

Epilepsy Foundation of Western/Central PA Seeks Legal Protection of its Assets from Epilepsy Foundation of America

July 31, 2018, Pittsburgh, PA - The Epilepsy Foundation Western/Central Pennsylvania, a former affiliate of the Epilepsy Foundation of America, filed a proceeding today in the Court of Common Pleas, Allegheny County, Pennsylvania, Orphans Court to seek protection of its charitable assets and obtain court clarification that funds raised in Pennsylvania for local epilepsy programs should be used to service Pennsylvanians.

At question is a fund balance of about \$5.6 million, all of which was raised in western and central Pennsylvania to provide and sustain local services in western and central Pennsylvania for individuals and families coping with epilepsy and seizure disorders.

“We are seeking this legal protection in order to remain a viable resource to the thousands of local individuals and families who rely on us for real-time, daily assistance,” said the former affiliate’s President and CEO, Peggy Beem Jelley.

The action is one step in the Epilepsy Foundation Western/Central Pennsylvania disaffiliation process from the Epilepsy Foundation of America (EFA).

Earlier this year, the EFA demanded that the former affiliate sign a new affiliation agreement. At its May meeting, the Epilepsy Foundation Western/Central Pennsylvania Board of Directors voted to decline signing the agreement. The Board determined that the new EFA agreement shifts its mission and agenda from the traditional emphasis on local services and personalized support to one that prioritizes research, fundraising for research, and public awareness related to research.

“While our organization certainly sees value in research, the EFA mission no longer aligns with the mission and vision of our local organization. The new national agreement shifts the EFA focus from providing support to affiliates to one of receiving support from affiliates. The Board felt that the new agreement would limit the Epilepsy Foundation Western/Central Pennsylvania’s ability to continue providing real-time, local programs that help people who are living with seizures today,” Beem Jelley said.

“Our organization has been recognized by the EFA as meeting national Standards of Excellence for years and we are unwilling to change that level of service. Our local mission is more personalized, more day-to-day, and more focused on the quality of life for people living with seizures today.”

In response to the Epilepsy Foundation Western/Central Pennsylvania’s May decision to not sign the agreement, EFA Board Chair Bob Smith and EFA CEO Phil Gattone sent an email in late June declaring that (1) the Epilepsy Foundation Western/Central PA is disaffiliated from the EFA; and (2) demanding that the Epilepsy Foundation Western/Central PA stop using the EFA brand.

“There will not be a disruption in our services at all,” Beem Jelley said. “We’ll have all the same great programs helping people on a daily basis, the same quality staff available in local communities, and the same passionate and dedicated board of directors. We will update our look and renew our commitment to improve the quality of life for those living with epilepsy through local services, neighborhood programs, and personalized support.”

Beem Jelley added that eight more groups around the country are also disaffiliating with the EFA because of the same circumstances: Cincinnati/Columbus (Ohio), Florida, Louisiana, New Jersey, North Carolina, Puerto Rico, Rochester (New York), and San Diego (California).

As for the legal petition to protect Pennsylvania funds, Beem Jelley explains that “The EFA can simply agree with the petition or they will come to Pittsburgh to argue otherwise.”

Epilepsy Foundation Western/Central Pennsylvania Background

About the Epilepsy Foundation Western/Central PA - EFA Working Relationship

- The former Epilepsy Foundation Western/Central Pennsylvania is a 501 C3 organization that has operated independently of the EFA since its inception 46 years ago.
- The EFA has never contributed to our operational budgets in a significant way.
- The Epilepsy Foundation Western/Central PA has never shared its donor information or donations with the EFA.
- Our local organization has a professional advisory committee, which consists of nationally recognized medical experts who advise and guide our board and staff.
- Funds raised by our local organization have always fueled local services here in western/central Pennsylvania that serve our neighbors, families, and friends affected by epilepsy.

Real-Time Services

- We provide highly customized help to individuals and their families, such as emergency medication assistance, summer and weekend camp programs, sleep monitors, seizure response dogs/service animals, respite services for caregivers, referral services, education advocacy in the schools, and employer education.
- We educate and train school nurses, teachers, bus drivers, and fellow students in western and central PA to ensure that children who have seizures have a safe learning environment, where people around them know how to respond to someone having a seizure.
- We work with the PA Department of Health to provide accredited training for first responders.

What Disaffiliation Means to Our Western and Central PA Constituents

- Families and individuals who benefit from the Epilepsy Foundation Western/Central Pennsylvania services will see NO CHANGE to the level of care and support they rely on.
- Behind the new look and feel of our materials are the SAME people, SAME great programs, and SAME high level of services.

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