Momentum. The force of our actions behind the weight of our accomplishments is building momentum in all aspects of our mission: support, advocacy and research. We are creating a wave we plan to ride to our desired goal of finding treatments and a cure for alopecia areata. In this report we share with you key actions and accomplishments from the past year and invite you to join with us as we continue to accelerate our efforts to improve the lives of people with alopecia areata. A wellspring of inspiration, momentum is an essential ingredient in the recipe for continued success.

In 2012, the National Alopecia Areata Foundation scored triumphs in numerous settings, from research laboratories to baseball diamonds, from grammar school classrooms to the corridors of Washington. These victories, detailed in the following pages, are something to celebrate in their own right. And they provide crucial propulsion for greater success leading toward the future we hope to chart for our community—a future where an effective, affordable treatment for alopecia areata is a reality.

What is contributing to this momentum? What is generating this wave? In part, it results from NAAF building on its 30-year legacy to press home initiatives like the Treatment Development Program that is strategically driving research investment, facilitating research collaboration, and paving the way to accelerate clinical trials of promising treatments. The 2012 Alopecia Areata Research Summit, held in Bethesda, Maryland, in November, crystallized past learning and charted the course for future research. Recognizing the promise of a key resource, NAAF took ownership and committed to funding the Alopecia Areata Registry, Biobank, and Clinical Trials Network (originally the National Alopecia Areata Registry). This is a veritable goldmine of patient data and biological samples combined with a network of institutions ready for clinical trials of potential treatments.

Momentum is increasing in the policy-making arena where we advocate for more federal investment and more favorable health insurance coverage for alopecia areata and all autoimmune diseases. During our Day on Capitol Hill in July our community so successfully elevated the importance of alopecia areata in the eyes of the Food and Drug Administration (FDA) that alopecia areata was selected as one of 39 out of 12,000 diseases being considered for targeted assistance through the FDA’s Patient-Focused Drug Development initiative.

Perhaps the greatest driver of momentum is the NAAF community of stakeholders: all of the individuals with alopecia areata, the young and the not so young, parents and teachers, doctors and researchers, friends and neighbors. We comprise a large and special NAAF family linked not just by a disease but by a spirit, by a belief in ourselves and our talents, our determination and our goals. We believe in victory because we dare not believe in the alternative. We will find a cure.

Can you feel the momentum building? We hope we can count on you to ride the wave for our next exciting journey together.

Brian Ter Haar
Chair, Board of Directors, 2012

Vicki Kalabokes
President and Chief Executive Officer

The nation’s leading nonprofit watchdog group, the BBB Wise Giving Alliance, has found that NAAF operates with the utmost integrity, transparency, and accountability. NAAF is proud to be one of the few nonprofits out of the almost 1.5 million nonprofits in the United States that meets these strict governance standards. In addition NAAF meets all 44 of the standards required for membership in the National Health Council.
We Support and Connect the Alopecia Areata Community Through Our Annual Conference

◆ Over 850 people came together to learn from each other, meet new friends and find a home in this NAAF community over four event-packed days at the 27th National Alopecia Areata Foundation Conference. And 360 of the attendees were VIPs—people attending their very first NAAF conference.

◆ The conference was held at the Hyatt Regency Washington to facilitate an empowering day of advocacy on Capitol Hill.

◆ A total of 78 Conference Scholarships were awarded to people in need, enabling them to attend the conference. That makes 1,296 total scholarships awarded since the Scholarship program was initiated.

◆ Conference attendees came not just from 42 states, but from Algeria, Australia, Brazil, Canada, New Zealand and Sweden. We’re building momentum abroad!

“What a blessing the conference was... We gained so much more knowledge and support than we ever can realize. [Our daughter] made several new friends this year and looks forward to next year already. We love what each of you do to make this a success each year and hope as a family we can be more a part of the NAAF family and help with this mission.”

— Ronnie, Michele, & Kaitlin White

We Leverage Technology to Reach a Broader Audience

◆ During 2012, the NAAF website received 3.7 million hits as it provided constantly updated information on research, support and resources, programs and events, and a whole lot more. Go to www.naaf.org and see what the site has to offer you!

◆ At the forefront of social media, NAAF’s Facebook page and Twitter feed provided followers the latest news regarding the alopecia areata community and its activities. We loved being able to interact with you in real time, answering your questions and concerns. As of December 31, 2012, the NAAF Facebook page had over 600 fans and over 6,000 likes, and the NAAF Twitter feed had over 1,000 followers.

◆ Over 16,000 readers in the alopecia areata community received the NAAF Electronic News (Beneath the Surface), providing a quick-reading summary of important and useful information.
We Know There are Different Kinds of People, So We Offer Different Kinds of Support

- Since alopecia areata most often manifests first in childhood, we have an abundance of resources focused on helping our amazing kids cope with the social and emotional challenges of sudden unexplained hair loss.
  - A nine-minute DVD/video designed for kids to share with family, friends, and schoolmates to help them understand how living with alopecia areata may impact a child was provided to 253 families upon request.
  - The Bullying section of our Education Awareness Packet has been expanded to help children with alopecia areata better cope with abuse from other kids.
  - An updated-for-2012 school guide, including NAAF’s first bibliography of books for kids with alopecia areata, was mailed to hundreds of parents and teachers.
  - We offer brochures for parents and kids addressing social and emotional challenges and offering coping strategies.
  - Children are welcome at all support groups, and we even have four support groups just for kids.
  - Our Children’s Conference Camp enabled 272 kids ages 5 to 17 to revel in the comfort of others who are dealing with similar challenges.
  - We offer secure and private message boards for children and teens to share with and learn from each other.
  - In a special KidNet section of the Alopecia Areata News we provide helpful information in a kid-friendly way.
  - Our Pen/Cyber Pal program attracted 1,345 participants of all ages and nationalities. It’s a fun and easy way to make a new friend across the globe!

“I noticed a change in my grandson as well. As he looked around at so many bald heads, I could see a sort of comfort come into his expressions; almost like a peaceful relief. Capitol Hill was very impressive and the legislative staff we spoke with appeared to have a sincere interest in the cause that brought us there.”

— Barbara Allen & William Walker

- In 2012, the Ascot Fund provided financial grants to 96 applicants to purchase hair prostheses. Additionally, 46 ready-made wigs were awarded to those in need. These grants changed the lives of those affected. Since the fund was established in 2004, a total of 643 people have been aided thanks to this very special program.

- The Alopecia Areata Marketplace provides easy access to hard-to-find and much-needed products for people with alopecia areata. Products from 51 merchants were tried and tested by trusted members of the alopecia areata community before being accepted in this online bazaar.

- 140 knowledgeable volunteers in NAAF’s International Support Network, serve 138 cities worldwide, organizing local support groups and providing telephone support. Additionally, hundreds of volunteers organized awareness events, hosted fundraisers, and helped at the Conference. We celebrate these support volunteers more fully in the quarterly newsletters.

- Our four updated Alopecia Areata brochures, From a Child’s Point-of-View, Helping You Cope, A Parent’s Guide, and What You Should Know were widely distributed to both those newly acquainted with alopecia areata, and those who are familiar with the disease but want the latest information and advice. They were mailed out to those requesting information, and distributed at awareness events and doctors’ offices.
We Build Awareness to Create Understanding


- NAAF took a very active role in educating medical professionals about alopecia areata and our Treatment Development Program, hosting informational exhibits at key medical and scientific conferences, including the American Academy of Dermatology, the Dermatology Nurses’ Association, the Society for Investigative Dermatology, and the American Academy of Pediatrics.

- Sixteen Major League and four Minor League baseball teams took part in 2012’s “Team Up for Alopecia Areata” campaign during Alopecia Awareness Month in September.

- Other awareness highlights included Lisa Vanderpump, star of *The Real Housewives of Beverly Hills*, bringing Giggy, her famous canine with alopecia areata, to meet Southern California children who suffer from the disease, and Abby Asistio, a talented songwriter, singer, and model, announcing she had alopecia areata in the most dramatic way she knew, by staging STRIPPED: A Coming Out Concert for Alopecia Areata Awareness, in her hometown of Manila.

“It want to show that having alopecia areata shouldn’t hold you back.”

— Lisa Vanderpump
Advocacy Day on Capitol Hill was the centerpiece of our Conference in July. Some 600 attendees marched to the hill to make their voices heard over the course of 200 appointments with their Senators and Congressional Representatives. Esteemed Congresswoman Jackie Speier, representing California’s 12th congressional district, inspired the NAAF advocates with a stirring address. NAAF advocates asked lawmakers for increased funding for the National Institutes of Health, guidance on alopecia areata treatment development from the Food and Drug Administration (FDA), and cosponsorship of the MODERN Cures Act. Our community successfully elevated the importance of alopecia areata in the eyes of the FDA: Alopecia Areata was selected as one of 39 out of 12,000 diseases for targeted assistance through the FDA’s Patient-Focused Drug Development initiative. That’s what we mean by momentum!

In the immediate wake of our Advocacy Day, eleven members of Congress signed a letter to the Commissioner of the FDA, urging that agency to develop industry guidance which would serve as a blueprint for the development of treatment options for alopecia areata. The letter specifically made mention that FDA guidance has historically served as a crucial factor in the development of treatments for other conditions.

Momentum from the incredibly successful Day on Capitol Hill resulted in development of the Alopecia Areata Legislative Liaison program. These specially selected advocates from across the United States continue to keep issues concerning alopecia areata a focus with their Senators and Congressional Representatives through both written correspondence and in-person office visits.

NAAF was a key sponsor of a Congressional Briefing on March 28, presented by the National Coalition of Autoimmune Patient Groups (NCAPG), including the American Autoimmune Related Diseases Association (AARDA). The theme of the briefing was America’s Silent Health Crisis, and included such topics as Genetics and Autoimmune Diseases, An Autoimmune Family’s Story, and Making Autoimmune Disease Families a National Priority.

On May 19 members of the Seattle Support Group and Laura Ralph, NAAF’s Director of Support & Education, joined others diagnosed with autoimmune diseases for the Living with Autoimmunity Community Dialogue, sponsored by the A3 Alliance. The A3 Alliance, of which NAAF is a member, is committed to raising awareness, educating and advocating on behalf of patients, healthcare professionals, and others focused on solving the mysteries of autoimmunity.

NAAF CEO Vicki Kalabokes and Communications Director Gary Sherwood attended the American Academy of Dermatology Association Conference in Washington, D.C. The main focus of the event was a day of advocacy on Capitol Hill, primarily in support of continued funding for the National Institutes of Health which in turn funds a significant portion of alopecia areata research. Vicki and Gary met with the offices of Senators Barbara Boxer and Dianne Feinstein, and Representatives Lynn Woolsey and Elton Gallegly, explaining why continued NIH funding is so critical.
We Inform and Inspire Our Community, Magnifying Efforts at the Local Level

- Our members were updated every quarter with information on the issues surrounding alopecia areata by our award-winning NAAF newsletter, *Alopecia Areata News*, regarded as one of the foremost patient periodicals by medical professionals.

> “People want to do good. So many individuals rallied behind us. It is beautiful to see the way that people’s hearts want to give.”
> — Amanda Shannon

- Some 300 volunteers led over 90 awareness and fundraising events reaching thousands of people and raising $176,100. These events ranged from a Tortoise & Hair™ Run/Walk in Pittsburgh to a Golden Gate Swim in San Francisco.

> “Here are women joining beauty pageants, running marathons, walking down runways, making music videos, documentaries, speaking at conventions and on national TV with big smiles on their faces... They were bald and proud and have chosen to proclaim how secure and at peace they are about themselves.”
> — Abby Asistio

- Another 140 knowledgeable volunteers comprise an International Support Network, serving 138 cities worldwide, organizing local support groups and providing telephone support.

> “My daughter knows that as long as I am alive, I will be supporting her with this disease. I will keep fundraising for NAAF until we find a cure.”
> — Rodrigo Gomez

- We offer our thanks to all the individuals and families who hosted—or participated in—these fantastic local outreach efforts! Can you feel the momentum building?
NAAF gratefully acknowledges all of the AWESOME individuals and families that raised money and spread awareness on our behalf during 2012.

Arizona
Tucson Support Group

California
Amy & Jillian Halloran
Carla Willis Jewelry
Courtney Velazquez
Francine & John Leipsic
Luso-American Life Insurance Society
Michelle Cherrick Family & Friends
Quezada de Carrillo Family & Friends
Susanna Davies Family & Friends

Colorado
Terri Auerbach

Connecticut
Kim Martino Jeans Day

Delaware
Delaware Support Group
Laura Pellicano Family & Friends

Florida
Rodrigo Gomez Family & Friends
Addison Harris Family & Friends

Illinois
Ken & Jennifer Anderson
Donna Herweg Family & Friends
Friends of Gardner Elementary
Danette Goggin Family & Friends
Anna Hall Family & Friends
Kathy Hodur Family & Friends
Levi, Ray & Shoup, Inc.
Marco Di Silvestro Family & Friends
Chicago Support Group

Iowa
Friends of Aplington/Parkersburg Schools

Kansas
Brianna Holt Family & Friends
Bishop Owen Family & Friends

Kentucky
Friends of Stuart Pepper Middle School

Louisiana
Marie Lirette Family & Friends

Maine
Jake Smart Family & Friends

Maryland
Baltimore Area Support Group
Maria Beckett Family & Friends
Ashley Zink Family & Friends

Massachusetts
Chrissa Kaselis Family & Friends
Laura Hathaway Family & Friends
Boston Area Support Group
Heidi Bratt Family & Friends
Maggie Cheesman Family & Friends

Michigan
Cassie McElwain Family & Friends
Community Programs Jeans Day
Mallory Crowner Family & Friends
Mayville Eagles
Joey Silvestri Family & Friends

Mississippi
JuNyla Silmon Family & Friends

Nebraska
Friends of Ezra Elementary

New Jersey
Lillianna Hakim Family & Friends
Jessica Laracuente Family & Friends
Marsh & McLennan Family & Friends
Christopher Passarella Family & Friends
Roosevelt School

New York
Brooklyn Lab School
Harrison Goldberg Family & Friends
Ethan Nijanken Family & Friends
Proskauer Rose LLP
First Niagara Jeans Day

Ohio
Mariemont Elementary
Cara Puccini Family & Friends

Oregon
Cascade Title Co. Jeans Day

Pennsylvania
Amanda Eakin Family & Friends
Friends of the Philadelphia Support Group
Lucy Cadwallader Family & Friends
HairDirect
Judy Hollingshead Family & Friends
Paragon Asset Recovery Services Inc.
Kathy Schreckengost Family & Friends
Amanda Shannon Family & Friends

Tennessee
Rebecca Hibbs Family & Friends

Texas
Patricia & Luis Davis Family & Friends
Friends of Houston Elementary
Guru Mathur Family & Friends
Tenton McGee Family & Friends

Virginia
Connolly Quarels Family & Friends

Washington
June Secreto Family & Friends
Keely Farrell Family & Friends

Washington DC
Washington Nationals
Washington DC Tortoise & Hair™

Wisconsin
Jade Gross Family & Friends
Whispering Willows Girl Scout Troop 314
Sarah Baumann Family & Friends
Stilettos on Steel
Kiah Lang Family & Friends
The Alopecia Areata Treatment Development Program (TDP) continued its seven-year mission to accelerate the quest for a viable alopecia areata treatment. This past year NAAF strengthened our concierge role, leveraging all of our available research resources and clinical partnerships. Our strategic goal is to discover a safe, effective, affordable treatment useful to millions of people with alopecia areata and to find a cure.

We Strategically Drive Research as Our Summits Chart the Course for Future Investigation

On November 29 and 30, NAAF hosted From Basepairs to Bedside: Innovations in the Immunology & Clinical Science of Alopecia Areata, our biennial Alopecia Areata Research Summit, in Bethesda, Maryland. The summit was convened to review recent progress in understanding alopecia areata as an autoimmune disease and to chart the course for the future of translational research. Featured were updates on key developments in the quickly advancing basic, genetic and immunologic science of alopecia areata, recent clinical research including a biomarker study, researcher-developed consensus documents on conducting alopecia areata clinical trials, meetings with the FDA and members of Congress to guide us on paving the way for clinical trial approval with critical resources like population

“I left the [research summit] feeling the speed of advances in alopecia areata research and treatment has really taken off and we are on the cusp of many more advances.”

— Bob Flint, NAAF Board of Directors

We Engage Companies in Treatment Development Partnerships

- We are excited to be working with a company on a clinical trial to test a promising treatment with an excimer laser. This is truly a partnership: NAAF is committed to funding the study and providing access to the Alopecia Areata Registry, Biobank and Clinical Trials Network to efficiently enroll patients; the company is providing expertise, instruction and maintenance of the devices; and, five trial sites are prepared to conduct the study. The objective is to assess the efficacy and safety of an excimer laser in the treatment of scalp alopecia areata.

- NAAF is growing our Corporate Leadership Council (CLC) comprised of companies that have drugs in the autoimmune disease and dermatology arena. We put ourselves at the center of dialogue with these biopharmaceutical industry representatives so we are poised to facilitate partnerships and support clinical trials as promising treatments for alopecia areata become apparent through research discoveries.

- On April 26, a CLC meeting was convened to share recent developments in our understanding of alopecia areata genetics and immunology that have come about through research driven by the Alopecia Areata Treatment Development Program. Companies large and small who are interested in new areas of autoimmune disease treatment and alopecia areata specifically attended this meeting. They were interested in participating in future CLC meetings and taking steps to learn more about alopecia areata.
We Build the Global Research Network to Leverage Your Investment

- We leverage your donations through the Alopecia Areata Treatment Development Program. NAAF funded $645,000 on research during 2012. Researchers that have received NAAF funding in the past secured an additional $2.5 million in follow-up funding through other sources, including the National Institutes of Health. We are building momentum by increasing the amount and scope of alopecia areata research beyond the direct reach of our organization.

- At the 8th International Congress on Autoimmunity held May 9 to 13 in Granada, Spain, NAAF officially sponsored a session entitled “Autoimmunity of the Skin,” which was chaired by Drs. E. Schmidt, A. Kuhn, and A. Gilhar, all of whom expressed their thanks for the support of NAAF. The speakers discussed the importance of animal models for understanding disease, particularly in regard to alopecia areata.

- That same week in May, over 200 scientific posters related to alopecia areata and focusing on autoimmunity, immunity, hair, genetics, clinical research, and animal models were displayed at the Society for Investigative Dermatology (SID) Annual Meeting & 75th Anniversary Celebration in Raleigh, North Carolina. Many of the posters referred to research done with NAAF funding, and credited NAAF for our support.

- NAAF’s Scientific Advisory Council and Clinical Research Task Force met to review progress on the Alopecia Areata Registry, Biobank and Clinical Trials Network and to discuss how to leverage this resource to facilitate upcoming clinical trials. This meeting was scheduled to coincide with the Annual Meeting of the Society for Investigative Dermatology (SID) to minimize expense and maximize utility.

- NAAF was heavily involved in 2012’s American Academy of Dermatology (AAD) Annual Meeting in San Diego from March 15 to 20. Among the highlights:
  - NAAF CEO Vicki Kalabokes gave a scientific talk on the status and accomplishments of the Alopecia Areata Registry, Biobank and Clinical Trials Network at the North American Hair Research Society Meeting, which was held in concert with the AAD.
  - NAAF Scientific Advisory Council member Wilma Bergfeld, MD, was awarded the Master Dermatologist award.
  - Sheila Belkin, NAAF’s Director of Patient and Partner Relations, was given an award of appreciation of her longtime work on behalf of hair loss patients by the Coalition of Skin Diseases.
  - Dr. Shadi Kourosh worked with the Coalition of Skin Diseases (CSD) to promote The Skin Advocate, an app she helped develop to provide immediate access to contact information for dermatologic patient advocacy groups in the CSD, including NAAF.
We Pave the Way for FDA Approval of Clinical Trials and Treatment

- In the wake of the selection of alopecia areata as one of just 39 diseases to be considered for targeted assistance through the FDA's Patient-Focused Drug Development initiative (out of 12,000 diseases total), Jan Wolf delivered testimony at the Food and Drug Administration’s public meeting held October 25. NAAF also submitted written comments with both empiric and anecdotal data emphasizing not only the physical but the psychological and social toll alopecia areata takes on those afflicted, with special emphasis on the experience of younger people. NAAF is advocating for alopecia areata being one of the patient communities the FDA decides to collaborate with to enhance regulatory assessment.

- NAAF coordinated alopecia areata prevalence and incidence studies (see below); this data can help determine the scope of the problem, which is of vital importance to commercial partners and the FDA when a treatment is evaluated.

- NAAF funded Quality of Life Studies (see below) to objectively demonstrate the burden of alopecia areata; this data is essential to the FDA when evaluating a treatment.

We Build the Infrastructure Needed for Clinical Research

- On April 1, NAAF assumed sole sponsorship of the Alopecia Areata Registry, Biobank and Clinical Trials Network (formerly known as the National Alopecia Areata Registry) after federal funding for it ended on March 31. Pharmaceutical companies and academic researchers consider this resource a goldmine for advancing research.

- There are two tiers of registrants. First-tier registrants provide personal data, while second-tier registrants also provide biological samples.

- The Network has successfully ascertained 8,709 first-tier and 3,515 second-tier participants, and has five sites in the clinical trials network. The potential for breakthrough medical investigation increases dramatically with this centralized collection of data, samples and clinical trial-ready sites, and NAAF is committed to continue its funding.

- We are grateful to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) within the National Institutes of Health (NIH) for providing millions of dollars in funding and considerable expertise to design and establish the registry and gather initial information and samples, with Award Number HHSN268200682279C.
We Provide Support for Clinical Studies

- NAAF partially funded the collection of skin samples used to find genes expressed in alopecia areata as part of the Alopecia Areata Biomarker Study being conducted by Drs. Angela Christiano and Ali Jabbari at Columbia University in New York, assisted by all Registry sites. In medicine, biomarkers are measurable characteristics that indicate the severity or presence of some disease state. In lay terms, biomarkers are an easy and reliable measure of whether someone has a disease and to what extent. They are also helpful indicators of the effectiveness of treatments under investigation.

- NAAF helped five researchers to continue their alopecia areata research with grants from the National Institutes of Health by writing strong letters of support.

- Utilizing the Alopecia Areata Registry, Biobank and Clinical Trials Network and the NAAF database to recruit patients, Allergan was able to complete the enrollment phase of its pediatric eyelash study far ahead of schedule.

We Invest to Find Targets and Test Possible Treatments and Cures

- NAAF invested in three studies to build on the momentum of our past discoveries and enhance our understanding of the mechanisms of alopecia areata, identifying targets and testing treatment hypotheses.
  - Aziz Ghahary, MD, is examining the ability of the enzyme IDO to prevent inflammation and hair loss at the University of British Columbia in Canada.
  - Robert Gensure, MD, PhD, and his colleagues are testing a novel drug design and potential treatment at Monefiore in the Bronx in New York.
  - Daisy Dai, PhD, is looking for alopecia areata disease targets through DNA sequencing at the University of Colorado, Denver.

“With the referral assistance provided by NAAF, the study completed enrollment 18 months ahead of projections.”

— Mark Sung, Allergan
## Research Investments of the Alopecia Areata Treatment Development Program in 2012

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<thead>
<tr>
<th>Research Project</th>
<th>Purpose</th>
<th>Significance</th>
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<tr>
<td><strong>PHASE I CLINICAL TRIAL — TESTING TREATMENT IN HUMANS</strong></td>
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<td><strong>Excimer Laser Clinical Study</strong></td>
<td>Assess the efficacy and safety of an excimer laser in the treatment of scalp alopecia areata, and compare the treatment outcomes to determine if longer duration of treatment provides additional improvement in the regrowth of hair in scalp alopecia areata.</td>
<td>If successful, this could be the first FDA-approved treatment for alopecia areata.</td>
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<tr>
<td>Amy McMichael, MD</td>
<td>Excimer Laser Clinical Study</td>
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<td>Wake Forest School of Medicine, Winston-Salem, NC</td>
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<td>James A. Solomon, MD, PhD</td>
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<td>College of Medicine, University of Central Florida</td>
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<td>Cheryl Gustafson, MD</td>
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<td>Emory School of Medicine, Atlanta, GA</td>
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<td><strong>INVESTMENTS IN CLINICAL RESEARCH INFRASTRUCTURE</strong></td>
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<td><strong>Alopecia Areata Registry, Biobank &amp; Clinical Trials Network (Registry)</strong></td>
<td>Ongoing efforts are focused on aggregating patient data and biological samples and developing a network of research institutions. At the end of 2012, we had 8,709 first-tier and 3,515 second-tier participants, and five sites in the clinical trials network.</td>
<td>NAAF is the trusted custodian of a centralized database and store of well-characterized samples. We link clinical trial-ready sites to the patient community and facilitate clinical trial enrollment and feedback.</td>
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<tr>
<td>Madeleine Duvic, MD</td>
<td>Alopecia Areata Registry, Biobank &amp; Clinical Trials Network (Registry)</td>
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<td>Joyce Osei, MPH, MHA</td>
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<td>MD Anderson Cancer Center, Houston, TX</td>
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<td><strong>Uniform Protocol</strong></td>
<td>Develop the initial Alopecia Areata Uniform Clinical Study Protocol, a standardized protocol for future studies that will enable us to judge the effectiveness of therapies and compare one therapy to another.</td>
<td>A preapproved published protocol template advances clinical studies. There will be no need for individual investigators to duplicate efforts.</td>
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<tr>
<td>Natasha Mesinkovska, MD, PhD</td>
<td>Uniform Protocol</td>
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<td>Cleveland Clinic, Cleveland, OH</td>
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<td><strong>PAVING THE WAY FOR FDA APPROVAL OF CLINICAL TRIALS AND TREATMENTS</strong></td>
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<td><strong>Incidence Study</strong></td>
<td>Determine the incidence of alopecia areata among residents of Olmsted County, Minnesota, and compare the results to those of a previous study conducted in the same geographic area.</td>
<td>Government regulatory agencies require this information to approve trials, and pharmaceutical companies evaluate this before deciding to pursue treatments for alopecia areata.</td>
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<tr>
<td>Sultan Mirzoyev, Medical Fellow</td>
<td>Incidence Study</td>
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<tr>
<td>Mark Davis, MD</td>
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<td>Rochelle Torgerson, MD, PhD</td>
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<td>Mayo Clinic, Rochester, MN</td>
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<tr>
<td>Research Project</td>
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<td><strong>Prevalence Study</strong></td>
<td>Evaluate the prevalence of patients with a diagnosis of alopecia areata presenting to a group of dermatology offices.</td>
<td>Pharmaceutical companies need this information to determine the marketplace viability of developing a drug for alopecia areata.</td>
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<tr>
<td>James A. Solomon, MD, PhD</td>
<td>Daquesha Chever, DO</td>
<td>Chauncey Caldwell, MSH</td>
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<tr>
<td><strong>Quality of Life Study</strong></td>
<td>Develop a scale to measure symptoms and analyze data from the registry to describe the quality of life of patients with alopecia areata.</td>
<td>This study is essential in convincing the FDA of the burden of alopecia areata and the unmet need for treatment.</td>
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<tr>
<td>Tito R. Mendoza, MS, MEd, PhD</td>
<td>The University of Texas MD Anderson Cancer Center, Houston, Texas</td>
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<tr>
<td><strong>Biomarker Study</strong></td>
<td>NAAF partially funded the collection of skin samples to find genes expressed in alopecia areata as part of the Alopecia Areata Biomarker Study.</td>
<td>A biomarker can be used to measure the progress of disease or the effects of treatment, and will be crucial for monitoring improvements during clinical trials in alopecia areata.</td>
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<tr>
<td>Angela Christiano, PhD</td>
<td>Ali Jabbari, MD, PhD</td>
<td>Columbia University, New York</td>
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<tr>
<td><strong>DISCOVERING TARGETS AND TESTING POTENTIAL TREATMENTS OR CURES</strong></td>
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</tr>
<tr>
<td><strong>Skin Cell Therapy Study</strong></td>
<td>Investigating the potential for cells that produce the enzyme IDO to inhibit inflammation and hair loss in an alopecia areata mouse model.</td>
<td>This study examines one theory to prevent alopecia areata.</td>
</tr>
<tr>
<td>Aziz Ghahary, MD</td>
<td>University of British Columbia, Canada</td>
<td></td>
</tr>
<tr>
<td><strong>Parathyroid Hormone Therapy Study</strong></td>
<td>Test PTH-CBD as a novel drug design using individual protein domains to create an agent with unique properties; C3H/HeJ–engrafted animals treated with PTH-CBD showed improvements in hair growth.</td>
<td>This study explores a possible treatment and immune cell targets.</td>
</tr>
<tr>
<td>Robert Gensure, MD, PhD</td>
<td>Tulasi Ponnapakkem, PhD</td>
<td>Ranjitha Katikaneni, MBBS</td>
</tr>
<tr>
<td><strong>Identify Antibody Targets</strong></td>
<td>Sequence DNA, create libraries and look for candidate targets in alopecia areata blood samples from the Registry</td>
<td>This study may identify what the immune system is attacking that results in alopecia areata.</td>
</tr>
<tr>
<td>Daisy Dai, PhD</td>
<td>University of Colorado, Denver</td>
<td></td>
</tr>
</tbody>
</table>
**Statement of Financial Position**

**December 31, 2012**

**ASSETS**

<table>
<thead>
<tr>
<th>Current assets:</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td></td>
</tr>
<tr>
<td>Marketable securities</td>
<td></td>
</tr>
<tr>
<td>Accounts receivable</td>
<td></td>
</tr>
<tr>
<td>Prepaid expenses and other current assets</td>
<td></td>
</tr>
<tr>
<td>Total current assets</td>
<td></td>
</tr>
<tr>
<td>Fixed assets, net of accumulated depreciation</td>
<td></td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$3,678,367</td>
</tr>
</tbody>
</table>

**Statement of Activities for the Year Ended**

**December 31, 2012**

**OPERATING REVENUES**

<table>
<thead>
<tr>
<th>UNRESTRICTED</th>
<th>TEMPORARILY RESTRICTED</th>
<th>2012 TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations – general</td>
<td>$505,744</td>
<td>$</td>
</tr>
<tr>
<td>Donations – stock and major donors</td>
<td>289,106</td>
<td></td>
</tr>
<tr>
<td>Restricted grants and donations</td>
<td>177,215</td>
<td></td>
</tr>
<tr>
<td>Conference</td>
<td>258,935</td>
<td></td>
</tr>
<tr>
<td>Special events – Links for Locks and Tortoise &amp; Hair</td>
<td>4,366</td>
<td></td>
</tr>
<tr>
<td>Awareness campaign</td>
<td>124,863</td>
<td></td>
</tr>
<tr>
<td>Newsletter and brochures</td>
<td>26,699</td>
<td></td>
</tr>
<tr>
<td>Alopecia Areata market place</td>
<td>8,230</td>
<td></td>
</tr>
<tr>
<td>Thirtieth anniversary</td>
<td>8,039</td>
<td></td>
</tr>
<tr>
<td>Prior year grant reimbursements</td>
<td>61,570</td>
<td></td>
</tr>
<tr>
<td>Net realized and unrealized gains on marketable securities</td>
<td>56,823</td>
<td></td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>(358,039)</td>
<td>(358,039)</td>
</tr>
<tr>
<td><strong>Total operating revenues</strong></td>
<td>1,855,306</td>
<td>(164,016)</td>
</tr>
</tbody>
</table>

**OPERATING EXPENSES**

<table>
<thead>
<tr>
<th>UNRESTRICTED</th>
<th>TEMPORARILY RESTRICTED</th>
<th>2012 TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>644,005</td>
<td></td>
</tr>
<tr>
<td>Education and support</td>
<td>946,621</td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>184,332</td>
<td></td>
</tr>
<tr>
<td>Management and general</td>
<td>112,517</td>
<td></td>
</tr>
<tr>
<td><strong>Total operating expenses</strong></td>
<td>1,887,475</td>
<td></td>
</tr>
</tbody>
</table>

**Change in net assets from operations**

<table>
<thead>
<tr>
<th>UNRESTRICTED</th>
<th>TEMPORARILY RESTRICTED</th>
<th>2012 TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>(32,169)</td>
<td>(164,016)</td>
<td>(196,185)</td>
</tr>
</tbody>
</table>

**Nonoperating revenues:**

<table>
<thead>
<tr>
<th>UNRESTRICTED</th>
<th>TEMPORARILY RESTRICTED</th>
<th>2012 TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment Development Fund</td>
<td>2,750,000</td>
<td></td>
</tr>
<tr>
<td><strong>Total nonoperating revenues</strong></td>
<td>2,750,000</td>
<td></td>
</tr>
</tbody>
</table>

**Change in net assets**

<table>
<thead>
<tr>
<th>UNRESTRICTED</th>
<th>TEMPORARILY RESTRICTED</th>
<th>2012 TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>(32,169)</td>
<td>2,585,984</td>
<td>2,553,815</td>
</tr>
<tr>
<td>Net assets, beginning of period</td>
<td>976,205</td>
<td>122,719</td>
</tr>
<tr>
<td><strong>Net assets, end of period</strong></td>
<td>944,036</td>
<td>2,708,703</td>
</tr>
</tbody>
</table>

**Spending Percentage**

- **Fundraising**: 11%
- **Program, Support, Research and Awareness**: 83%
- **Management**: 6%

The Statement of Financial Position of the National Alopecia Areata Foundation as of December 31, 2012, was audited by R. J. Riccardi, Certified Public Accountant. A copy of the complete report, including notes, is available for public review from the National Alopecia Areata Foundation, 14 Mitchell Boulevard, San Rafael, CA 94903 or on the website www.naaf.org.
Mission

The National Alopecia Areata Foundation (NAAF) supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata.