

News Release
Sept. 17, 2019

Media Contacts:

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

Liz Caldwell, 501-686-8995
Wireless phone: 501-350-4364
liz@uams.edu

Study Co-authored by UAMS Doctor Shows Benefit Of Facebook Patient Support Groups in Rare Cancer Research

LITTLE ROCK – An article co-authored by Jerad Gardner, M.D., at the University of Arkansas for Medical Sciences (UAMS) demonstrates the ability to use international Facebook patient support groups to rapidly reach large numbers of rare cancer survivors.

The study titled [“Perspectives of Patients with Dermatofibrosarcoma Protuberans on Diagnostic Delays, Surgical Outcomes, and Nonprotuberance”](#) was published online Aug. 30 in the open-access journal JAMA Network Open.

The study reports international disease-relevant statistics from 214 survivors of dermatofibrosarcoma protuberans (DFSP). Researchers believe this to represent the largest-ever survey of patients with DFSP, a very rare soft tissue sarcoma that occurs in the deep layers of skin. Soft tissue sarcomas are a diverse group of rare cancers arising from connective tissues such as fat, tendon, muscle, blood vessels or nerves.

Gardner, a dermatopathologist and bone/soft tissue sarcoma pathologist, developed the idea for the study in 2014 after connecting with DFSP survivors on a Facebook patient support group. Dermatopathology is a medical subspecialty that focuses on the microscopic diagnosis of skin disease.

“I collaborated with several UAMS colleagues and an international group of DFSP survivors I met on Facebook to develop a formal research study about their experiences with delays in diagnosis, risk of disease recurrence and how their disease presented itself,” said Gardner, who also serves as associate professor of pathology and dermatology in the UAMS College of Medicine.

Marjorie David, M.D., director of the Molecular Diagnostic Laboratory at UT Health San Antonio and former UAMS pathology resident, serves as the article’s lead author and worked closely with Gardner throughout the research process.

“Patients with rare diseases like DFSP can feel neglected by the medical community because the rarity of their tumor makes it difficult to find enough patients to put together a study. By working with previously established social media support groups, we were

able to connect with hundreds of survivors and managed to overcome that hurdle," David said.

According to the National Institutes of Health, DFSP is estimated to occur in somewhere between 1 in 100,000 to 1 in 1 million people per year.

The study includes results of 214 surveys administered to patients and family members, who answered on behalf of patients, from international DFSP Facebook patient support groups and a database provided by the nonprofit organization Sarcoma Foundation of America.

The survey questions, which were developed by a team of medical practitioners and patients with DFSP, were designed to determine risk of disease recurrence and spread, surgical outcomes, sources of delay in diagnosis, symptoms and number of recurrences, scar size, and number of medical professionals seen before a biopsy was performed.

The classic textbook description of DFSP is a large irregular mass protruding out of the skin. However, in this study, 44.8% of cases first appeared as a flat plaque rather than a raised bump or mass. Because of this, the authors propose to re-name the tumor dermatofibrosarcoma, often protuberant.

This rare malignancy is often confused with more common benign skin conditions, resulting in misdiagnosis or delay in diagnosis. A total of 52.3% of respondents believe they were initially misdiagnosed, and 19.6% made five or more visits to a clinician before undergoing a biopsy.

Additional findings are available [here](#).

In addition to Gardner and David, five DFSP survivors served on a Patient Advisory Board, participated in research-related training and are listed as co-authors of the article, including Pip M. Caliskan of the United Kingdom and Gayle Dicker of Chicago.

As founder of the Facebook patient support group titled DFSP-Dermatofibrosarcoma Protuberans, Caliskan welcomed Gardner's participation with its members and played a key role in development of the research study.

Caliskan's group was created in 2008 and includes more than 1,800 members worldwide. As a closed group, interested persons must request to join, and information posted on the group's site is not available to nonmembers.

"Pip changed my life by showing me that when pathologists and other doctors volunteer in rare cancer Facebook patient support groups, it can lead to amazing benefits for everyone. Without her, I never would have thought to do this type of research," Gardner said.

Dicker said she hopes the study will spread awareness of DFSP and inform doctors about the disease and how it presents itself in different patients.

"DFSP is commonly left untreated for years, resulting in more aggressive surgery and a higher risk of disfigurement. Being part of this research project is important to me because it's all about raising awareness among health care providers. All lumps and bumps deserve attention," Dicker said.

This study was supported by a research grant from the Patient-Centered Outcomes Research Institute (PCORI) to Gardner and Pam Williams, Ph.D., formerly of the UAMS College of Nursing.

Williams, Ashley Funderburg of the UAMS Office of Sponsored Programs Administrative Network and Leah Fisher, formerly of the UAMS College of Nursing, worked directly with patient partners designing and implementing the survey. James Selig, Ph.D., associate professor in the UAMS Department of Biostatistics, assisted with data analysis.

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. It is the only adult Level 1 trauma center in the state. *U.S. News & World Report* named UAMS Medical Center the state's Best Hospital; ranked its ear, nose and throat program among the top 50 nationwide; and named six areas as high performing — cancer, colon cancer surgery, heart failure, hip replacement, knee replacement and lung cancer surgery. UAMS has 2,727 students, 870 medical residents and five 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 Hospital, the VA Medical Center and Baptist Health. Visit www.uams.edu or www.uamshealth.com. Find us on [Facebook](#), [Twitter](#), [YouTube](#) or [Instagram](#).

Like us, we're social:    

###