National Alopecia Areata Foundation


This report represents National Alopecia Areata Foundation's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

National Alopecia Areata Foundation
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Mission:
The Foundation funds medical research to find a cure or acceptable treatment, supports those with the disease, and educates the public about alopecia areata.

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1. What are we aiming to accomplish?
NAAF endeavors to find potential treatments and a cure for alopecia areata. NAAF also strives to educate as many as possible about alopecia areata including our legislators, while providing support to all those with the disease as well as their loved ones.

2. What are our strategies for making this happen?
NAAF’s Alopecia Areata Treatment Development Program is designed to leverage the building blocks already in place to accelerate research. The driving focus will be the facilitation of clinical trials for potential treatments, while sustaining attention to the root causes of the disease to find a potential cure. The overall strategies of the TDP going forward are: 1. Host NAAF sponsored Research Summits to distill learning from recent discoveries and focus future research initiatives that have the highest probability to yield potential treatments and to chart the path forward on an ongoing basis. 2. Make strategic investments in promising research based on shared knowledge from the research summits and through ongoing peer review. Be opportunistic in identifying and funding research on an ad hoc basis that emerges in the rapidly changing field of immunology. 3. Sustain and grow the Alopecia Areata Registry, Biobank and Clinical Trials Network (the Registry) to enable, facilitate, and accelerate clinical research. 4. Raise the profile of alopecia areata as an accessible autoimmune disease to study, make key strategic contacts, draw new researchers to the field, and increase awareness of NAAF as a valuable strategic research partner by participating in and sponsoring relevant scientific meetings. 5. Continue to focus on organizational planning, policy development and implementation, including solid business plans and action plans for guidance and review. Sustain key support resources including key contract research staff, communications resources/personnel dedicated to plan implementation. NAAF guides the planning and promotion of awareness and fundraising events throughout the year, with emphasis on the Alopecia Areata Awareness Month of September. These events increase the public profile of alopecia areata as they better educate the general public about the disease. NAAF’s Alopecia Areata Legislative Liaisons strive to build and maintain a Congressional environment that is knowledgeable about alopecia areata, sympathetic to the needs of the alopecia areata community, well-versed on the need for further research, and disposed toward continued or increased funding for such investigation. The overall strategies of the Legislative Liaisons are: 1. Contact their congressional representatives whenever there are current legislative issues involving alopecia areata, particularly those that pertain to research funding or insurance coverage for those with alopecia areata. 2. Meet with their congressional representatives at both the local and national level to keep the legislators apprised of those issues and legislation most critical for the alopecia areata community. NAAF has a strong support network with groups in the United States and such countries as Argentina, Australia, Barbados, India, the Philippines and throughout Europe and the UK. This support helps provide morale and sense of community to those with alopecia areata and their families.

3. What are our organization’s capabilities for doing this?
NAAF has a track record for trustworthiness, accomplishment, transparency, and devotion to its community that reaches back over three decades. NAAF has a Scientific Advisory Council providing us the benefit of its members’ combined knowledge and connections to the research community. NAAF has a library of resources - packets, brochures, newsletters, videos, DVDs, and school packs - we share free upon request, covering a wide array of topics about alopecia areata. These materials are distributed to health professionals, as well as those affected. NAAF has a committed staff with combined decades of experience helping those with alopecia areata, along with 140 volunteers in 138 cities. NAAF has an informative website, Facebook page and Twitter feed. NAAF has a nation-wide pool of 100 Legislative Liaisons who actively advocate on governmental issues most critical to the alopecia areata community.
4. How will we know if we're making progress?

NAAF is dedicated to knowing whether we are making progress. NAAF’s board annually assesses the organization’s performance and effectiveness, and produces a written report. Additionally, NAAF produces an annual report summarizing not only our programs, finances and governance, but our research progress as well. The annual report is available to the public.

5. What have and haven't we accomplished so far?

Scientists identified genetic variations associated with the development of alopecia areata. It has been discovered alopecia areata shares more genetic similarities with other autoimmune diseases (rheumatoid arthritis, type 1 diabetes and celiac disease) than with other strictly hair loss-related diseases. This finding not only identifies potential targets for alopecia areata therapy, but suggests a shared disease mechanism that could help scientists study the immune pathology and develop treatments for all four diseases. In 2012 following successful visits on Capitol Hill, alopecia areata was selected as one of 39 out of 12,000 known diseases for targeted assistance through the Food and Drug Administration’s Patient-Focused Drug Development initiative. In June 2013, the National Institutes of Health’s (NIH) announced that NIH scientists and their colleagues have discovered that a gene called BACH2 may play a central role in the development of autoimmune diseases. Since alopecia areata is the most common autoimmune disease – and there are currently no FDA-approved treatments for it – these findings are of great interest as they point to another promising avenue of research for developing an effective therapy for this disease.