

Virginia Advocacy Group Joins Global Coalition to Shine Light on Life-Altering Disease Striking Young People

VA4PA brings visibility to devastating illness through the illumination of seven iconic structures across Virginia on World PANS/PANDAS Awareness Day

ARLINGTON, VA, UNITED STATES, October 9, 2024 /EINPresswire.com/ -- The Virginia Alliance for

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*Daniela Sosa-Sarkar, PhD,
VA4PA founding member*

[PANS/PANDAS](#) Action ([VA4PA](#)) announced today that it is joining a coalition of 14 advocacy groups around the world to put a spotlight on PANS/PANDAS, a little-known but devastating illness that strikes young people after common infections. This groundbreaking initiative, Light Up 4 PANS, includes the illumination of seven iconic structures throughout the Commonwealth of Virginia on October 9, World PANS/PANDAS Awareness Day.

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) are serious, life-altering conditions that affect young people

globally, causing sudden and debilitating changes in behavior, mood, and neurological function. The onset is triggered by infections such as strep throat and the flu.

Despite its prevalence, estimated to be between 1/2,000 and 1/11,000 people, families typically struggle to find appropriate medical help and even to get a diagnosis. The problem is due to a lack of awareness and understanding among healthcare professionals and the public.

“PANS/PANDAS is a devastating illness that literally robs young people of their lives,” says Daniela Sosa-Sarkar, founding member of VA4PA, clinical psychologist, and mother to a child with PANS/PANDAS. “Early treatment is critical to avoid permanent damage. Unaddressed, the illness can even cause death. That's why it's so essential for us to urgently raise awareness among the medical community and public in general.”

Spearheaded by the Canada-based Inflamed Brain Alliance, the global initiative will bring light to the illness through the illumination of landmarks, buildings, and homes in red or green lights.

The colors reflect the battle against brain inflammation (red) and hope (green) for the young people and families impacted by PANS and PANDAS. (See a full list of structures being illuminated here; <https://inflamedbrain.org/wp-content/uploads/sites/261/2024/09/2024-LightUp4PANS-approvals-2024-09-25.pdf>.)

The coalition encompasses non-profit organizations and advocacy groups hailing from Canada, Italy, UK, US, Peru, and Poland. Among the organizations are Associazione Genitori PANS PANDAS BGE ODV, ASPIRE, Look. Foundation, Inflamed Brain Alliance, Northwest PANDAS/PANS Network, PANS PANDAS Italia APS, PANDAS Network, PANS PANDAS Peru, PANDAS Poland, PANS PANDAS UK, The Alex Manfull Fund, NY PANS/PANDAS Alliance, CalCoalition for PANS/PANDAS Advocacy, and VA4PA.

VA4PA is a grassroots community of parents, patients and other advocates from all corners of Virginia, fighting to ensure that every Virginian has access to private insurance or Medicaid coverage for the timely diagnosis and treatment of PANS/PANDAS. The group also works to improve awareness, detection, and treatment of the disease. VA4PA is currently collaborating with Delegate Patrick Hope and the Virginia General Assembly on legislation mandating insurance coverage for treatment: <https://legacylis.virginia.gov/cgi-bin/legp604.exe?241+sum+HB513>.

"I've seen first-hand the physical, emotional and financial devastation this illness inflicts," says Delegate Hope. "That's why I'm fighting to help ensure that the medical community is aware of and able to diagnose the illness and that health insurers cover the treatments prescribed by doctors when patients need it."

Buildings being illuminated throughout the Commonwealth of Virginia on Oct. 9 include:

Chesapeake City Hall | Chesapeake, VA
Beachcrest Place | Chesterfield, VA
Culpeper Visitor Center | Culpeper, VA
Gloucester Administrative Building | Gloucester, VA
Wells Fargo Building | Roanoke, VA
Silverline Center | McLean, VA
Building 30 - Chamber of Commerce | Virginia Beach, VA

The Light Up 4 PANS initiative builds on the recent designation by Governor Glenn Youngkin of October 9, 2024 as Virginia PANS/PANDAS Awareness Day (https://www.va4pa.org/files/ugd/654815_fc6baf99241e4932b51ca678a05293d7.pdf) and reinstatement through 2028 of the Governor's Advisory Council on PANS/PANDAS, a state body charged with advising the Commissioner of Health on research, diagnosis, treatment, and education. Henrico County and the City of Winchester, VA, both issued statements recognizing World PANS/PANDAS Awareness Day.

“By working together, we can ensure that every child with PANS or PANDAS receives the timely diagnosis and treatment they deserve,” says Sosa-Sarkar.

In addition to lighting up structures, the partners are launching a series of education campaigns and public outreach to support research and treatment for PANS and PANDAS. Social media users are encouraged to share photos and messages using the hashtag #LightUp4PANS and #VA4PA.

To learn more about VA4PA, please visit <https://www.va4pa.org> or contact Daniela Sosa-Sarkar at daniela.vaporpa@gmail.com.

For more information about Light Up 4 PANS, please visit www.inflamedbrain.org/awareness-day or contact Marnie Deschenes, Co-Founder, Inflamed Brain Alliance, marnie@inflamedbrain.org, +1 403.463.4453.

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