

RESOURCES

The following resources offer useful information about scleroderma. Listings do not constitute endorsement by the Scleroderma Foundation Michigan Chapter.

HEALTH INFORMATION

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse National Institutes of Health

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases.

If you want health information, contact:

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
Information Clearinghouse
National Institutes of Health

1 AMS Circle
Bethesda, MD 20892-3675
Phone: 301-495-4484
Toll Free: 877-22-NIAMS
TTY: 301-565-2966
Fax: 301-718-6366
Email: NIAMInfo@mail.nih.gov
Website: <http://www.niams.nih.gov>

Office of Communications and Public Liaison
National Institute of Arthritis and Musculoskeletal and Skin Diseases
National Institutes of Health
Bldg. 31, Room 4C02
31 Center Dr. - MSC 2350
Bethesda, MD 20892-2350
Phone: (301) 496-8190
Fax: (301) 480-2814

ORGANIZATIONS OF INTEREST

Pulmonary Hypertension Association

The mission of the Pulmonary Hypertension Association (PHA) is to seek a cure, and to provide hope, support and education, and to promote awareness and to advocate for the pulmonary hypertension community.

850 Sligo Avenue, Suite 800
Silver Spring, MD 20910
Phone: 301-565-3004
Phone: 800-748-7274
Web site: <http://www.phassociation.org>

Raynaud's Association

The Raynaud's Association is a national nonprofit organization whose mission is to provide support and education to the millions of sufferers of Raynaud's phenomenon.

94 Mercer Ave.
Hartsdale, NY 10530
Phone: 800-280-8055
Website: <http://www.raynauds.org>

The Office of Rare Diseases Research

The ORDR's mission is to answer questions about rare diseases and the activities of the ORDR for patients, their families, healthcare providers, researchers, educators, students and anyone with concern for an interest in rare diseases. The website is an excellent source of information of research projects and educational conferences for various rare diseases. A great resource to check out!

Office of Rare Diseases Research
National Institutes of Health
6100 Executive Boulevard
Room 3B01, MSC 7518
Bethesda, Maryland 20892-7518
Phone: 301-402-4336
Fax: 301-480-9655
Email: ordr@od.nih.gov
Website: <http://rarediseases.info.nih.gov/>

National Family Caregivers Association

The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

Phone: 800-896-3650
Website: <http://www.nfcacares.org/>

Patient Advocate Foundation

The mission of the Patient Advocate Foundation is to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

Phone: 800-532-5274

Website: <http://www.patientadvocate.org/>

EMPLOYMENT/WORK ASSISTANCE

Equal Employment Opportunity Commission (EEOC)

The U.S. Equal Employment Opportunity Commission (EEOC) is responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit. The laws apply to all types of work situations, including hiring, firing, promotions, harassment, training, wages, and benefits. The EEOC has the authority to investigate charges of discrimination against employers who are covered by the law. They work to prevent discrimination before it occurs through outreach, education and technical assistance programs.

ADA (Americans with Disabilities Act) makes it unlawful to discriminate in employment against a qualified individual with a disability. If you think you have been discriminated against because of a disability you can contact the EEOC to determine what your rights are.

Website: <http://www.ada.gov/>

Ticket to Work and Self-Sufficiency Program

The Ticket to Work and Self-Sufficiency Program is an employment program for people with disabilities who are interested in going to work. The Ticket Program is part of the Ticket to Work and Work Incentives Improvement Act of 1999 – legislation designed to remove many of the barriers that previously influenced people's decisions about going to work because of the concerns over losing health care coverage. The goal of the Ticket Program is to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, vocational rehabilitation (VR), and other support services from public and private providers, employers, and other organizations.

Under the Ticket Program, the Social Security Administration (also referred to as the Agency) provides disability beneficiaries with a Ticket they may use to obtain the services and jobs they need from a new universe of organizations called Employment Networks (ENs).

MAXIMUS, a private company, has been contracted by the Social Security Administration to function as the Operations Support Manager (OSM) and the Ticket Program Data Operations Center Manager (TPDOCM). It is MAXIMUS responsibility to administer oversight and process support necessary to sustain ongoing Ticket Program Operations.

The Ticket to Work Program provides most people receiving Social Security benefits (beneficiaries) more choices for receiving employment services.

Visit their Web site for more specific information on Ticket to Work.

Website: <http://www.ssa.gov/work/aboutticket.html>

DISABILITY SERVICES

The Law Center for Social Security Rights

A Service of Weisberg & Walkon P.C., Attorneys at Law
21650 West Eleven Mile Road
Suite 202
Southfield, MI 48076-3768
(800) 832-3471

Levin Benjamin

Gary Bimberg
27700 Northwestern Highway
100 Galleria Officentre
Suite 411
Southfield, MI 48034
(248) 352-5700

Social Security Disability Insurance (SSDI)

The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.

[Social Security Disability Insurance](#) pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes.

When you apply for either program, we will collect medical and other information from you and make a decision about whether or not you meet [Social Security's definition of disability](#).

The Social Security disability insurance program (sometimes referred to as SSDI) pays benefits to you and certain family members if you meet certain criteria, such as length of time worked and contribution of Social Security taxes.

Your adult child also may qualify for benefits on your earnings record if he or she has a disability that started before age 22.

If your application has recently been denied, the [Internet Appeal](#) is a starting point to request a review of the decision about your eligibility for disability benefits.

If your application is denied for:

- Medical reasons, you can complete and submit the required [Appeal Request and Appeal Disability Report](#) online.

The disability report asks you for updated information about your medical condition and any treatment, tests or doctor visits since we made our decision.

- Non-medical reasons, you should [contact your local Social Security Office](#) to request the review. You also may call our toll-free number, 1-800-772-1213, to request an appeal. People who are deaf or hard of hearing can call our toll-free TTY number, 1-800-325-0778.

Website: <http://www.ssa.gov>

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes):

- It is designed to help aged, blind, and disabled people, who have little or no income; and
- It provides cash to meet basic needs for food, clothing, and shelter.

The Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.

SSI benefits also are payable to people 65 and older without disabilities who meet the financial limits.

Phone: 800-772-1213

Website: <http://www.ssa.gov>

SCLERODERMA RESOURCES

The Scleroderma Foundation Michigan Chapter
23999 Telegraph
Southfield, MI 48033
(800) 716-6554
e-mail: MIchapter@scleroderma.org

The Scleroderma Foundation National Office

300 Rosewood Drive, Suite 105

Danvers, MA 01923

Phone: 800-722-4673

Website: <http://www.scleroderma.org>

University of Michigan Health System Rheumatology/Scleroderma Clinics

1500 E. Medical Center Drive

3rd Level Taubman Center - Clinic Areas A & C

Ann Arbor, MI 48109-0370

The University of Michigan Scleroderma Program is a multidisciplinary group of care givers, scientists and clinical researchers dedicated to advancing knowledge about scleroderma and related conditions. The overarching goal of the Program is to develop effective therapies for the disease and its complications.

CORE elements are:

Clinical care with emphasis on cost-effective outpatient management

Outreach to the community of patients and physicians

Research into the cause, mechanisms and treatment

Education of physicians and allied health professionals

Dr. Richard W. Martin, MD

West Michigan Rheumatology

1155 East Paris Avenue South East Suite 100

Grand Rapids, MI 49546

(616) 459-8088

Morphea Registry and DNA Repository

Roughly 2 in 1000 people in the United States have morphea, a skin disorder that causes hardening of the skin and possibly deeper tissues such as muscle and fascia. There are many different variations of morphea, including linear, deep, plaque, guttate, generalized, lichen sclerosus/morphea overlap and mixed subtypes. Many of the affected persons are children who often have the more severe forms of the disease with disfigurement and neurologic complications. The cause of the disease is not known and there is no cure at this time. However, researchers feel that genetic factors may play a major role in this disease. Dermatologists at UT Southwestern are establishing a national registry for morphea patients and their relatives in order to gather the large number of patients necessary for genetic studies. Another aim to the registry is to elucidate the association of morphea with other diseases in the hopes that this will further research in the area of morphea. **This registry is a significant advancement in morphea research as it is the only morphea DNA repository for both adults and children in the United States.** This registry will provide a resource for investigators to make discoveries in regards to both the clinical and genetic aspects of the disease.

Patients enrolled in the study will be first in line for clinical trials conducted at UT Southwestern for morphea patients.

Registration of study participants is already underway and participants need not visit UT Southwestern to enroll.

For further details and any questions, please contact Memoree Lee at the Morphea Registry office:

Phone: 214-645-8973

Email: morphearegistry@utouthwestern.edu

Web: <http://www.utsouthwestern.edu/utsw/cda/dept25717/files/384413.html>

Scleroderma Family Registry & DNA Repository

The Scleroderma Family overall Registry and DNA Repository is a research study whose objective is to identify the genes that influence scleroderma. Families with only one case of scleroderma (singleton families) and those with more than one case (multiplex families) will be included in the study.

The Scleroderma Family Registry and DNA Repository

University of Texas-Houston Health Science Center

6431 Fannin, MSB 5.245

Houston, TX 77030

Phone: 713-500-7196

Phone: (800) 736-6864

Fax: 713-500-0723

Email: sclerodermaregistry@uth.tmc.edu



[Maureen D. Mayes, M.D., M.P.H.](#)

Project Director

Professor of Internal Medicine

Division of Rheumatology

Marilyn Perry, B.S.
Registry Coordinator

Dawn Simmons
Assistant Coordinator

Marcia Kerr
Senior Research Nurse

MEDICARE INFORMATION

Medicare Rights Center

The Medicare Rights Center is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives.

Phone: 800-333-4114

Web: <http://www.medicarerights.org/>

MEDICAL PROGRAMS IN MICHIGAN

Caretaker Relatives

Medicaid is available to eligible parents and people who act as parents, caring for a dependent child. These people are called caretaker relatives. There is an income test and an asset test (beginning May 1, 2006) for this program. If the income test is over the income limit, persons may incur medical expenses that equal or exceed the deductible and still qualify for this program. Beneficiaries receive a comprehensive package of

health care benefits including vision, dental, and mental health services. Contact the local MDHS office in your county to apply for this program.

Supplemental Security Income (SSI)

SSI is a cash benefit to low income adults who are aged, disabled, or blind. The Social Security Administration (SSA) determines SSI eligibility. SSI beneficiaries are automatically eligible for Medicaid and the comprehensive package of health care benefits including, vision, dental, and mental health services. Medicaid may continue even if SSI stops. Contact the Social Security Administration to apply for this program.

Aged, Blind, Disabled

Medicaid is available to persons who are aged, blind, or disabled. There are income and asset tests. If the income is over the income limit, persons may incur medical expenses that equal or exceed the deductible and still qualify for this program. Most beneficiaries are enrolled in a Medicaid health plan and receive a comprehensive package of health care benefits including vision, dental, and mental health services. Contact the local MDHS office in your county to apply for this program.

Disabled Adult Children (DAC)

A person who had a disability or blindness that began before age 22 may be eligible to receive Medicaid benefits in his adult years. He must also be receiving DAC benefits from Social Security. Most beneficiaries are enrolled in a Medicaid health plan and receive a comprehensive package of health care benefits including vision, dental, and mental health services. Contact the local MDHS office in your county to apply for this program.

MIChoice

The MIChoice waiver provides home and community based health care services for aged and disabled persons. The program's goal is to allow persons to remain at home to receive health services. If they did not receive such services, these persons would require nursing home care. The cost of care at home must be less than the cost of care in a nursing home. MIChoice Beneficiaries are not enrolled in a Medicaid health plan but still receive a comprehensive package of health care benefits including vision, dental, and mental health services. In addition, the waiver may provide other benefits to help the person remain at home. Contact the local MDHS office in your county to apply for this program.

Medicare Savings Program (MSP)

The Medicare Savings Program pays for certain Medicare costs. There is an asset test. The income amount determines what is covered. The Michigan Department of Community Health (MDCH) may help pay the following, depending on the income amounts:

- Medicare premiums
- Medicare coinsurance
- Medicare deductible

In some cases, the Michigan Department of Community Health (MDCH) may refund the beneficiary a portion of the Medicare Part B premium on an annual basis. Contact the local MDHS office in your county to apply for this program.

Adult Benefits Waiver (ABW), a.k.a., Adult Medical Program (AMP)

ABW/AMP provides basic medical care to low income childless adults who do not qualify for Medicaid. There are asset and income tests. ABW/AMP medical coverage is limited (e.g., inpatient coverage is not covered). However, pharmacy is included. Some counties have a county health plan that the person must be enrolled in to receive ABW/AMP benefits. Some services may require prior authorization from the county health plan or

state (if there is no health plan in the county of residence). Contact the local MDHS office in your county to apply for this program.

FAMILIES Many times, the entire family may be eligible for health care benefits:

Low Income Families (LIF)

Medicaid is available to families under the Low Income Family (LIF) Program. There are income and asset tests. Families that receive cash assistance (Family Independence Program or FIP) are automatically eligible for this program. Other families must apply at the local MDHS office. Families don't have to apply for FIP in order to receive health care coverage under this program. Most beneficiaries are enrolled in a Medicaid health plan and receive a comprehensive package of health care benefits including vision, dental, and mental health services.

Special N Support

Special N Support is available to families that received Low Income Families (LIF) Medicaid or cash assistance (FIP) but are no longer eligible due to income from child support payments. Special N Support is available for 4 months. Most beneficiaries are enrolled in a Medicaid health plan and receive a comprehensive package of health care benefits including vision, dental, and mental health services. Your Family Independence specialist will let you know if you qualify for this program.

Transitional Medical Assistance (TMA)

TMA is available to families that have received LIF or cash assistance (FIP) in at least 3 of the last 6 months. The family is no longer LIF/FIP eligible because a parent has too much income from employment. TMA is available for up to 12 months and the family does not need to fill out a new application. Most beneficiaries are enrolled in a Medicaid health plan and receive a comprehensive package of health care benefits including vision, dental, and mental health services. Your Family Independence Specialist at the Department of Human Services will let you know if you qualify for this program.

Transitional Medical Assistance Plus (TMA-Plus)

TMA-Plus assists beneficiaries in achieving self-sufficiency by extending medical coverage for families unable to purchase employer-sponsored health care coverage. TMA-Plus is available to adults after the 12 months of TMA. The family must apply and be eligible for the TMA-Plus program. There is only an income limit. There are monthly premiums based on the number of adults and how long they have been in the TMA-Plus program. TMA-Plus is not available for children. The DHS specialist will tell you about health care coverage for the children in the family. If available, the beneficiaries must be enrolled in a Medicaid health plan. Beneficiaries receive a comprehensive package of health care benefits including vision, dental, and mental health services. Your DHS specialist will let you know if you qualify for this program.

For more information on all of these programs go to: www.michigan.gov