A COPY OF THIS PAGE MUST ACCOMPANY SPECIMENS

CONTROL ONLY LONG FORM

Fill out the top form to identify the patient's blood specimen. This top form accompanies the Long Form Questionnaire.

Short Form ID# ________Long Form ID#__________MR#______Date: ____/___/_____
Site: ❑ CO ❑ MN ❑ NY ❑ SF ❑TX ❑PRIVATE-Name:______________ MM DD YYYY
Name:_______________________________ Gender: ❑M ❑F Date of Birth:_____________
Last First M.I. MM DD YYYY

Group	AA Type	Not Affected
Control	Non AA	❑ Family w/o AA ❑ Spouse of AA patients ❑ Others _________________

Biological Father's Last Name:_______________________________
Biological Mother's Maiden Name:___________________________

✂...✂

CONTROL ONLY LONG FORM

Please cut this bottom form: Ship it with the DATED blood tubes and label the tubes with the patient's name and Short Form ID#.

Short Form ID# ________Long Form ID#__________MR#______Date: ____/___/_____
Site: ❑ CO ❑ MN ❑ NY ❑ SF ❑TX ❑PRIVATE-Name:______________ MM DD YYYY
Name:_______________________________ Gender: ❑M ❑F Date of Birth:_____________
Last First M.I. MM DD YYYY

Group	AA Type	Not Affected
Control	Non AA	❑ Family w/o AA ❑ Spouse of AA patients ❑ Others _________________

Biological Father's Last Name:_______________________________
Biological Mother's Maiden Name:___________________________

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER

National Alopecia Areata Registry Patient Data "Control"

Part I: Patient Section

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

The goal of the study is to determine the susceptibility genes in a disease called Alopecia Areata (AA). AA is considered an autoimmune disease, in which the immune system mistakenly attacks the hair follicles. Alopecia areata is characterized as a patchy hair loss (AA), or complete scalp hair loss with or without some body hair loss (Alopecia Totalis, AT) or complete entire scalp and body hair loss (Alopecia Universalis, AU). ***In order to be able to find the susceptibility genes we need biological specimens from normal unaffected controls. Individuals who are participating as a control should have no blood relation with anyone who has AA*** **(as described above.)**

Please fill in all the blanks or check the appropriate boxes: Date: _____ /______/______

A. Contact & Personal Information

1. Last Name (Registrant): ____

First Name: _______________________Middle:______________ Maiden:__________

2. Current Address: ____
Street City State Zip Country

Telephone Number: (Day)_____________________(Evening)____________________

FAX: _____________________Email: ___________________________________

3. Sex: ❑ Male ❑ Female

4. Date of Birth: (MM/DD/YY) -----/-----/-----

5. Are you adopted? ❑ No ❑ Yes

6.What is your Current Marital status? (Check one)

❑ Never married ❑ Widowed ❑ Separated ❑ Divorced ❑ Married (Number of times___)

7. Have you EVER had at ANY TIME in your life patches of baldness (ALOPECIA AREATA; AA), or total scalp hair loss (ALOPECIA TOTALIS;AT), or total scalp and entire body hair loss (ALOPECIA UNIVERSALIS; AU)? ❑ No (continue the next question) ❑ Yes

8. Do you have any blood relatives with AA, AT, or AU (as explained above)? ❑ No ❑ Yes

	AA/AT/AU	Other type of hair loss (if known)	Age of onset
Biological mother	----------------------	--------------	------------------
Parents of mother	----------------------	--------------	------------------
Aunts-Uncles (mother side	----------------------	--------------	------------------
Cousins (mother side)	----------------------	--------------	------------------
Biological father	----------------------	--------------	------------------
Parents of father	----------------------	--------------	------------------
Aunts-Uncles (father side)	----------------------	--------------	------------------
Cousins (father side)	---------------------	--------------	------------------
Sister(s)	----------------------	--------------	------------------
Brother(s)	----------------------	--------------	------------------
Daughter(s)	----------------------	--------------	------------------
Son(s)	----------------------	--------------	------------------
Grand children	----------------------	--------------	------------------

9. Are you willing to have blood drawn for research as a control? ❑ No ❑ Yes

B. Ethnic/Racial Background

10. Where were you born?
____ or ❑ Don't Know
city state country

11. Where was your mother born?
____ or ❑ Don't Know
city state country

12. Where was your father born?
____ or ❑ Don't Know
city state country

13. Maternal grandmother?
____ or ❑ Don't Know
city state country

14. Maternal grandfather?
____ or ❑ Don't Know
city state country

15. Paternal grandmother?
____ or ❑ Don't Know
city state country

16. Paternal grandfather?
____ or ❑ Don't Know
city state country

Site: ❑MN ❑SF ❑CO ❑TX ❑NY ❑Private MD Short Form I.D. _______ Long Form I.D. _________

Please look at the ethnic group categories below and choose the best **one or two** ancestries for your closest blood relatives to fill squares in with the letters that match the ancestries.

Biological Mother		Maternal Grandmother		Maternal Grandfather		Biological Father		Paternal Grandmother		Paternal Grandfather	

A. **American Indian or Alaskan Native.** A person having origins in any of the original peoples of North and South America(including Central America), and who maintains tribal affiliation

B. **Asian.** A person having origins in any of the original peoples of Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Island, Thailand, and Vietnam.

C. **Black or African American.** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro can be used in addition to "Black or African American"

D. **Hispanic or Latino**. A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central America, or other Spanish culture or origin, regardless of race. Terms such as "Spanish origin" can be used in addition to "Hispanic or Latino".

E. **Native Hawaiian or Other Pacific Islander**. A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

R. **White**. A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

S. **Other,** describe: ____

T. Unknown (Don't know)

17. Do you have allergies? **Please check all that apply**.

❑ Poison ivy or oak ❑ Drugs (specify)------------------------ ❑ Aspirin

❑ Foods (specify) ____

❑ Ragweed ❑ Pollen ❑ Animal dander ❑ Mold

❑ Other ___________________________________

18. Please check any you have had:

❑ Warts ❑ Fungal infection (location: scalp, feet, groin, body, other________)

❑ Candida/yeast infection?

19. Have you ever smoked? ❑No ❑Yes→ Packs/day______ Number of years_______

20. Do you drink caffeine? ❑No ❑Yes→ ❑Coffee ❑Tea ❑Chocolate ❑Soft drinks.

21. Were you breastfed as a baby? ❑No ❑Yes ❑ partially ❑don't know

22. Did you experience any of the following events within past several months?

If ❑ **No,** go to next question. If ❑ **Yes,** please **check all that apply:**

Loss or change of job ❑ "Stress" at work ❑ Stress in family❑

Emotional stress ❑ Illness ❑ -type - please list:_______________

23. Did you experience any of the following within past several months?

If ❑ **No,** go to next question.

If ❑**Yes,** please check

Surgery with local or general anesthesia ❑

Vaccination (types) ❑

Allergy shots (number, types) ❑

Therapy with any immunologic agent (list agent)❑

Had allergic reaction(s) to ❑

Had chemotherapy (types) ❑

Had radiation therapy ❑

Changed diet or lost weight ❑

Others ❑

24. Have you ever had any of the allergic, rheumatic, collagen vascular, or autoimmune diseases listed below? If ❑ **No,** go to next question.

❑ **Yes,** please **check all that apply** and **provide the approximate date** of diagnosis and any **documentation** if available.

Condition	No	Yes	Details
Addison's disease	❑No	❑Yes	Age of onset: ________
ALLERGIES			
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: ________________________________
Allergy shots	❑No	❑Yes	Time period: From_______(Year) To_______(Year) Allergy Shots Type:___________________________________
ARTHRITIS			
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.			
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 active hepatitis)	❑No	❑Yes	Age of onset: ________
Behcet's disease	❑No	❑Yes	Age of onset: ________
AUTOIMMUNE BLISTERING DIS.			
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 diab ❑Non-insulin dependent diabetes mellitus (Type II, adult onset) ❑Unknown; Other:____________________________ Type of Treatment: (3all that apply) ❑Pills ❑Diet ❑Insulin ❑No treatment
Down Syndrome	❑No	❑Yes	Age of onset: ________
Idiopathic thrombocytopenic purpura (ITP)	❑No	❑Yes	Age of onset: ________
Immunodeficiency syndrome	❑No	❑Yes	Age of onset: ________

Inflammatory bowel disease	❑No	❑Yes	Age of onset: _______ Type : ❑Crohn's disease, ❑Ulcerative colitis, ❑ Irritable bowel syndrome
Clinical Depression Bipolar Disease **ADHD**	❑No ❑No ❑No	❑Yes ❑Yes ❑Yes	Age of onset: _____ Medication/Treatment:___________________________ Age of onset: _____ Medication/Treatment:___________________________ Age of onset: _____ Medication/Treatment:___________________________
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 Chronic inflammatory demyelinating polyneuropathy Guillain-Barré syndrome Multiple sclerosis Myasthenia gravis	 ❑No ❑No ❑No ❑No	 ❑Yes ❑Yes ❑Yes ❑Yes	 Age of onset: ________ Age of onset: ________ Age of onset: ________ Age of onset: ________
Pernicious anemia	❑No	❑Yes	Age of onset: ________
Piebaldism	❑No	❑Yes	Congenital: Date of birth:_________
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 Churg-Strass syndrome (Allergic granulomatosis) Cold agglutinin disease Essential mixed cryoglobulinemia Polyarteritis nodosa Polymyalgia rheumatica Takayasu arteritis Temporal arteritis (Giant cell arteritis)	 ❑No ❑No ❑No ❑No ❑No ❑No ❑No	 ❑Yes ❑Yes ❑Yes ❑Yes ❑Yes ❑Yes ❑Yes	 Age of onset: ________ Age of onset: ________ Age of onset: ________ Age of onset: ________ Age of onset: ________ Age of onset: ________ Age of onset: ________
Vitiligo(white skin spots)	❑No	❑Yes	Age of onset: ________
Waardenburg syndrome	❑No	❑Yes	Congenital: no date of onset

25. Do any of your relatives have any of the above disease? ❑ No ❑ 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:

	Type of diseases	Age of onset	Alive/Dead
Biological mother	-------------------------	---------------	❑ / ❑
Parents of mother (please indicate mother or father)	-------------------------	---------------	❑ / ❑
Aunts (mother side)	------------------------	---------------	❑ / ❑
Uncles (mother side)	------------------------	---------------	❑ / ❑
Cousins (mother side)	-------------------------	---------------	❑ / ❑
Biological father	-------------------------	---------------	❑ / ❑
Parents of father (please indicate mother or father)	-------------------------	---------------	❑ / ❑
Aunts (father side)	-------------------------	---------------	❑ / ❑
Uncles (father side)	--------------------------	---------------	❑ / ❑
Cousins (father side)	-------------------------	---------------	❑ / ❑
Sister(s)	------------------------	---------------	❑ / ❑
Brother(s)	---------------------------	---------------	❑ / ❑
Daughter(s)	---------------------------	---------------	❑ / ❑
Son(s)	--------------------------	---------------	❑ / ❑
Grand children	--------------------------	---------------	❑ / ❑

26. Do you have any conditions you've been diagnosed with? (eg: Infection diseases, Cancer, Genetic diseases,…). Please explain.

____

____

____

____

27. Please list all current medications you take FOR ANY DISORDER and explain why. List their dosages. Include over the counter medications and vitamins or herbs and special diets.

____

____

____

____

____

Site: ❑MN ❑SF ❑CO ❑TX ❑NY ❑Private MD Short Form I.D. _______ Long Form I.D. _________

Physician: Please review Part I with patient before you continue with Part II

Part II: Physician Section

Site of Long form Registration: ❑MN ❑SF ❑CO ❑TX ❑NY ❑Other------------------------

Date of interview: -----/-----/----- (MM/DD/YYYY)   Name of interviewer: ____________________

1. Height? ----ft.----in./- ---m.-----cm.   2. Weight? --------lb./-------kg

3. Please Circle any other skin conditions on exam:

- ❑ Alopecia Areata
- ❑ Androgenic Alopecia
- ❑ Cicatricial Alopecia
- ❑ Fingernails or toenails: pitting, dystrophy, onycholysis, onychomycosis
- ❑ Acne or Acne rosacea
- ❑ Atopic dematitis or eczema (nummular)
- ❑ Bacterial skin infection, impetigo, boils, Other____________________________
- ❑ Benign skin growth: Seborrheic keratoses, skin tags, Other__________________
- ❑ Candidiasis Mouth, nails, intertrigo
- ❑ Dysplastic moles
- ❑ Freckles or Photodamaged skin or Actinic keratoses
- ❑ Icthyosis vulgaris
- ❑ Inflammatory skin disorder: Lichen planus, Lupus, Other __________________
- ❑ Necrobiosis lipoidica diabeticorum, Diabetic dermopathy
- ❑ Psoriasis
- ❑ Pretibial myxedema
- ❑ Scleroderma
- ❑ Seborrhea / dandruff
- ❑ Nail bed telangiectasias, Raynaud's phenomenon
- ❑ Tinea pedis, capitus, corporis, unguum
- ❑ Warts or molluscum or other viral ____________________________
- ❑ Vitiligo, Idiopathic guttate hypomelanosis
- ❑ Other:____
- ❑ None

OFFICIAL USE ONLY

Long Form Questionnaire: Received: MM / DD / YYYY
Person who reviewed Long For- Questionnaire at Central Site: ____

Long Form Questionnaire: Entered: MM / DD / YYYY
Person Who Entered Long Form Questionnaire into Database: ____