

INFORMATION FOR PATIENTS AND FAMILIES



*Supported by
The Dermatology Foundation*



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Search 'morphea registry' at
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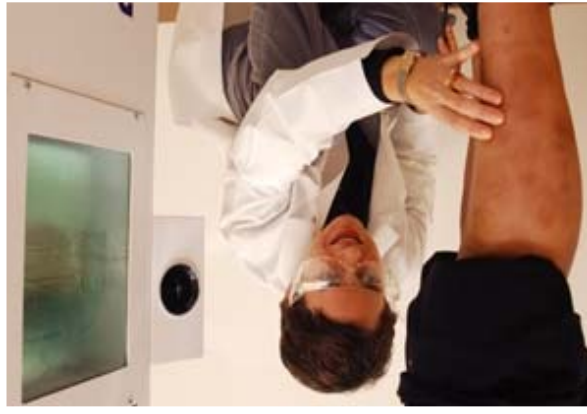
What is the Morphea Registry?

The Morphea Registry is a research study that was created in May 2007 by Dr. Heidi Jacobe with funding from The Dermatology Foundation. The overall objective is to identify genes that influence morphea. For this study, all patients with morphea (localized scleroderma) older than 3 years-of-age will be eligible to participate.

What is the purpose of the Registry?

In order to accomplish its overall objective, the project has the following three specific goals:

1. To determine the characteristics of morphea - age-of-onset, natural course and relationship to other medical problems in patient and their families.
2. To identify the genes associated with morphea.
3. To establish a center for blood and DNA that is available to the scientific community for further research.



What will happen if I participate?

Study participants will be asked to complete the following:

1. Informed consent
2. Questionnaires about quality-of life, morphea, general medical and family histories.
3. Photographs of affected skin areas
4. Blood sample (two tablespoons)
5. Skin sample for microscope examination*
6. Ultrasound examination of skin*
7. Sign a permission to release prior physician records and skin sample slides
8. Provide contact information for annual follow-up

*Performed in study visit at UT Southwestern in Dallas, TX

How will blood samples be utilized?

1. Detect and identify genes associated with morphea.
2. Determine the presence and significance of autoantibodies.

DNA, blood, and cells will be isolated and stored in a freezer for the future study of morphea and related diseases.

If I live outside the Dallas area, can I still be included in the Registry?

Yes, simply contact our study coordinator who will mail the needed materials to you with instructions for completion. All blood collection will be handled through your local doctor at your convenience. We will pay all shipping and handling charges accrued.

Will children be included?

Yes, we include children age 3 or older. A parent or guardian must sign a consent form for the child to be enrolled in the Registry.

Will the Registry provide new treatments for morphea?

No, the Registry's objective is to gather information for the understanding of morphea, from which future treatments may result.

How do I enroll?

Simply contact our study coordinator by telephone or email.

Study Coordinator:
Christina Carrigan

Phone: 214-645-8973

Email: MorpheaRegistry@utsouthwestern.edu

Website: <http://www.utsouthwestern.edu> and search for 'Morphea Registry'

