



UAMS News Bureau

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Children's Tumor Foundation Joins with UAMS Winthrop P. Rockefeller Cancer Institute to Pilot Clinic for Adults with Neurofibromatosis

LITTLE ROCK—The Children's Tumor Foundation and the [Winthrop P. Rockefeller Cancer Institute](#) at the University of Arkansas for Medical Sciences are pleased to announce plans for the first dedicated Neurofibromatosis Adult Clinic in the region.

The Children's Tumor Foundation is the leading non-governmental organization dedicated to funding all types of neurofibromatosis (NF) research.

This newly established clinic located on the seventh floor of the Cancer Institute will deliver multidisciplinary care to adults living with neurofibromatosis. In addition, it will build clinical data sets to provide information that could inform the expansion of adult care and recruit and mentor new clinicians into the NF clinical care community. In conjunction with a pilot launching at the University of California Los Angeles (UCLA) later this year, the vision is to partner with hospitals across the country to open more NF adult clinics and make outstanding medical care accessible for the complex needs of adults living with neurofibromatosis.

“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 spearhead the first-ever NF clinic in Arkansas and surrounding regions dedicated solely to the needs of adults living with NF,” said Annette Bakker, Ph.D., Children's Tumor Foundation president. “Together we will ensure that at any given point in a NF patient's care journey, there are resources and care options available that will improve lives.”

Neurofibromatosis is a group of genetic disorders that cause tumors to grow on nerves throughout the body and affects 2.5 million people worldwide. Currently there is no

cure. There are three types of NF, neurofibromatosis type 1 (NF1), neurofibromatosis type 2 (NF2), and schwannomatosis. Currently there is one FDA-approved drug for the treatment of inoperable plexiform neurofibromas, impacting only a subset of NF1 patients.

Children living with neurofibromatosis grow up to become adults living with NF, and they experience different and complex issues that demand multidisciplinary practitioners knowledgeable to their particular needs. This includes transition of care out of the pediatric setting; navigating health insurance; aspects of dating, intimacy and fertility; and continuity of care and integrated care.

“The NF Clinic at the UAMS Winthrop P. Rockefeller Cancer Institute will be the hub for adult NF care in Arkansas,” said [Erika Santos Horta](#), M.D., a neuro-oncologist at UAMS who will lead the clinic. “The multidisciplinary nature of the clinic will allow patients to be treated for problems they are dealing with as possible complications that neurofibromatosis can bring.”

Adult NF care throughout the country is a significant unmet health care need. A majority of NF clinics in the United States 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. Adult neurofibromatosis care is complex, requiring a multidisciplinary team of specialists. Adults with NF may face increased risks of cancer or major tumor burden, visual or hearing deficits, bone abnormalities, pain and learning challenges. There may also be insurance issues, job challenges, disability, and many other health and quality-of-life issues, including a lack of access to care in their local community or even their state. In addition, a diagnosis of NF2 or schwannomatosis often comes after the age of 18. Dedicated Adult NF Clinics will address these precise needs, said Horta.

“Three-quarters of NF patients in Arkansas are adults without proper clinical attention,” said Natalie Rockefeller, UAMS Winthrop P. Rockefeller Cancer Institute board member and member of the Arkansas Advisory Board for the Children’s Tumor Foundation. “When I hear this, I think of Myleigh Marshall, a young girl I met when I competed in the Dancing with Our Stars Gala Fundraiser a few years ago. Myleigh will soon be a young woman, facing new and particular needs in her NF care, and it’s important that we make sure she has access to the care and guidance she and all other young adults and adults in Arkansas living with NF need.”

“This new NF clinic will provide 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 Cancer Institute.

About the Children’s Tumor Foundation

The Children’s Tumor Foundation established the NF Clinic Network (NFCN) in 2007 to standardize and raise the level of NF clinical care nationally and establish best practices for treating those living with NF. The NFCN is overseen by the foundation’s Clinical Care Advisory Board, which is composed of NF clinicians, patient advocates, and foundation staff. There are currently 67 clinics within the NFCN, which see more than 15,000 patients a year. Based upon the results of this two- to three-year pilot adult clinic program, CTF may develop a grant program to fund the implementation of additional Adult Clinics across the country.

To learn more about the pediatric care provided at NF Clinic at Arkansas Children's Hospital, please visit www.archildrens.org/programs-and-services/neuroscience-center/neurofibromatosis-clinic.

To learn more about the NF Clinic Network, please visit <https://www.ctf.org/research/nf-clinic-network>.

To learn more about the Children's Tumor Foundation, please visit www.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; 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 including its hospital, regional clinics and clinics it operates or staffs in cooperation with other providers. UAMS is the only adult Level 1 trauma center in the state. *U.S. News & World Report* recognized UAMS Medical Center as a Best Hospital for 2021-22; ranked its ear, nose and throat program among the top 50 nationwide for the third year; and named five areas as high performing — colon cancer surgery, diabetes, hip replacement, knee replacement and stroke. *Forbes* magazine ranked UAMS as seventh in the nation on its Best Employers for Diversity list. UAMS also ranked in the top 30% nationwide on *Forbes*' Best Employers for Women list and was the only Arkansas employer included. UAMS has 2,876 students, 898 medical residents and six dental residents. It is the state's largest public employer with more than 10,000 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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