**Title:** The Relationship Between Patient-Reported Severity of Hair Loss and Health-Related Quality of Life and Treatment Patterns Among Patients with Alopecia Areata

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| Participant Sociodemographic Characteristic    | Total (N=1327)        |  |  |  |  |
|--|-----------------------|--|--|--|--|
| Age, years, Mean (SD) [range]                  | 39.7 (12.3) [18 – 84] |  |  |  |  |
| Gender, n (%)                                  |                       |  |  |  |  |
| Female   | 775 (58.4%)           |  |  |  |  |
| Racial Background/Ethnicity, n %               |                       |  |  |  |  |
| Asian, non-Hispanic                            | 27 (2.0 %)            |  |  |  |  |
| Black, non-Hispanic                            | 341 (25.7 %)          |  |  |  |  |
| Hispanic only                                  | 42 (3.2 %)            |  |  |  |  |
| Multi-racial                                   | 156 (11.8 %)          |  |  |  |  |
| Other  | 57 (4.3 %)            |  |  |  |  |
| White, non-Hispanic                            | 699 (52.7 %)          |  |  |  |  |
| Prefer not to say                              | 5 (0.4 %)             |  |  |  |  |
| Relationship Status, n (%)                     |                       |  |  |  |  |
| Single   | 261 (19.7 %)          |  |  |  |  |
| Married  | 928 (69.9 %)          |  |  |  |  |
| Domestic Partnership, unmarried                | 56 (4.2 %)            |  |  |  |  |
| Separated or Divorced                          | 70 (5.3 %)            |  |  |  |  |
| Widowed  | 12 (0.9 %)            |  |  |  |  |
| Highest Education Level, n (%)                 |                       |  |  |  |  |
| Less than high school                          | 15 (1.13 %)           |  |  |  |  |
| Secondary/high school/GED                      | 147 (11.1 %)          |  |  |  |  |
| Associate degree, technical, or trade school   | 376 (28.3 %)          |  |  |  |  |
| College/university degree (e.g., BA, BS)       | 591 (44.5 %)          |  |  |  |  |
| Post-graduate degree (e.g., MA, MBA, PhD)      | 198 (14.9 %)          |  |  |  |  |
| Type of Health Insurance <sup>1</sup> , n (%)  |                       |  |  |  |  |
| Employer-provided insurance                    | 660 (49.7 %)          |  |  |  |  |
| Self-provided insurance (including Obama Care) | 142(10.7 %)           |  |  |  |  |
| Veterans Affairs/Military healthcare           | 21 (1.6 %)            |  |  |  |  |
| Medicare                                       | 339 (25.6 %)          |  |  |  |  |
| Medicaid                                       | 90 (6.8 %)            |  |  |  |  |
| None (uninsured)                               | 75 (5.7 %)            |  |  |  |  |

## Supplemental Table 1. Sociodemographic Characteristics

|   |  | Curren                                    | t Scalp Hair I                                 | LOSS                                     |  |       |             |
|---|--|---|--|--|--|-------|-------------|
|   | No missing<br>hair<br>(0%)<br>(n = 34) | A limited<br>area<br>(1-20%)<br>(n = 528) | A<br>moderate<br>area<br>(21-49%)<br>(n = 347) | A large<br>area<br>(50-94%)<br>(n = 135) | Nearly all<br>or all<br>(95-<br>100%)<br>(n = 283) | χ²    | P-<br>Value |
| Eyebrow: current, n (%)   |  |   |  |  |  |       | •           |
| I have full eyebrows on each eye  | 23 (67.7%)                             | 205 (38.8%)                               | 87 (25.1%)                                     | 23<br>(17.0%)                            | 15 (5.3%)  |       | <0.001      |
| I have a minimal gap(s) or a<br>minimal amount of thinning<br>in at least one of my<br>eyebrows | 11 (32.4%)                             | 251 (47.5%)                               | 175<br>(50.4%)                                 | 42<br>(31.1%)                            | 36<br>(12.7%)                                      | 744.1 |             |
| I have a large gap(s) or a<br>large amount of thinning in<br>at least one of my eyebrows        | 0 (0.0%)                               | 51 (9.7%)                                 | 69 (19.9%)                                     | 42<br>(31.1%)                            | 23 (8.1%)  |       |             |
| I have no or barely any eyebrow hairs   | 0 (0.0%)                               | 21 (4.0%)                                 | 16 (4.6%)                                      | 28<br>(20.7%)                            | 209<br>(73.9%)                                     |       |             |
| Upper and Lower Eyelashes: cur  | <b>rent</b> , n (%)                    |   | -  |  |  |       |             |
| I have full eyelashes on each eyelid  | 26 (76.5%)                             | 218 (41.3%)                               | 110<br>(31.7%)                                 | 43<br>(31.9%)                            | 34<br>(12.0%)                                      | 501.0 | <0.001      |
| I have a minimal gap or<br>minimal gaps along the<br>eyelids                                    | 4 (11.8%)                              | 221 (41.9%)                               | 141<br>(40.6%)                                 | 42<br>(31.1%)                            | 44<br>(15.6%)                                      |       |             |
| I have a large gap or large gaps along the eyelids  | 4 (11.8%)                              | 64 (12.1%)                                | 67 (19.3%)                                     | 26<br>(19.3%)                            | 26 (9.2%)  |       |             |
| I have no or barely any eyelash hair  | 0 (0.0%)                               | 25 (4.7%)                                 | 29 (8.4%)                                      | 24<br>(17.8%)                            | 179<br>(63.3%)                                     |       |             |
| Fingernails and Toenails: current   | t, n (%)                               |   |  |  |  |       |             |
| Nails are not at all damaged  | 27 (79.4%)                             | 300 (56.8%)                               | 134<br>(38.6%)                                 | 60<br>(44.4%)                            | 110<br>(38.9%)                                     |       | <0.001      |
| At least one nail is a little damaged   | 3 (8.8%)                               | 164 (31.1%)                               | 127<br>(36.6%)                                 | 34<br>(25.2%)                            | 79<br>(27.9%)                                      |       |             |
| At least one nail is moderately damaged   | 4 (11.8%)                              | 57 (10.8%)                                | 76 (21.9%)                                     | 31<br>(23.0%)                            | 72<br>(25.4%)                                      | 95.7  |             |
| At least one nail is very<br>damaged, or you have lost at<br>least one nail                     | 0 (0.0%)                               | 7 (1.3%)                                  | 10 (2.9%)                                      | 10 (7.4%)                                | 22 (7.8%)  |       |             |
| Eye Irritation: in the past 7 days,   | n (%)                                  |   |  |  |  |       |             |
| My eyes have not been irritated   | 23 (67.7%)                             | 275 (52.1%)                               | 138<br>(39.8%)                                 | 33<br>(24.4%)                            | 119<br>(42.1%)                                     |       | <0.001      |
| My eyes have been a little irritated  | 8 (23.5%)                              | 181 (34.3%)                               | 133<br>(38.3%)                                 | 63<br>(46.7%)                            | 94<br>(33.2%)                                      | 66.3  |             |
| My eyes have been moderately irritated  | 3 (8.8%)                               | 67 (12.7%)                                | 68 (19.6%)                                     | 29<br>(21.5%)                            | 57<br>(20.1%)                                      | 00.5  |             |
| My eyes have been severely irritated  | 0 (0.0%)                               | 5 (1.0%)                                  | 8 (2.3%)                                       | 10 (7.4%)                                | 13 (4.6%)  |       |             |

## Supplemental Table 2. Current Alopecia Non-Scalp Sign/Symptoms by Scalp Hair Loss Severity

|   | Current Scalp Hair Loss                |   |   |  |  |                    |             |  |
|---|--|---|---|--|--|--------------------|-------------|--|
|   | No missing<br>hair<br>(0%)<br>(n = 34) | A limited<br>area<br>(1-20%)<br>(n = 528) | A<br>moderate<br>area<br>(21-49%)<br>(n = 347)              | A large<br>area<br>(50-94%)<br>(n = 135) | Nearly all<br>or all<br>(95-100%)<br>(n = 283) | Overall<br>F-value | P-<br>Value |  |
| Duration of Alopecia Areata, years  |  |   |   |  |  |                    |             |  |
| Mean (SD) [range]   | $7.1 \pm 6.2$<br>[1 - 24.3]            | $5.0 \pm 6.9$<br>[ $0.2 - 54.1$ ]         | $7.3 \pm 9.4$<br>[0.4 - 52.2]                               | $14.4 \pm 12.0$<br>[0.9 - 53.7]          | $22.9 \pm 13.9$<br>[0.3 - 67.4]                | 165.8              | < 0.001     |  |
| Number of Episodes of Hair<br>Loss <sup>2</sup>   | n = 34                                 | n = 526                                   | n = 341   | n = 134                                  | n = 276  |                    |             |  |
| Mean (SD) [range]   | $1.8 \pm 1.3^{a}$<br>[1 - 8]           | $3.5 \pm 5.6^{a}$<br>[0 - 60]             | $\begin{array}{c} 4.2 \pm 5.3^{ab} \\ [0 - 50] \end{array}$ | 7.4 ± 9.3°<br>[0 - 50]                   | $5.4 \pm 8.5^{b}$<br>[0 - 60]                  | 12.3               | <0.001      |  |
| Since the time you first<br>started experiencing<br>symptoms of alopecia<br>areata, how would you<br>describe your hair loss over<br>time?, n (%) |  |   |   |  |  | χ²                 | P-<br>Value |  |
| Improving   | 23 (67.7%)                             | 140<br>(26.5%)                            | 35 (10.1%)  | 8 (5.9%)                                 | 8 (2.8%)                                       |                    |             |  |
| Stable/no changes   | 4 (11.8%)                              | 169<br>(32.0%)                            | 83 (23.9%)  | 8 (5.9%)                                 | 47 (16.6%)                                     |                    | <0.001      |  |
| Worsening slowly  | 2 (5.9%)                               | 126<br>(23.9%)                            | 139<br>(40.1%)  | 52 (38.5%)                               | 52 (18.4%)                                     | 485.5              |             |  |
| Worsening rapidly   | 1 (2.9%)                               | 29 (5.5%)                                 | 15 (4.3%)   | 18 (13.3%)                               | 116<br>(41.0%)                                 |                    |             |  |
| Unpredictable hair loss and regrowth  | 3 (8.8%)                               | 62 (11.7%)                                | 74 (21.3%)  | 49 (36.3%)                               | 53 (18.7%)                                     |                    |             |  |
| Not Sure  | 1 (2.9%)                               | 2 (0.4%)                                  | 1 (0.3%)  | 0 (0.0%)                                 | 7 (2.5%)                                       |                    |             |  |
| Current Hair Loss Lasted for, n (%)   |  |   |   |  |  | χ <sup>2</sup>     | P-<br>Value |  |
| Less than 1 year  | 20 (58.8%)                             | 248<br>(47.0%)                            | 90 (25.9%)  | 32 (23.7%)                               | 27 (9.5%)                                      |                    |             |  |
| 1 – 4 years   | 13 (38.2%)                             | 247<br>(46.8%)                            | 182<br>(52.5%)  | 60 (44.4%)                               | 39 (13.8%)                                     | 509.6              | < 0.001     |  |
| More than 4 years   | 1 (2.9%)                               | 33 (6.3%)                                 | 75 (21.6%)  | 43 (31.9%)                               | 217<br>(76.7%)                                 |                    |             |  |

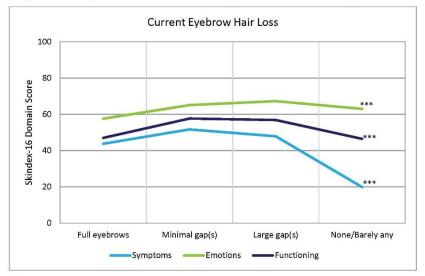
## Supplemental Table 3. Duration of Alopecia Areata and History of Hair Loss by Current Scalp Hair Loss

 $^{1}$ Pairwise comparisons between means were performed using Tukey's test adjusting for multiple comparisons at p <0.05. Means followed by a common letter are not significantly different.

<sup>2</sup>Analysis performed using Episodes of Hair Loss variable trimmed to exclude observations with reported values of 61 episodes or more (n = 1311).

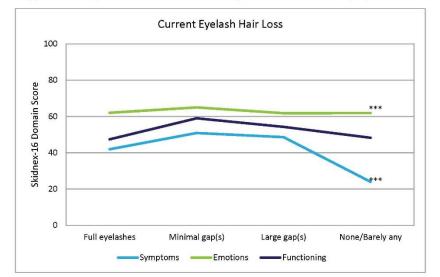
Supplemental Table 4. Treatment Experience by Current Scalp Hair Loss

|   |                       |                                       | Current Scalp Hair Loss                                   |               |                                   |                             |                                       |  |  |
|---|-----------------------|---------------------------------------|---|---------------|-----------------------------------|-----------------------------|---------------------------------------|--|--|
| Alopecia Areata Treatment                                   | Ever<br>Used<br>n (%) | Currently<br>on<br>n (%) <sup>1</sup> | No<br>missing<br>hair<br>(0%)A limited<br>area<br>(1-20%) |               | A<br>moderate<br>area<br>(21-49%) | A large<br>area<br>(50-94%) | Nearly all<br>or all<br>(95-<br>100%) |  |  |
| Oral Treatments   | 364<br>(33.8%)        | 208<br>(24.3%)                        | 4 (1.9%)  | 97<br>(46.6%) | 67<br>(32.2%)                     | 12 (5.8%)                   | 28<br>(13.5%)                         |  |  |
| Topical Treatments (applied to the skin)                    | 624<br>(57.9%)        | 230<br>(26.9%)                        | 2 (0.9%)  | 90<br>(39.1%) | 88<br>(38.3%)                     | 34<br>(14.8%)               | 16 (7.0%)                             |  |  |
| Injection Treatments  | 445<br>(41.3%)        | 113<br>(13.2%)                        | 3 (2.7%)  | 61<br>(54.0%) | 35<br>(31.0%)                     | 7 (6.2%)                    | 7 (6.2%)                              |  |  |
| Phototherapy (e.g. PUVA, psoralen plus UVB)                 | 165<br>(15.3%)        | 94<br>(11.0%)                         | 2 (2.1%)  | 49<br>(52.1%) | 36<br>(38.3%)                     | 7 (7.5%)                    | 0 (0.0%)                              |  |  |
| Laser Therapy   | 137<br>(12.7%)        | 74 (8.7%)                             | 1 (1.4%)  | 42<br>(56.8%) | 26<br>(35.1%)                     | 5 (6.8%)                    | 0 (0.0%)                              |  |  |
| Platelet-Rich Plasma (PRP)                                  | 44<br>(4.1%)          | 21 (2.5%)                             | 0 (0.0%)  | 10<br>(47.6%) | 10<br>(47.6%)                     | 1 (4.8%)                    | 0 (0.0%)                              |  |  |
| Dietary changes or supplements                              | 354<br>(32.8%)        | 228<br>(26.7%)                        | 3 (1.3%)  | 86<br>(37.7%) | 76<br>(33.3%)                     | 33<br>(14.5%)               | 30<br>(13.2%)                         |  |  |
| Acupuncture   | 108<br>(10.0%)        | 26 (3.0%)                             | 0 (0.0%)  | 16<br>(61.5%) | 6 (23.1%)                         | 2 (7.7%)                    | 2 (7.7%)                              |  |  |
| Therapy with a psychologist or psychiatrist                 | 191<br>(17.7%)        | 74 (8.7%)                             | 1 (1.4%)  | 24<br>(32.4%) | 23<br>(31.1%)                     | 8 (10.8%)                   | 18<br>(24.3%)                         |  |  |
| Non-medical intervention (e.g., wearing wigs or camouflage) | 373<br>(34.6%)        | 266<br>(31.1%)                        | 0 (0.0%)  | 34<br>(12.8%) | 40<br>(15.0%)                     | 44<br>(16.5%)               | 148<br>(55.6%)                        |  |  |
| Other   | 38<br>(3.5%)          | 18 (2.1%)                             | 0 (0.0%)  | 6 (33.3%)     | 3 (16.7%)                         | 5 (27.8%)                   | 4 (22.2%)                             |  |  |
| No Previous Treatment<br>Experience                         | 249<br>(23.1%)        |                                       |   |               |                                   |                             |                                       |  |  |
| No Current Treatment<br>Experience                          |                       | 472<br>(35.6%)                        |   |               |                                   |                             |                                       |  |  |



Supplemental Figure 1. Health-Related Quality of Life (Skindex-16) by Eyebrow Hair Loss

\*\*\* p<0.0001; Pairwise comparisons between group means were performed using the Tukey-Kramer test adjusting for multiple comparisons



Supplemental Figure 2. Health-Related Quality of Life (Skindex-16) by Eyelash Hair Loss

\*\*\* p<0.0001; Pairwise comparisons between group means were performed using the Tukey-Kramer test adjusting for multiple comparisons