

## **FOR IMMEDIATE RELEASE**

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VF Power Pedal Ride for Rare Diseases Web Site: <http://www.vasculitisfoundation.org/vfpowerpedal>

## **CYCLISTS TO RIDE FROM PITTSBURGH, PA TO WASHINGTON, DC TO CALL ATTENTION TO VASCULITIS AND OTHER RARE DISEASES**

*Riders to deliver letter signed by hundreds to U. S. Congress*

Fourteen bicyclists will leave Pittsburgh on June 24 for a six-day ride to Washington, DC to raise awareness and encourage research for all types of vasculitis and other rare diseases.

The event, the “**VF Power Pedal Ride for Rare Diseases**,” is sponsored by the Vasculitis Foundation. The team members are men and women from Pennsylvania, Ohio and Missouri.

The group will begin its 325-mile trip at Point State Park in downtown Pittsburgh, and follow the Great Allegheny Passage Rail Trail and the C & O Canal Trail, stopping in five towns along the way.

Upon reaching Washington, the team will pedal the length of the National Mall to the steps of the U.S. Capitol, where they will deliver a letter signed by hundreds of rare disease patients, caregivers and medical professionals to a congressional representative on the U.S. Capitol steps.

Team leaders are Joyce Kullman, Executive Director of the Vasculitis Foundation; Ed Becker, Director of the Polyarteritis Nodosa Research and Support Network; and Heather Nagy of the National Adrenal Diseases Foundation. All belong to the Coalition of Patient Advocacy Groups funded by the National Institutes of Health’s Office of Rare Diseases Research. The ORDR coordinates research into rare diseases and disorders.

“By taking part in this initiative, I am hoping to bring attention to the Vasculitis Foundation,” says Ms. Kullman. “Our organization serves thousands of patients who have one of the 15 vasculitic diseases. However, it’s equally important to have legislators understand that the rare disease community is a huge demographic.”

“By definition, a rare or ‘orphan’ disease affects fewer than 200,000 people in the United States,” explains Heather Nagy. “While it may appear that not enough people would benefit from research as to make it cost effective, the numbers tell a different story. There are more than 6,000 rare disorders, and they affect the daily lives of 25 million Americans.” Research into rare disorders often leads to cures for more common diseases. For example, statins, which have lowered the incidence of heart disease around the globe, came about because of a tiny study into a rare disorder.

Ed Becker, one of the event coordinators, notes, “There is a real need to support rare disease patient advocacy groups, and this seemed like a natural extension of taking a message to Washington DC.

Those of us on the team are fortunate that we are healthy enough to do this ride on behalf of all the people who cannot because of their illness.”

The VF Power Pedal Team is accepting sponsorships from individuals or groups. All donations will support education and awareness of the patient and medical community about vasculitis and other rare diseases. Supporters should go to <http://www.vasculitisfoundation.org/vfpowerpedal>.

A link on this page will allow rare disease patients, caregivers, and medical specialists to leave a message that will be delivered to Washington via the Power Pedal Biking Team.

“We’re the messengers,” says Kullman. “However, we’re asking rare disease patients to be ‘the voice’. We will put many of these comments into a letter that will be hand-delivered to the US Capitol. This bike trip is all about the power of the individual connecting with the powerful lawmakers in Washington DC.”

## **FACTS ABOUT VASCULITIS AND THE VF POWER PEDAL RIDE FOR RARE DISEASES**

Vasculitis is an inflammation of the blood vessels, arteries, veins or capillaries. When such inflammation occurs, it causes changes in the walls of blood vessels, such as weakening and narrowing that can progress to the point of blood vessel blockage.

A critical key to continuing rare disease research is the Office of Rare Diseases Research (ORDR), which operates with a very limited yearly budget of 16 million dollars. The Vasculitis Foundation and the VF Power Team believe that it is critical to let senators and representatives know that funding must be increased. This ride provides its participants with a very visible way to accomplish that.

Members of the public wishing to sponsor the VF Power Team and submit a message for delivery by the team are invited to visit the event web page at <http://www.vasculitisfoundation.org/vfpowerpedal>.

### **Organizations supporting the VF Power Pedal Ride for Rare Diseases include:**

- National Urea Cycle Disorders Foundation
- Platelet Disorder Support Association
- National Adrenal Diseases Foundation
- National Institutes of Health Office of Rare Diseases Research
- The Polyarteritis Nodosa Research and Support Network
- Aplastic Anemia & MDS International Foundation
- CARES Foundation, Inc.
- Children's Liver Association for Support Services
- National Organization for Rare Disorders
- Churg Strauss Syndrome Association
- Vasculitis Foundation

The web page also features a blog on which members of the biking team share how they are preparing for the event and why the cause is important to them. It will also allow visitors to follow the riders while they are en route to Washington. Visit the blog at: <http://vfpowerpedal.blogspot.com/>

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