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UT Southwestern establishes first U.S. morphea registry and DNA repository for both adults and children

DALLAS – May 31, 2007 – Dermatologists at UT Southwestern Medical Center are establishing a DNA repository aimed at people with morphea, a poorly understood, incurable and sometimes disfiguring disease that causes patches of skin to thicken and harden.

Once established, the facility will be the only morphea DNA repository for both adults and children in the U.S. Researchers hope to shed light on both clinical and genetic aspects of the disease.

"Morphea is a disease we don't know much about in terms of causative factors or its association with other potential health problems," said Dr. Heidi Jacobe, assistant professor of dermatology at UT Southwestern, who heads the phototherapy unit. "We aim to address this by creating a registry of patients with morphea in which we collect information about other health conditions present. We'll also collect information about family history, and collect blood and skin samples to further define the genes associated with morphea and the genetic faces of morphea."

Also known as localized scleroderma, morphea often causes discolorations of the thickened skin, often red or purple in color, and therefore can be disfiguring, an underappreciated aspect of the disease.

"It commonly can start out looking like a bruise, but it doesn't go away," Dr. Jacobe said. "Many don't get diagnosed for a long period of time, often until they meet a dermatologist who knows what is going on with their skin."

Participants in the repository will need to come to the medical center for exams and to provide blood and skin samples. To join, contact the morphea registry office at 214-645-8971 or by e-mail at Christina.Carrigan@UTSouthwestern.edu. Information is also available at www.utsouthwestern.edu.

Researchers plan to use the blood and skin samples to investigate genes and blood markers associated with morphea. Other information will be used to identify and clarify its prevalence, its demographic distribution among race, gender and age, and recurrence rates. Currently, more women are diagnosed with the disease, but other factors aren't known.

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UT Southwestern dermatologists also hope to identify associated health problems that may be common for those with morphea, particularly rheumatic diseases such as lupus and rheumatoid arthritis.

The exact cause of morphea is unknown, but researchers believe that a reaction of the immune system may play a role in its development.

Morphea has no known cure. Treatments are aimed at slowing its spread and controlling symptoms such as itching or pain, usually with medications. UT Southwestern is using an experimental treatment that utilizes a highly specific range of ultraviolet light (UVA-1) for some patients. Other treatments may include topical corticosteroids, antimalarials, systemic immunosuppressive medications and physical therapy.

"Treating the disease early on is important because that is when it is most likely to respond," Dr. Jacobe said. "The response to treatment is much decreased when people have had it for a long time and it is near its end stages.

"The other problem is that frequently these patients are told they have systemic scleroderma, which is quite anxiety-provoking."

Systemic scleroderma is a more potent and potentially deadly form of scleroderma that not only causes the skin thickening, but also can affect internal organs such as the heart, lungs or gastrointestinal tract. Localized scleroderma is isolated to the skin and does not involve damage to internal organs.

Because of its more drastic outcomes, more attention is given to the systemic form of scleroderma. Very few morphea registries currently exist worldwide, and all are aimed at children rather than adults, Dr. Jacobe said. Researchers hope the new morphea registry will complement a larger, NIH-funded registry for systemic scleroderma at the UT Health Science Center at Houston.

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