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THE NATIONAL PKU ALLIANCE EXPANDS LEADERSHIP AND NAMES CHRISTINE BROWN AS EXECUTIVE DIRECTOR

Experienced Leader Brings 15 Years of Nonprofit Expertise to National Organization

SPRINGFIELD, VA – April 7, 2009 – The National PKU Alliance (NPKUA), the only national organization dedicated to supporting those affected by the genetic disorder phenylketonuria (PKU), today announced that it has selected Christine Brown to be its first Executive Director. Brown brings extensive experience in nonprofit management, program development, fundraising and advocacy relations to the role.

As the NPKUA continues to grow, Brown will work directly with the Board of Directors and organization volunteers to advance the NPKUA mission and to ensure that the PKU community has a strong national voice. One of Brown's key priorities will be to encourage additional local organizations to take advantage of the benefits of membership. In the next few months, Brown will lead a membership drive and encourage alliance groups to share best practices in areas such as fundraising, advocacy and education.

"As the only national coalition of local and regional organizations serving the PKU community, we needed an experienced nonprofit professional who could further advance our ambitious plans," said NPKUA President Dick Michaux. "Brown has a very successful history of working with healthcare coalitions in tobacco control. As a result, we feel this makes her an ideal choice to move the organization forward."

"I am very excited and honored to be chosen as the first Executive Director of the National PKU Alliance," Brown said. "After spending the past 15 years building and leading nonprofit organizations, I look forward to doing so for the NPKUA. As a mother of two children with PKU, I am passionate about creating awareness for the cause and furthering the NPKUA's mission." Before joining the NPKUA as Executive Director, Brown also provided her expertise to the organization as a volunteer.

One of Brown's key initiatives will be to help the NPKUA take additional steps to further PKU research and treatment. Brown will facilitate the creation of a Board of Scientific Advisors, consisting of scientific and research experts, to identify and evaluate promising PKU research. She also will manage a campaign to improve insurance coverage for PKU monitoring and medically necessary foods. Because children and adults with PKU depend on highly specialized diets featuring costly prepared food and protein replacements, the NPKUA will work to help families get assistance in paying for these foods.

Most recently, Brown served as Executive Director at the Tomahawk Regional Chamber of Commerce in Tomahawk, WI, where she was responsible for economic development, community relations, tourism and organizing events. Previously, she was Director of the Coalition for a Tobacco Free Vermont. Other positions have included Executive Director at Umbrella Inc., a women's resource center in Vermont, and Coordinator at the Anne Arundel County Domestic Violence Coordinating Council in Maryland.

About PKU

PKU, or phenylketonuria (pronounced *fen-il-Key-to-New-ree-uh*) is a lifelong genetic disorder in which a deficient enzyme prevents the body from metabolizing an essential amino acid, called Phenylalanine (Phe), which is found in most foods, including meat, bread, eggs, dairy, nuts and some fruits and vegetables. When left untreated, PKU patients who consume too much Phe are at risk for severe neurological complications, including IQ loss, memory loss, concentration problems, mood disorders, and in some cases, severe mental retardation. PKU affects approximately 13,000 people in the U.S. and 50,000 people worldwide. Patients must adhere to a Phe restricted diet which may be supplemented with low protein foods and medication.

About the National PKU Alliance

Established in 2008, the National PKU Alliance is a coalition of the many local, state and regional organizations that support PKU families. The National PKU Alliance is dedicated to improving the lives of individuals and families affected by PKU, through research, education, support and advocacy, while ultimately seeking a cure. Visit www.npkua.org to learn more.

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