

This questionnaire is only for people who live in the U.S.A and who have personal or family documentation of Alopecia Areata or Alopecia Totalis or Alopecia Universalis by a Dermatologist

ALOPECIA AREATA Registry and Family Study

I have read the description of the study, and I have decided to participate in the research project described here. I understand that I may refuse to answer any (or all) of the questions at this or any other time. I understand that there is a possibility that I might be contacted in the future about this, but that I am free to refuse any further participation if I wish.

Please fill in all the blanks or check the appropriate boxes, the starred fields (*) are optional:

Last Name (Registrant): _____ Date: ___ / ___ / _____

First Name: _____ Middle _____ Maiden _____

Primary Contact Address: _____

City/State/Zip Code: _____

Telephone Number: (Home) _____ (Work) _____

*FAX: _____ *Email: _____

If you have alopecia, has a dermatologist ever diagnosed or confirmed your alopecia areata? No Yes

If **yes**, Your Dermatologist's Name _____ Phone # _____
Last First Middle

Your Dermatologist's Address _____

Other Doctors:

Doctor's Name: _____ MR#: _____
Last First Middle

Doctor's Address: _____
Street City State Zip Country

Specialty: _____ Fax: _____ Tel # _____

Doctor's Name: _____ MR#: _____
Last First Middle

Doctor's Address: _____
Street City State Zip Country

Specialty: _____ Fax: _____ Tel # _____

I am registering as a CONTROL, unaffected person not blood-related to anyone with AA: No Yes

Biological Mother's Name: _____
Last First Maiden

Is she alive? No/Unknown Yes → Phone # _____

Biological Father's Name: _____
Last First Middle

Is he alive? No/Unknown Yes → Phone # _____

I am filling this form out for Myself My child Other: _____
(My spouse, my friend, my patient, etc....)

If you are filling this out for someone else, please give your name: _____
Last First Middle

If someone in your family with AA has already registered please give his/her name and contact information so that the computer can connect relatives. Everyone in the family should list the same "family AA person" even if there are multiple family members who have AA. Please identify how you are

related to this family AA person (father, aunt, cousin) AND whether you are related on the maternal (mother's) or paternal (father's) side of the family.

No → My spouse or significant other has AA Other _____

- Yes, I am related to proband by blood and my relationship to him/her is: Myself
- Brother Sister Identical twin Fraternal twin Mother Father Uncle
- Aunt Cousin Parents of mother Parents of father Other _____

Name: _____ I am this person's: _____
Last First Middle

Telephone Number: (Primary) _____ (Secondary) _____ FAX: _____

Primary Contact Address: _____

The following information is required (unless starred) to participate in the Registry:

1. Sex: Male Female 2. Date of Birth: ___ / ___ / ____ 3. Are you adopted? No Yes
4. *What is your current marital status? (Check one)
 - Never married Widowed Separated Divorced Married → Number of times _____.
5. *Race: American Indian or Alaska Native Asian Black or African American Hispanic or Latino
 - Native Hawaiian/Other Pacific Islander White Mixed Race: _____ Other: _____
6. My natural hair color is: Red Blonde Brown Auburn Black Gray White Other: _____
7. Are you a Twin? No or Yes: Fraternal Identical Unknown type Triplets or more
8. **HAVE YOU EVER HAD AT ANY TIME IN YOUR LIFE PATCHY ALOPECIA AREATA (AA), TOTALIS (AT) OR UNIVERSALIS (AU)?** No → go to question 17 Yes -(continue)
9. Age of first onset of AA/AT/AU: _____ Under 6 months of age at onset? No or Yes
10. Did you ever have a biopsy of your scalp? No Yes
11. The greatest amount of hair loss ever experienced on your scalp is
 - None Up to 25% 26-50% 51-75% 76-99% 100% (completely bald)
12. Did this episode last for less than 6 months 6 months-1 year 1-2 years greater than 2 years ?
13. Have you lost body hair? No or Yes → Some hair, All hair
14. Are nails involved? No or Yes → Some nails All nails
15. How many episodes of AA/AT/AU have you had?
 - Only 1(Including Continuous) 2-5 6-10 more than 10 Too many to count Don't know
16. Was there an environmental trigger, an event/exposure, or an infection within 6 months of the first episode?
 - No or Yes, explain: _____

***** Do you have seasonal flares of AA? No Yes → Spring Summer Fall Winter

17. Has anyone in your family, not including yourself, ever had patchy AA/AT or AU? No, go to question #19. Or Yes → Are they related by marriage No Yes → Spouse Stepchild Other _____

Are they related by blood? No or Yes → Number of **living blood relatives** with AA in family (**NOT INCLUDING YOU**) is: _____. Number of **living brothers** with AA is _____. Number of **living sisters** with AA is: _____. If you have other **living blood relatives with AA**, check any that apply.

- Mother Parents of mother Uncle(s)(mother's side) Aunt(s)(mother's side) Cousin(s)(mother's side)
 Father Parents of father Uncle(s)(father's side) Aunt(s)(father's side) Cousin(s)(father's side)
 Identical twin Fraternal twin Son Daughter Grandson Granddaughter Multiple children
 Other (please indicate mother's side versus father's side of the family): _____

Number of **dead blood relatives** with AA in family is: _____. If you have **dead blood relatives** with AA, list the relationships of these people to you (mother's versus father's side of the family): _____

18. If your brother(s) or sister(s) have AA/AT/AU, what kind(s) of alopecia do they have? AA AT AU

Do you have **living** family members with AA/AT/AU that are not your brother(s) or sister(s)? No Yes

19. Are you interested in future research on treatments or other research studies, and would you wish to be informed about these studies by Registry personnel? No Yes

20. Are you willing to have blood drawn for research either as AA patient, family member or control? No Yes

21. Are you willing to participate in the Second Tier at any of the following sites? No or Yes → Check all that apply Houston New York Denver Minneapolis San Francisco Private (Local)MD _____

Note: The Registry is unable to pay for travel

22. Have you had blood drawn for HLA in past? No or Yes

23. Have you participated in any alopecia research study in the past? No or Yes

24. Do you have any of the allergic, rheumatic, collagen vascular, or autoimmune diseases listed below?

No →go to end of last page. Yes Please check all that apply and give an approximate age of onset:

Addison's disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
ALLERGIES	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Asthma	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Atopic dermatitis or eczema	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Hay fever/allergic rhinitis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Urticaria (hives) or angioedema	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Other allergies	<input type="checkbox"/> No <input type="checkbox"/> Yes	Specify Type and age of onset: _____
Allergy shots	<input type="checkbox"/> No <input type="checkbox"/> Yes	Time period: From _____ (Year) To _____ (Year) Allergy Shots For: _____
ARTHRITIS	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Ankylosing spondylitis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Spondyloarthritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Juvenile arthritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Reiter's syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Rheumatoid arthritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Other forms of arthritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Specify Type: _____ Age of onset: _____
COLLAGEN VASCULAR DIS.	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Antiphospholipid syndrome (Anticardiolipin syndrome)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Fibromyalgia-fibromyositis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Polymyositis/dermatomyositis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Raynaud's syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
CREST syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Scleroderma	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Sjogren's syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Systemic lupus erythematosus (Lupus, SLE)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Autoimmune polyendocrinopathy- candidosis-ectodermal dystrophy (APS1 = autoimmune polyendocrine syndrome type1)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Autoimmune hemolytic anemia	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Autoimmune hepatitis (non- infectious chronic active hepatitis)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Behcet's disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
AUTOIMMUNE BLISTERING DIS.	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Bullous pemphigoid	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Cicatricial pemphigoid	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Dermatitis herpetiformis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Type: _____
Pemphigus vulgaris	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Type: _____
Cardiomyopathy	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Celiac disease/sprue	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Diabetes	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Type of diabetes : <input type="checkbox"/> Insulin dependent diabetes mellitus (Type I, juvenile diabetes); <input type="checkbox"/> Non-insulin dependent diabetes mellitus (Type II, adult onset) <input type="checkbox"/> Unknown; <input type="checkbox"/> Other: _____ Type of Treatment: (<input type="checkbox"/> All that apply) <input type="checkbox"/> Pills <input type="checkbox"/> Diet <input type="checkbox"/> Insulin <input type="checkbox"/> No treatment
Idiopathic thrombocytopenic purpura (ITP)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Inflammatory bowel disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Type: <input type="checkbox"/> Crohn's disease, <input type="checkbox"/> Ulcerative colitis, <input type="checkbox"/> Irritable bowel syndrome
Clinical Depression	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
ADHD	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Bipolar Disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____

Kidney disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Type of Kidney disease: <input type="checkbox"/> IgA nephropathy, <input type="checkbox"/> Glomerulonephritis, <input type="checkbox"/> Nephrosis, <input type="checkbox"/> Nephrotic syndrome; <input type="checkbox"/> Other _____
Lichen planus	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
NEUROLOGICAL DISEASE	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Chronic inflammatory demyelinating polyneuropathy	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Guillain-Barré syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Multiple sclerosis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Myasthenia gravis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Pernicious anemia	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Polychondritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Primary biliary cirrhosis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Psoriasis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Rheumatic fever	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Sarcoidosis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Schmidt syndrome (APS2 = autoimmune polyendocrine syndrome type2)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Stiff-man syndrome (Moersch-Woltmann syndrome)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Thyroid disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	1.) Age of onset: _____ Do you take thyroid replacement ? <input type="checkbox"/> No <input type="checkbox"/> Yes 2.) Type of thyroid disease: <input type="checkbox"/> Graves disease; <input type="checkbox"/> Myxedema; <input type="checkbox"/> Hyperthyroidism; <input type="checkbox"/> Hashimoto's thyroiditis; <input type="checkbox"/> Goiter; <input type="checkbox"/> Hypothyroidism; <input type="checkbox"/> Other _____
Uveitis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
VASCULITIS	<input type="checkbox"/> No <input type="checkbox"/> Yes	
Churg-Strass syndrome (Allergic granulomatosis)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Cold agglutinin disease	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Essential mixed cryoglobulinemia	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Polyarteritis nodosa	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Polymyalgia rheumatica	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Takayasu arteritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Temporal arteritis (Giant cell arteritis)	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____
Vitiligo	<input type="checkbox"/> No <input type="checkbox"/> Yes	Age of onset: _____ Extent of Vitiligo _____
Waardenburg syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	Congenital: no date of onset

25. Do any of your relatives have any of the above diseases? No or Yes → Please list 1) the diseases, 2) the relationships of these people to you, and 3) whether they are on your mother's side or father's side of the family:

Thank you for participating in the initial questionnaire for the Alopecia Areata Registry. We will contact you again after we review your information. You may withdraw from the Registry at any time. You can contact us and mail, fax, or email your forms and questions to:

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1400 Pressler Street, Houston, Texas 77030 Tel: 1-866-837-1050 Fax: 713-794-1491
 E-Mail: alopeciaregistry@mdanderson.org Website: <http://www.alopeciaareataregistry.org>