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The National Alopecia Areata Registry—Update

Madeleine Duvic¹, Angela M. Christiano², Maria K. Hordinsky³, David A. Norris⁴, Vera H. Price⁵, and Christopher I. Amos¹

¹Department of Dermatology, University of Texas, MD Anderson Cancer Center, Houston, Texas, USA

²Department of Dermatology, Columbia University, New York, New York, USA

³Department of Dermatology, University of Minnesota, Minneapolis, Minnesota, USA

⁴Department of Dermatology, University of Colorado, Denver, Colorado, USA

⁵Department of Dermatology, University of California, San Francisco, California, USA

The National Alopecia Areata Registry (NAAR) was established as a collaborative effort of five academic centers and was funded by the NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases) on 23 September 2000 and now has been transferred to the National Alopecia Areata Foundation (NAAF). The NAAR has an internet domain and website <http://www alopeciaareataregistry.com>, which allows patients to self-register in the first tier. Patients were then invited to one of the five centers to have an examination and blood was drawn for samples of DNA, sera, and lymphoblast lines to be used for genetic studies. This will update the progress of the NAAR over the past 10 years and its emergence as a clinical trials network and biobank.

At the time of the Summit, 6,153 of the 8,942 first-tier registrants had dermatologist-confirmed alopecia areata (AA), including 2,202 with alopecia areata persistent (AAP)>1 year, 2,142 with alopecia universalis AU, 897 with alopecia totalis (AT), and 823 with transient AA (AAT)<1 year. There were 2,609 AA patients examined in tier 2, including 729 with AAP, 526 with AAT, 339 with AT, and 1,015 with AU as well as 396 unrelated controls and 463 related but unaffected. The distribution of age of onset is shown in Figure 1. We have identified 264 multiplex families and acquired 40 for linkage analysis.

The Registry has been used for a number of projects relating to the pathogenesis and quality of life: (1) confirming the reported human leukocyte antigen associations; (2) studies of cytokine profiles in AA with or without atopy; (3) case-control study—incidence of autoimmunity in AA patients; (4) EBV (Epstein–Barr virus) as a trigger for AA in adolescents; (5) treatment practices in AA; (6) quality of life in adolescents and adults with AA; (7) self-reported trigger factors for AA; and last but not least (8) association and

Correspondence: Madeleine Duvic, Department of Dermatology, University of Texas, MD Anderson Cancer Center, 1400 Pressler Street, Unit 1452, Houston, Texas 77030, USA. mduvic@mdanderson.or

CONFLICT OF INTEREST

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linkage studies—genome-wide association studies revealing eight novel genes associated with AA that have been confirmed and being translated into clinical trials.

The NAAR continues to accept patient registrations. NAAR is involved in an NIH (National Institutes of Health)-funded biomarker study to acquire scalp biopsies and DNA samples. The five centers in the Registry (University of Texas MD Anderson Cancer Center; Columbia University; University of Minnesota; University of Colorado; University of California, San Francisco) are a consortium for clinical trials, and the Registry sample collection represents an existing biobank for future translational studies.

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Abbreviations

AA	alopecia areata
NAAR	National Alopecia Areata Registry

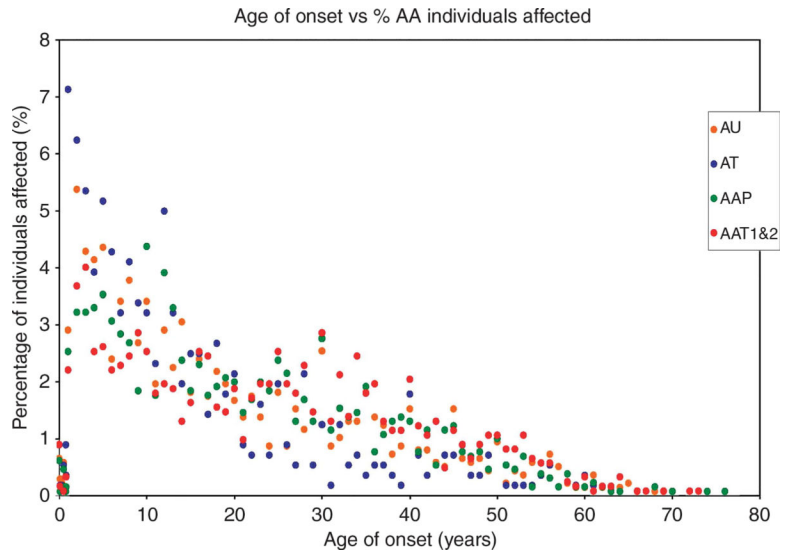


Figure 1. Age distribution of onset of alopecia areata.
 AU, alopecia universalis; AT, alopecia totalis; AAP, alopecia areata persistent, duration >1 year; AAT1 and 2, alopecia areata transient—1 is duration <6 months, 2 is duration 6 months to 1 year.

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