Data Repository, the VCRC Biospecimen Repository, the RDCRN VCRC Patient Contact Registry, the VCRC-NIH Data and Safety Monitoring Board.

Join the VCRC Contact Registry!

Research offers no guarantees, but research cannot move forward without your help. Every active role a patient takes may play a part in discovering new groundbreaking research and finding new treatments.

**Participating Institutions:**

- Boston University School of Medicine Vasculitis Center
- Cedars-Sinai Medical Center (United States)
- The Cleveland Clinic
- Hospital for Special Surgery Vasculitis & Scleroderma Center
- Istanbul University
- The Mayo Clinic College of Medicine
- Mount Sinai Hospital
- Northwell Health
- Oregon Health & Science University
- St. Joseph’s Healthcare, Hamilton
- University of California, Los Angeles Health
- University of California, San Francisco
- University of Kansas Medical Center
- University of Michigan
- University of Pennsylvania
- University of Pittsburgh
- University of Utah

Please visit the VCRC website to join the registry and to review the complete list of all current research studies available for patients to participate in. [www.rarediseasesnetwork.org/cms/vcrc/](http://www.rarediseasesnetwork.org/cms/vcrc/)

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**IN MEMORIAM**

Thank you to all those who made donations to the VF in memory of a loved one.

Ruth Arch
George Barker
Edward Harold Bennett
Ryan Bunck
Shane Burke
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Saturday, September 21, 2019
14th Annual Celebrating A Life: Keesha Vessell Vasculitis Walk
- Newnan City Veteran’s Park, 38 Jackson St., Newnan, Georgia
- Registration starts at 8 a.m., welcome at 8:30 a.m., and walk starts at 8:45 a.m.
- Contact Diann Alford at diannrip12@aol.com

Thursday, October 24, 2019
Brett Hack Vasculitis Charities 2019 Fundraiser
- Chart House Restaurant, 11287 Klamath Trail, Lakeville, Minnesota
- 6 - 10 p.m.
- There will be appetizers, live entertainment, and a silent auction. Tickets are $30 per person.
- Register by October 1, 2019
- www.bhvcharities.org

Sunday, October 27, 2019
Vasculitis Foundation Canada 2019 Annual Fall Lectures
- Toronto Western Hospital, Toronto, Ontario, Canada
- Guest speaker is Dr. Peter Merkel, Chief, Division of Rheumatology, Professor of Medicine, at the University of Pennsylvania. Other speakers to be announced.
- Visit www.vasculitis.ca for updates.

Saturday, November 9, 2019
Behcet’s Disease Patient Summit
- Renaissance Atlanta Midtown Hotel, Atlanta, Georgia
- 9 a.m. - 12:30 p.m. (breakfast and lunch to be provided)
- Free of charge
- Live stream will be available.
- To receive updates, please email behcet’s@dna-comms.com.

Saturday, November 16, 2019
North Carolina Vasculitis Support Group Meeting
- University of North Carolina Wellness Center at Meadowmont, 100 Sprunt St., Chapel Hill, North Carolina
- 10 a.m. - 2 p.m. (includes lunch)
- Contact Brandon Hudgins at bdhudg@gmail.com