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'sAddress:_____
Street City State Zip Country

Specialty:_____ Fax: _____Tel #_____

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

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

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

Alopecia Areata Registry M. D. Anderson Cancer Center Department of Dermatology Box 1452
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