



UAMS News Bureau

Office of Communications & Marketing
4301 West Markham # 890
Little Rock, AR 72205-7199

uamshealth.com/news

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Media Contacts:

Leslie W. Taylor, 501-686-8998
Wireless phone: 501-951-7260
leslie@uams.edu

Simon Vukelj, 212-344-7568
svukelj@ctf.org

Children's Tumor Foundation, UAMS Open Country's First Adult Neurofibromatosis Clinic

LITTLE ROCK, AR — [The Children's Tumor Foundation \(CTF\)](#) and the University of Arkansas for Medical Sciences (UAMS) announced the opening of the first CTF-sponsored, fully multidisciplinary clinic dedicated to the care of adults with neurofibromatosis (NF) at the [UAMS Winthrop P. Rockefeller Cancer Institute](#).

“We are honored to be designated by the Children's Tumor Foundation as the site of the first CTF-designated adult neurofibromatosis clinic in the country. We look forward to welcoming patients and their families to our Cancer Institute, where patients already come from around the world to be treated for rare blood cancers and other diseases,” said UAMS Chancellor Cam Patterson, M.D., MBA.

NF is a group of rare genetic disorders that cause tumors to grow on nerves throughout the body and affects 2.5 million people worldwide. Although there is no cure for NF, there are treatments that help manage the disease.

With a two-year commitment of \$500,000 from the Children's Tumor Foundation, the [Adult NF Clinic](#) at the UAMS Cancer Institute will be staffed with specialists who can address the complex medical needs of patients with neurofibromatosis as they navigate adulthood.

“Children with NF grow up to become adults with NF, and they experience different and complex issues that demand multidisciplinary practitioners knowledgeable to their particular needs,” said Annette Bakker, Ph.D., Children's Tumor Foundation president.

"The Children's Tumor Foundation is committed to establishing a high standard of care for NF patients across the country, and we're excited and grateful to partner with the UAMS Winthrop P. Rockefeller Cancer Institute and Arkansas Children's Hospital to ensure that at any given point in a NF patient's care journey, there are resources and care options available that will improve lives," she said.

"Until now, there was no dedicated clinic in Arkansas or surrounding states where an adult with NF could go to be treated by doctors who understood the unique challenges of their condition," said Erika Santos Horta, M.D., UAMS neuro-oncologist who specializes in brain and spine cancers and leads the UAMS Adult NF Clinic.

Piloted in October 2021, the clinic is now in full operation and treats patients 18 and older from Arkansas and neighboring states. Patients can make appointments by calling 501-296-1200.

Among the challenges that adult NF patients face are increased risk of cancer or major tumor burden, visual and hearing deficits, bone abnormalities, pain and learning challenges. Patients may also need support with insurance issues, job challenges, disability and many other health and quality-of-life issues.

"This new NF clinic provides a critical continuity in care for these patients, which has been desperately needed," said Michael Birrer, M.D., Ph.D., UAMS vice chancellor and director of the UAMS Winthrop P. Rockefeller Cancer Institute.

Adult NF care throughout the country is a significant unmet health care need. A majority of NF clinics in the U.S. provide care to pediatric patients, yet many adults living with NF do not have access to knowledgeable medical expertise once they leave the pediatric setting.

"The Adult NF Clinic at the UAMS Winthrop P. Rockefeller Cancer Institute is a 20-year dream come true," said Kathleen Sullivan, whose husband and two sons live with NF and struggled to find first-rate care as adults. "We had such excellent comprehensive care at the NF Clinic at Arkansas Children's Hospital, but when my sons aged out and there was nothing, it was frustrating and scary. The Adult NF Clinic is an assurance of quality, comprehensive care for my family so they can lead the best life possible."

About the Children's Tumor Foundation

The Children's Tumor Foundation is the world's leading nonprofit dedicated to funding and driving innovative research that will result in effective treatments for the millions of people worldwide living with NF, a group of genetic disorders that causes tumors to grow on nerves throughout the body. One in every 3,000 people is born with some type of neurofibromatosis or schwannomatosis, which may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, or cancer. NF affects all populations equally, and while there is no cure yet, the Children's Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF

community fosters our vision of one day ending NF. For more information, please visit:
ctf.org.

About UAMS

UAMS is the state's only health sciences university, with colleges of Medicine, Nursing, Pharmacy, Health Professions and Public Health; a graduate school; a hospital; a main campus in Little Rock; a Northwest Arkansas regional campus in Fayetteville; a statewide network of regional campuses; and seven institutes: the Winthrop P. Rockefeller Cancer Institute, Jackson T. Stephens Spine & Neurosciences Institute, Harvey & Bernice Jones Eye Institute, Psychiatric Research Institute, Donald W. Reynolds Institute on Aging, Translational Research Institute and Institute for Digital Health & Innovation. UAMS includes UAMS Health, a statewide health system that encompasses all of UAMS' clinical enterprise. UAMS is the only adult Level 1 trauma center in the state. UAMS has 3,240 students, 913 medical residents and fellows, and five dental residents. It is the state's largest public employer with more than 11,000 employees, including 1,200 physicians who provide care to patients at UAMS, its regional campuses, Arkansas Children's, the VA Medical Center and Baptist Health. Visit www.uams.edu or www.uamshealth.com. Find us on [Facebook](#), [Twitter](#), [YouTube](#) or [Instagram](#).

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