

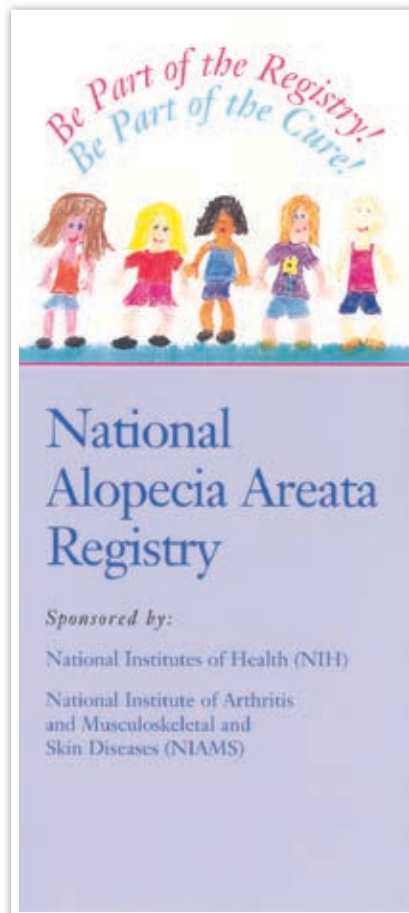
Gain Insight into the National Alopecia Areata Registry at the NAAF Conference

Let's Reach Our Goal of 10,000 Registrants by September 30, 2010!

The National Alopecia Areata Registry is based in Houston, Texas, where the 2009 NAAF Conference will take place, so there will be many opportunities during the conference for you and your family to learn more about the registry, to enroll in it, and to help us promote its use. One conference panel composed of our registry investigators is certain to excite everyone about the registry in this year—its last year of US government funding.

How was this registry created?

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), one of the National Institutes of Health (NIH), has funded the National Alopecia Areata Registry since 2000, providing over six million dollars to establish it and to gather initial information and samples. Federal funding for the registry ends on September 30, 2010, and then NAAF will continue to maintain it. In helping the registry to get underway, NIAMS indicated its strong commitment to research regarding alopecia areata. The registry creates an enormous opportunity to advance basic, clinical, and translational studies in alopecia areata. It also provides an essential resource for all investigators interested in studying alopecia areata, and it stimulates opportunities for additional research support from federal and private sources.



Why is this registry important?

Have you ever asked, “Who gets alopecia areata?” “How did I get it when no one in my family has it?” “Is it related to another disease?” “What are the chances my children will get it?” “What is the chance that my alopecia areata will turn into alopecia areata totalis or alopecia areata universalis?”

The registry is designed to answer those types of questions. The more people who participate in the registry, the more questions we can answer and the more resources we can provide for researchers and pharmaceutical companies to advance more studies and possibly find a treatment for this disease.

What is a disease registry?

A disease registry is an organized network of centers that identify and register patients with a particular disease, collect relevant research samples, catalogue and store information on the patients in a central database, and make this information available to investigators interested in studying the disease.

The disease registry does not conduct research itself, but it facilitates research by all investigators who need patient populations that are well characterized by accepted criteria, especially patients from families with multiple members affected by the disease in question. Once established, a disease registry is a research resource that can support many diverse types of investigations and clinical trials. It provides critical structure and uniformity to research, and it enables many different investigators to pursue promising research directions. A disease registry is like the pint of water used to prime a pump that can then deliver gallons of cool, fresh water.

Call NAAF at 415.472.3780 for your copy of the Registry brochure.

How does the National Alopecia Areata Registry work?

The National Alopecia Areata Registry is located at five sites across the United States where patients are examined and registered, and blood and tissue samples are taken when appropriate. The samples and data are sent to Houston, Texas, where they are collected and stored by the Principal Investigator. A Steering Committee made up of key members of the registry oversees the functions of the registry and determines the distribution of material to appropriate investigators. NAAF's CEO serves on this Steering Committee.

How can I participate in this registry?

You can register online at www.AlopeciaAreataRegistry.org or at any of the five registry sites. The registry website includes a comprehensive explanation of the registry.

The registration process is simple. You first complete a screening questionnaire called the Short Form, which provides the registry with both epidemiological and statistical information about alopecia areata. You can complete this form directly online or you can download the form, complete it, and mail it in to the address that is right on the form. If you do not have internet access and you want this form to be mailed to you, please call 866.837.1050 or email the Clinical Coordinator at alopeciaregistry@mdanderson.org. You can then mail or fax the forms back (again, the proper address and contact numbers are right on the Short Form).

It is important to answer all of the questions on the Short Form, including those about other diseases, and to state whether affected family members are on your mother's side or father's side of the family—or both. The Short Form also includes some questions asking about the “proband” in your family. The proband refers to the first affected person in your family who registered. If you are the first or only person registering, you automatically become the proband and do not need to fill in that portion of the form. We connect families in the computer database by this information, so it is important for you to list any proband if you know that someone in your family has registered before you.

We also encourage everyone to complete the Quality of Life questionnaire, which is also available online or via mail. The registry personnel know that this life-altering disease can affect your life as deeply as a life-threatening disease. They will use the information they gather from this questionnaire in order to approach health insurance companies for better coverage. Your name will not be listed on any of this information.

The second part of the registry is optional. It involves completing a longer questionnaire called the Long Form, traveling to one of the participating sites (in Houston, Denver, Minneapolis, New York, or San Francisco), having a brief skin exam, and donating blood for genetic and other research. The registry cannot pay for any travel expenses, but there is no charge for going to one of the sites and participating in the second part of the registry.

You can also have your own physician do the examination and send the blood samples to the registry. Please call 866.837.1050 or email the Clinical Coordinator at alopeciaregistry@mdanderson.org for information on how to do this. ■



2007 Conference attendees sign up for the National Alopecia Areata Registry.



Volunteer Harold Koessner with Registry Coordinator, Joyce Osei