Registry Sites

M. D. Anderson Cancer Center, Houston, TX

Principal Investigator: Madeleine Duvic, M.D.
Coordinator, Clinical Research Programs: Kathleen Hunzicker, M.D.
Informatics Coordinator: Joan Breuer-McHam, Ph.D.
Department of Dematology
Box 434, 1515 Holcombe Blvd., Houston, TX 77030
Phone: 713-792-5999 **Fax:** 713-794-1491
E-mail: alopeciaregistry@mdanderson.org
Website: www.mdanderson.org/departments/alopecia/
Registration Website: **www.AlopeciaAreataRegistry.org/**

University of Colorado, Denver, CO

Co-Principal Investigator: David Norris, M.D.
12801 East 17th Avenue, Aurora, CO 80010-7163
Phone: 303-724-4030 **Fax:** 303-724-4048
E-mail: david.norris@uchsc.edu
Administrative Assistant: Pat Somerset
E-mail: pat.somerset@uchsc.edu

Columbia University, New York, NY

Collaborator: Angela Christiano, Ph.D.
630 West 168th Street, VC15, New York, NY 10032
Phone: 212-305-9739 **Fax:** 212-305-7391
E-mail: amc65@columbia.edu
Clinical Research Manager: Carol Coppola, RN
Phone: 212-305-6953 **Fax:** 212-305-0286
E-mail: cc2241@columbia.edu

University of Minnesota, Minneapolis, MN

Department of Dermatology
Collaborator: Maria Hordinsky, M.D.
Senior Clinical Research Nurse: Cathy Boeck, R.N.
Clinical Research Assistant: Cheri Schoonveld
4-240 Phillips Wangensteen Building
420 Delaware Street, MMC 98, Minneapolis, MN 55455
Phone: 612-625-8625 **Fax:** 612-624-6678
Phone: 612-625-4973 (Cathy Boeck, R.N.)
E-mail: aaregmn@umn.edu
E-mail: boeck001@umn.edu (Cathy Boeck, R.N.)

University of California, San Francisco, CA

Collaborator: Vera Price, M.D.
Clinical Coordinator: Jennifer Chwolek, M.D.
1701 Divisadero Street
Box 0316, San Francisco, CA 94143-0316
Phone: 415-353-4333 **Fax:** 415-353-2265
E-mail: hair@derm.ucsf.edu

Additional Resources *

National Alopecia Areata Foundation

Phone: 415-472-3780
E-mail: info@naaf.org
Website: www.naaf.org

Site of Dan Victor

E-mail: dcv@scn.org
Website: www.scn.org/~dcv/alopecia.html

Site of Kevin McElwee, Ph.D.

Alopecia Areata: History, Biology, Diagnosis, Treatments, etc.
E-mail: kevin@keratin.com
Website: www.keratin.com/ad/adindex.shtml

*Disclaimer: The National Alopecia Areata Registry is not responsible for information provided by other sources.

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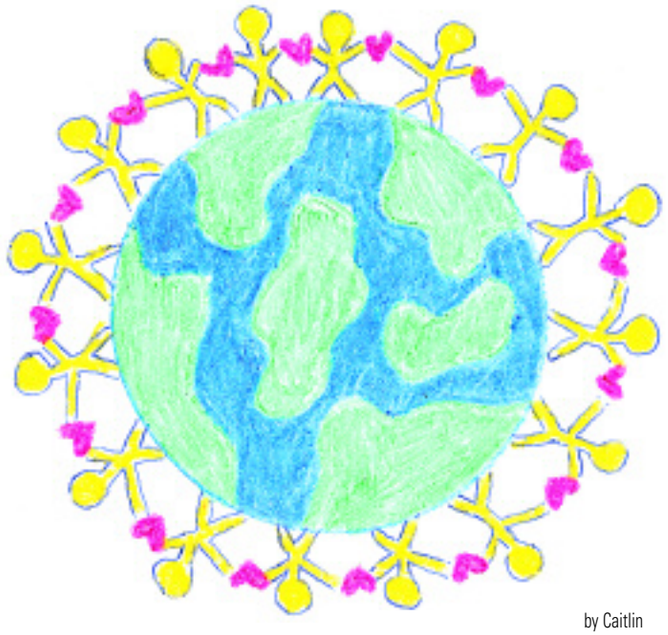

by Caitlin



National Alopecia Areata Registry

Sponsored by:

National Institutes of Health (NIH)

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

What is Alopecia Areata?

Alopecia areata is a T cell mediated autoimmune disease that targets hair follicles and results in hair loss ranging from patchy loss to total scalp and body hair loss.



by Melinda

Purpose of Registry

The Registry will be a resource of clinical data and selected biological research samples, stored in a central repository and available to investigators studying the disease. ***The Registry does not offer treatment for alopecia areata.*** But, in collecting genetic and environmental factors that predispose for alopecia areata, we may develop better medications, new clinical trials, and perhaps a cure.

Cover drawing by Erika

Description of Registry Process

The Registry is composed of two stages. All persons with alopecia areata, both adults and children, ***whose diagnosis has been confirmed by a Dermatologist*** and who live in the U.S.A., may participate in the first stage of the Registry by completing a Short Form questionnaire. This is called the First Tier Registration. Likewise, unaffected family members of these persons may participate in order to help us understand environmental triggers and other related medical problems. These Short Form questionnaires may be filled out on line at **www.AlopeciaAreataRegistry.org/**. They may also be obtained by contacting one of the five Registry sites. Registrants may print out the form, mail it in, or fax it to the Central Site, M. D. Anderson Cancer Center. Short Form questionnaires will be reviewed by Registry physicians to select those who meet certain criteria, as listed below, to participate in the Second Tier Registration. The Second Tier includes a longer questionnaire (the Long Form), blood samples, photos (optional), previous biopsies (if available), and an examination by a physician at one of the sites.



by Sophie



by Andrew

The Registry is Seeking the Following Participants for the Second Tier Registration:

- **Multiplex Families**: Persons with at least three family members with AA or AT/AU.
- **Sibling pairs**: Two or more siblings with AA or AT/AU and their parents.
- **Identical or fraternal twins**: One or both twins with AA or AT/AU and their parents.
- **Persistent AA**: Persons with AA for at least one full year at anytime in their life and who have never had AT/AU.
- **Persistent AT/AU**: Persons with AT/AU for at least one full year at anytime in their life.
- **Mild Transient AA**: Persons with repeated transient episodes of AA in patches that regrow completely within six months.
- **Unaffected spouses or friends** of patients with AA or AT or AU. Unaffected, non-blood-related people are needed as controls.