Dear Friends,

The game of chess teaches us that to best a formidable opponent, there must be a marriage of nuanced planning and decisive action. There is no quick victory; the game cannot be won in a single stroke. It takes consideration, foresight, an ability to weigh the opposition—and yes, a certain amount of luck. When these elements align, key moves can be made that gradually eliminate obstacles, wrest control of the board, and seize victory.

In 2013, the National Alopecia Areata Foundation made several key moves against a disease that robs too many of us of not only our hair but our self-confidence and joy in life.

These moves were made in school classrooms and summer ballparks, under the microscopes of laboratories and under the dome of our nation’s Capitol. We took ever more aggressive gambits in research utilizing those most powerful of game pieces, the Alopecia Areata Treatment Development Program and the Alopecia Areata Registry, Biobank & Clinical Trials Network. We made deeper forays into guaranteeing government support for alopecia areata research using our well-chosen knights, the Legislative Liaisons. And the 145 million people affected by alopecia areata proved they were no pawns, stepping forward in their own defense and demanding, in accord with our Awareness Month theme, “Look at us!”

From the bayous of New Orleans to the moors of Edinburgh, from the beachfront of Miami to the bustle of Manhattan, NAAF met with researchers and medical professionals to gain and spread scientific knowledge, strengthen ties, and keep alopecia areata at the forefront of clinical discussions. As further proof that we are playing to win, the Journal of Investigative Dermatology (JID) published the proceedings of NAAF’s most recent Alopecia Areata Research Summit, From Basepairs to Bedside: Innovations in the Immunology & Clinical Science of Alopecia Areata.

Three significant video projects put the spotlight on alopecia areata, our community, and our research efforts. And we made aggressive moves in the political sphere, where our Legislative Liaisons made their Washington, DC debut, convincing their congressional representatives to restore research funding cut by sequestration.

No single move has won the game. But taken together, these moves and others described in the following pages ensure that the ultimate outcome will be victory. For over three decades, our goal has been nothing less. NAAF has and always will endeavor toward one outcome: telling alopecia areata, “Checkmate.”
Our Annual Conference Inspires and Invigorates . . .

- NAAF’s 28th Annual International Family Conference, held in St. Louis, welcomed over 700 people—including 311 VIPs (first time attendees)—for four days of fun events, fascinating guest speakers, empowering support sessions, educational workshops, celebrity appearances, and our most successful Tortoise & Hair™ walk, all under the awe-inspiring Gateway Arch.

- We awarded a total of 90 Conference Scholarships enabling people in need to attend the conference. Since this program was initiated, a total of 1,386 scholarships have been awarded.

- We welcomed conference guests from all over the world! There were attendees from 39 states, as well as Algeria, Australia, Canada, Guinea, New Zealand and Sweden.

Our Online Reach Informs and Educates . . .

- The NAAF website provides the latest information on research, support and resources, programs and events, and much, much more. During 2013 it received over 3.8 million hits. Go to www.naaf.org to see for yourself what the NAAF website has to offer!

- We leveraged NAAF’s social media presence on Facebook and Twitter to bring you up-to-the-minute news regarding the alopecia areata community and its activities. Best of all, you shared your comments and questions, and we loved being able to interact with you. By the end of 2013, our Facebook page earned 4,000 new likes for a total of 10,200, and our Twitter feed gained 900 new followers for a total of 1,880.

- NAAF’s monthly electronic newsletter, Beneath the Surface, continued to provide a quick summary of important information of use to 17,500 readers in the alopecia areata community.

“Every time I go to a NAAF Conference (this is my third), I learn that even though I have alopecia areata it doesn’t make me different from any other kids, teens and adults. I just may wear a wig and not have the same amount of hair but I am still human and the same.”

—Demeiah Chatfield
Our Multi-faceted Support Empowers and Resonates . . .

- NAAF continued its long tradition of providing an abundance of resources to help our amazing kids cope with the social and emotional challenges of sudden unexplained hair loss, as alopecia areata most often manifests first in childhood.
  - We provided to 253 families upon request a nine-minute DVD entitled *Why My Hair Falls Out*, designed for kids to share with family, friends, and schoolmates to help them understand how living with alopecia areata may impact a child.
  - We mailed a school guide, including a NAAF bibliography of books for kids with alopecia areata, to parents and teachers in need of this information, which can’t be found elsewhere.
  - We sent out thousands of brochures for parents and kids addressing the social and emotional challenges of alopecia areata and offering coping strategies.
  - We made sure children were welcomed at all support groups; we even had four support groups just for kids.
  - Our Children’s Conference Camp enabled 209 kids ages 5 to 17 to revel in the comfort of others who are dealing with similar challenges.
  - We offered secure and private message boards for children and teens to share with and learn from each other.
  - We provided helpful information in a kid-friendly way in a special section of the *Alopecia Areata News* entitled KidNet.
  - Our Pen/Cyber Pal program attracted 1,381 participants of all ages and nationalities. It’s a fun and easy way to make a new friend across the globe!

“So thank you! Thank you for giving us the opportunity to attend the 2013 NAAF Conference! Thank you for helping my family to see we are not the only family dealing with alopecia areata! Thank you for helping us to connect to people who are also learning to cope with alopecia areata! Thank you for helping us to find ways to educate others! Thank you for everything! Being able to attend the conference was such a blessing for our family!”

— The Spaude Family

- NAAF awarded financial grants from the Ascot Fund to a total of 93 children, women and men in 2013 so they could purchase hair prostheses. We also provided 96 ready-made wigs to those in need. These grants make an incredible difference in the lives of those affected. A total of 736 people have been aided thanks to this very special program since the fund was established in 2004.

- The Alopecia Areata Marketplace connected people with alopecia areata to hard-to-find and much-needed products from 53 different merchants. A wide variety of products were tried and tested to ensure exceptional quality.

- NAAF’s 130 motivated support volunteers organized local support groups and provided telephone support as part of NAAF’s International Support Network, serving 144 cities worldwide. We celebrate these support volunteers in each quarterly newsletter.

- Thousands of individuals and medical professionals were sent our four primary NAAF brochures (*Alopecia Areata: What You Should Know; A Parent’s Guide; Helping You Cope; and From a Child’s Point-of-View*). We help those newly acquainted with alopecia areata as well as those more familiar with the disease who are seeking the most up-to-date information. Additionally, these informative brochures were distributed at awareness events and provided to doctors’ offices.

“I feel very confident about myself now. I even took my yearbook photo without my wig. The conference has changed me—in a good way. I feel so liberated, it’s great. I can’t wait for next year’s conference!”

— Danielle Candray
Our chessboard ranges from ballparks to bowling alleys, classrooms to Congress, St. Louis to cyberspace.

Awareness AND Advocacy

We Strive to Create Awareness and Understanding . . .

We asked our friends, neighbors, co-workers and everyone else who could hear our voice to “Look at Us!” This was not only the theme of Alopecia Areata Awareness Month in September, but a year-long affirmation, a rallying call drawing attention to us from people who may not yet fully see or understand us, but soon will. And when people understand, they help. Here is how we invited the world to “Look at Us!” in 2013:


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

- We partnered with 16 Major League and 3 Minor League Baseball teams for 2013’s “Team Up for Alopecia Areata” campaign during Alopecia Areata Awareness Month in September, attracting some 320 fans from the alopecia areata community and spreading awareness to thousands.

- Detroit Pistons power forward Charlie Villanueva participated in Meet & Greet events in 14 cities as part of NAAF’s Charlie’s Angels program, giving almost 300 fans in the alopecia areata community a chance to meet and have their picture taken alongside the most famous athlete with alopecia areata.

- We made information on alopecia areata more accessible than ever with new video projects:
  - NAAF produced and unveiled the Alopecia Areata Treatment Development Program Video, a compelling and informative seven-minute presentation of stories, reflections, and personal accounts from both lay people and experts who understand and care about what is needed to help those with alopecia areata. The video, originally proposed at NAAF’s board meeting in January 2013, illustrates why the Alopecia Areata Treatment Development Program is so vital to achieving one of NAAF’s most important goals: finding effective, FDA-approved treatments that restore hair growth for people affected by alopecia areata. Those who watched the video on NAAF’s website were encouraged to give their feedback in a survey designed to measure the film’s overall effectiveness and gauge its application as both an informational tool and a stirring document. Most significantly, 93 percent of viewers surveyed agreed they felt moved by the video and considered it “accessible” to someone who might be unfamiliar with alopecia areata. A similar number said they would consider showing the video at an awareness event or fundraiser. By the end of 2013, approximately 1,000 people had watched the video on our website and some 3,000 had viewed it on NAAF’s YouTube page. Watch it now at www.naaf.org/TDPvideo
• NAAF Chief Financial Officer Bob Flint gave an excellent overview of alopecia areata and what NAAF is doing in the fight for treatments and a cure in a video produced by The Giving Library. By the end of 2013, it had been seen by over 500 viewers. Check it out at www.givinglibrary.org.

• In close cooperation with NAAF, the Society of Dermatology Physician Assistants produced four films providing an overview of alopecia areata, its effect on patients, and the state of current research. By the end of 2013, these videos attracted over 2,200 viewings. All four can be viewed on www.dermcast.tv.

■ On August 21, Dr. Marc Glashofer, a dermatologist on NAAF’s Scientific Advisory Council, educated listeners about alopecia areata on SiriusXM’s Doctor Radio. Two weeks later Dr. Glashofer and NAAF Communications Director Gary Sherwood discussed alopecia areata and the Foundation’s efforts as guests on another SiriusXM program, The Maggie Linton Show.

■ NAAF was proud to be one of only three organizations chosen to receive Ella, the bald friend of Mattel’s iconic Barbie. Mattel also made a generous donation to NAAF to pay for shipping these dolls to children with alopecia areata, who overwhelmingly took the dolls to heart. As one lucky recipient told her parent, “Daddy, she looks JUST LIKE ME”

Our Advocacy Efforts Are Growing and Expanding . . .

■ At the National Health Council’s 26th Annual Voluntary Health Leadership Conference held February 13 to 15 in Ponte Vedra, Florida, Vicki Kalabokes delivered a presentation in support of the MODDERN Cures Act, illustrating how this important legislation will accelerate alopecia areata research by promoting the development of dormant therapies and attendant regulatory protection.

“...I felt honored to be taking the message of NAAF and the alopecia areata community as a whole to the Hill. Having the opportunity to create awareness and push for the support of our senators and representatives on key issues impacting our community was an experience I am proud to have been part of.”

— Deirdre Nero

■ Twenty-seven Alopecia Areata Legislative Liaisons responded to a February Action Alert urging their congressperson to defend funding for medical research so that the U.S. maintain its position as the world leader in this field by guaranteeing that the NIH receive an allocation of at least $32 billion for Fiscal Year 2014, returning to pre-sequestration levels.

■ The Alopecia Areata Legislative Liaison program celebrated its first year anniversary with a victory as Congresswomen Anna Eshoo (D-CA) and Zoe Lofgren (D-CA) contacted both the Food and Drug Administration (FDA) and the Centers for Medicare and Medicaid Services (CMS) on behalf of the alopecia areata community. This came as a direct result of NAAF’s Day on Capitol Hill, held September 11th. Fourteen Legislative Liaisons from 12 states, along with NAAF Communications Director Gary Sherwood and Chief Administrative Officer Jeanné Rappoport, met with the health aides of some two dozen senators and congressional representatives. The Legislative Liaisons asked for their lawmakers’ support in advancing alopecia areata research in three key areas, all critical components of the Alopecia Areata Treatment Development Program:

1. Support an allocation of $32 billion for the National Institutes of Health (NIH) in fiscal year 2014 to provide the agency with adequate resources and to offset the 5 percent funding cut NIH took this year due to sequestration. This includes funding for research of alopecia areata.

2. Support the FDA and encourage the agency to engage alopecia areata patients as part of its Patient-Focused Drug Development Initiative. This initiative has the potential to greatly improve development, oversight and access to treatment options for the alopecia areata community.

3. Request the CMS rewrite current policy to make Medicare benefits available to patients who require cranial prosthetics as a result of alopecia areata. As it stands now, Medicare only covers cranial hair prosthetics for “secondary alopecia” (i.e. hair loss caused by chemotherapy and other temporary reasons) and excludes alopecia areata.

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Awareness on a Local Level is Nothing Short of Outstanding!

- We provided updates to our constituents offering the latest information on the issues affecting them via the *Alopecia Areata News*, NAAF’s award-winning newsletter, which is regarded as one of the foremost patient periodicals.

- Our annual report won the 2013 APEX Award for Publication Excellence in the field of Annual Report Writing.

- The inaugural “Cheers for cHAIRity: NYC NAAF” was nothing short of a huge success. Organizers Rob and Margery Goldberg joined forces with Soho Events NYC to host this topflight event in New York’s hip Meatpacking District, complete with cocktails, hors d’oeuvres, DJ, photographer, and silent auction. All told, the Friday night soiree raised close to $40,000. Now that’s partying with a purpose!

- NAAF received a $5,000 grant thanks to Becky Hibbs who was chosen out of more than 60,000 entries from across the United States as a winner of Mary Kay Inc.’s One Woman Can™ Global Makeover Contest. To enter the contest, Becky submitted a statement about her passion for alopecia areata awareness, and what it means to her.

- Close to 200 volunteers led 54 events reaching thousands of people and raising alopecia areata awareness in their communities along with $210,000. Among these events were the Who Needs Hair talent revue in New York City; the Wiggin’ Out social event in San Diego; the Big Hairy Deal in Neillsville, Wisconsin; and the 2nd Annual Bowl-a-thon in Houma, Louisiana.

In concert with other organizations serving people with skin and autoimmune diseases, NAAF advocated for greater legislative awareness and support of research.

- We were a sponsor of the *American Autoimmune Related Diseases Association’s* (AARDA) Congressional Briefing held March 20, 2013, in Washington, DC. In collaboration with the National Coalition of Autoimmune Patient Groups, AARDAs aim was to bring health and policy issues to the attention of U.S. legislators, highlighting work that is being done in research and the need for further investigation into environmental triggers of autoimmune disease, the genetics of autoimmune diseases and why they tend to cluster in families, and the emotional and financial cost to American families struggling with these 100+ chronic autoimmune diseases.

- NAAF collaborated with other member organizations within the Coalition of Skin Diseases (CSD), advocating for the importance of skin disease research that will benefit all of our patient communities. Gary Sherwood and Jeanné Rappoport met with their CSD partners to discuss goals and strategies while attending the American Academy of Dermatology Association Legislative Conference, held September 8–10 in Washington, DC. The main focus of the conference was a day of advocacy on Capitol Hill, primarily in support of restoring sequestration cuts to the NIH via the same allocation described above. This allocation would provide an additional amount toward new medical research, including that for alopecia areata. Gary and Jeanné met with the offices of Senators Dianne Feinstein and Barbara Boxer to explain why NIH funding is so critical to the cause of finding treatment and a cure.

- Senior members of NAAF met in December with high-level representatives from the NIH to discuss the state of alopecia areata research, its future, and the role these organizations can play as they identify research synergies and emerging opportunities. NIH representatives met with NAAF President and CEO Vicki Kalabokes; Leonard Sperling, MD, from NAAF’s Scientific Advisory Council; and Richard Gelula, Director of the Alopecia Areata Treatment Development Program, at the NIH campus in Bethesda, Maryland.
NAAF gratefully acknowledges all of the AWESOME individuals and families that raised money and spread awareness on our behalf during 2013.

Walks and Runs
Addison Harris Family & Friends
Dirty Mudders Run ............................................FL
Amanda Shannon Family & Friends • 5K Run ...........PA
Ann Adams Family & Friends • Marathon ...............IL
Brittany Taurisano Family & Friends
Walkathon and Raffle .......................................NY
Chris Passarella Family & Friends • 5K Run/Walk......NJ
Deyanne Urbahn Family & Friends • 5K Walkathon ...NY
Guru Mathur Family & Friends • 5K Run/Walk .........TX
Jill Hayes Family & Friends • Marathon ...............IL
Kristin Cheeks Family & Friends • 5K Run/Walk ...NY
Rodrigo Gomez Family & Friends
Miami Half Iron Triathlon ..................................FL
Samantha Berlin Family & Friends • 5K Run/Walk....NY

Awareness Days and Festivals
Cale Schremp Family & Friends
Awareness Bracelets ........................................MO
Jade Gross Family & Friends • Big Hairy Deal ..........WI
Juwayne Silmon Family & Friends
Baseball Awareness & Bracelets .............................MS
Kiah Lang Family & Friends with Morgan McIwee
Family & Friends • Rock For Locks .......................WI
Samantha Impson • Awareness Day at School ......CA

Galas
Deb Wolf Family & Friends • Wigsgiving ...............WA
Harrison Goldberg Family & Friends
Cheers for chAIRity ........................................NY
Shae Haskins Family & Friends • Aloha Alopecia ....TN
Tara Maazel Family & Friends • Who Needs Hair ....NY

Movie Screenings
Christie Alonso Family & Friends
Baby Let Your Hair Hang Down ..........................AL
Margaret Staib Family & Friends
Baby Let Your Hair Hang Down ..........................NY

Bowling Parties
Laura Pellicano Family & Friends ........................DE
Marie Lirette Family & Friends .............................LA
Patricia Carter Family & Friends ..........................CA
Tuscon AZ Support Group ....................................AZ

Jeans Days
Holy Spirit Regional Catholic School .....................AL
Kim Martino Family & Friends ............................CT
Stephanie & Courtney Whitney ...........................KS

Concerts
Ariel Quinn Family & Friends • Music Night ..........NY
Caitlin Riley Family & Friends • Who Gives a Hair ....MI
Darlenys Rosa Family & Friends • Concert ..........NJ
Erin Salisbury Family & Friends • Bluegrass Fest ...SC

Art Fundraisers
Jordan Slack Family & Friends Art & Silent Auction ..WA

Salon Fundraisers
Jimmie Sanders Family & Friends
Bold, Bald & Beautiful ....................................TX
Lucinda Beatty • Day of Beauty ...........................CT
Michele Zaret Family & Friends • Blowout-a-Thon ..NY
San Diego Support Group • Spa Day ....................CA

Hats Days
Ann Sansone Family & Friends
Blackrock Elementary School ............................RI
Carly Beiter Family & Friends
Devon Elementary ..........................................PA

Restaurant Fundraisers
Chelsea Duhs • Dine at Ruby’s .........................CA
Cheryl Ann Torner Family & Friends ..................PA
Kristin Cheeks & Kayla Campbell
Chipotle & Buffalo Wild Wings .........................MD
Susanne O’Connor Family & Friends
Martini’s Matter ............................................VA

Miscellaneous
Amelia Warner Family & Friends
Free to Be Me Luau Pool Party .........................NJ
Ashley Guzman • Zumbathon .............................FL
Becky Hibbs • Mary Kay Writing Beauty Contest ....TN
Bonnie Stern Family & Friends • Donation Page ....NY
CarlaIine Willis Family & Friends
Jewelry Fundraiser .........................................CA
C athi Buros • Letter Writing Campaign ..............NY
Claudia Quesada de Carillo • Car Wash ...............CA
Grace Duhs Family & Friends • Lemonade Stand ...CA
Janelle Fleites • Basketball Shoot Out .................FL
Maniscalco Family & Friends
Backyard Dance Party ......................................NY
Maria Mahnken Family & Friends
Chocolate Tour ............................................IL
Mindy Parsons • Fun Day & Garage Sale ..............OR
Monica Zink Family & Friends • Donation Page ....MD
Susanna Davies Family & Friends • Casino Night ...CA
Terri Echols • U Paint It ..................................TX
Through the Alopecia Areata Treatment Development Program, NAAF continued the quest to find a viable alopecia areata treatment and a cure.

We Strategically Drive Research

- A series of research summits have played a key role in strategically directing NAAF’s research investments. Following a successful summit in December 2012, which led to publication of the proceedings in the Journal of Investigative Dermatology, NAAF began to plan for the next research summit to be held December 4 – 5, 2014, in Bethesda, Maryland. Working closely with Medical and Scientific Co-Chairs Dr. David Norris (University of Colorado Denver), Dr. Julian Mackay-Wiggan (Columbia University in New York) and Dr. Jeff Frelinger (University of Arizona), NAAF associates developed an engaging agenda to bring seasoned experts and bright new minds together to distill learning from recent advances in autoimmune, skin, hair and related disease research and chart the path forward. An application was submitted to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for financial support and received the best possible score of 10.

- NAAF CEO Vicki Kalabokes and CPO Dory Kranz learned the latest research acceleration tools and techniques at FasterCures’ fifth Partnering for Cures meeting held November 3 – 5 in New York City. FasterCures, a center of the Milken Institute, is determined to remove barriers to medical progress, and works to improve the medical research process so that it speeds up the time it takes to get important new medicines from discovery to patients.

- We conducted a strategic review of our Scientific Advisory Council and restructured it into two groups offering separate counsel on 1) basic research and 2) clinical research. The goal is to foster an open, collaborative system involving all the critical stakeholders without overly burdening these volunteers who so graciously contribute their time and expertise. The objective of these two committees, known as the Basic Research Advisory Council and Clinical Research Advisory Council, is to have smaller, more-focused groups that can work together more efficiently to advance the Alopecia Areata Treatment Development Program. Before restructuring, the NAAF Scientific Advisory Council met and reviewed the progress of this program. The subcommittees created at the Alopecia Areata Research Summit in November 2012 reported on their assignments and progress.

- On June 28, NAAF convened a Corporate Leadership Council (CLC) meeting 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 were invited guests at this meeting. They were interested in participating in future CLC meetings and taking steps to learn more about alopecia areata.
We Raise the Profile of Alopecia Areata Research to Attract Researchers and Facilitate Collaboration

- The prestigious *Journal of Investigative Dermatology (JID)* published the proceedings of NAAF’s 2012 Alopecia Areata Research Summit, *From Basepairs to Bedside: Innovations in the Immunology & Clinical Science of Alopecia Areata*, which distilled and articulated the progress made in alopecia areata research over the previous two years. Publication of the proceedings was an honor as the *JID* is widely recognized as a leading voice in dermatologic research, and only publishes work that has been thoroughly peer-reviewed. The supplement was distributed to all subscribers of the journal across the world, spreading the word about new studies and furthering the progress of alopecia areata research.

- The *Society of Dermatology Physician Assistants* interviewed alopecia areata researchers and patients during the NAAF Annual Conference to produce four videos which can be viewed on Dermcast.tv. The four films are “Treating Alopecia - Jennifer DeFreece - National Alopecia Areata Foundation,” “Alopecia 101 - Maria Hordinsky MD,” “Treating Alopecia - Matthew Cogan - National Alopecia Areata Foundation” and “On the National Alopecia Areata Foundation - Maureen McGettigan.” The *Journal of Dermatology for Physician Assistants* also began publishing a series of articles on different aspects of alopecia areata.

- A video on the *Alopecia Areata Treatment Development Program* was produced by NAAF to inform and inspire potential partners in research funding. This compelling and informative seven-minute presentation of stories, reflections, and personal accounts from lay people and experts illustrates why the program is vital to achieving FDA-approved treatments that restore hair growth for people affected by alopecia areata.

- NAAF participated in the *American Academy of Dermatology* (AAD) Annual Meeting in Miami Beach March 1 – 5 which featured the following:
  - Alopecia Areata was the highlight of the North American Hair Research Society Meeting, held in tandem with the AAD. Rox Anderson, MD, presented all the possible devices that might be used to treat alopecia areata. Angela Christiano, PhD, presented the progress in translational research resulting from her incredible genetics findings that point to a promising future.
  - Several posters and scientific presentations on alopecia areata were given by NAAF-funded researchers and Scientific Advisory Council members. One presentation focused on new prevalence and incidence data funded through our Alopecia Areata Treatment Development Program.
  - NAAF staff members met with over 10 interested pharmaceutical companies to promote and partner with the Alopecia Areata Treatment Development Program. We continue to push them to consider developing a therapy for alopecia areata.
  - The Dermatology Foundation presented NAAF’s Founding Chair, Vera H. Price, MD, with its Lifetime Career Educator Award. This award recognizes academic dermatologists who have been inspirational teachers and mentors to generations of medical students and residents.
  - The Women’s Dermatologic Society held a Legacy Dinner Honoring NAAF Scientific Advisory Council Member, Wilma Bergfeld, MD. The event celebrated Dr. Bergfeld’s legacy as founding president of the society and her immense contributions promoting women in the medical field.

- At the 31st Annual *Dermatology Nurses’ Association* Convention, held April 4 – 7 in New Orleans, Louisiana, NAAF staffers promoted the Alopecia Areata Treatment Development Program and discussed partnership opportunities with various pharmaceutical companies in attendance. NAAF representatives also provided hundreds of grateful dermatology nurses with alopecia areata patient education materials.

Continued on page 10
NAAF representatives promoted hair research and encouraged young investigators to study alopecia areata at the International Investigative Dermatology Conference held May 8–11 in Edinburgh, Scotland. The conference featured over 200 scientific posters on autoimmunity, immunology, hair, genetics, clinical research, and animal models related to alopecia areata. Over 20 posters were dedicated solely to alopecia areata research studies, and the posters related to research funded by NAAF all credited NAAF for its support. While at the conference, NAAF’s Scientific Advisory Council met to review the current status of the core uniform alopecia areata clinical trials protocol and to discuss upcoming clinical trials.

Dr. Marc Glashofer, a dermatologist on NAAF’s Scientific Advisory Council, and Richard Gelula, our Alopecia Areata Treatment Development Program Director, attended the 1st Annual Autoimmunity Prevention Summit, held October 17–20 in New York. In light of increasing evidence that autoimmune diseases are active before symptoms begin to show, this meeting was convened to synthesize and advance efforts to identify and define autoimmunity at the early stages of “genetic risk” and “autoimmune activation” before the clinical expression of symptoms would lead someone to seek medical advice. The summit was an opportunity to connect with researchers focused on preclinical markers for type 1 diabetes and rheumatoid arthritis, which have genetic similarities to alopecia areata, and to learn about resources like the Department of Defense Serum Repository, which has proven to be a useful resource for retrospective studies.

NAAF sponsored the 62nd Annual Montagna Symposium on the Biology of Skin highlighting pioneering advances in dermatology research that have contributed to other scientific and medical fields, such as oncology, genetics, autoimmune disease and structural biology. Dory Kranz, NAAF’s Chief Program Officer, represented NAAF and alopecia areata at the Montagna Symposium held October 10–14 in Stevenson, Washington, which focused on how light sustains, damages, treats, images, and modifies skin biology. At this three-day symposium, Dory was able to learn from and network with thought leaders and young scientists and hear about breakthroughs in imaging techniques that make it possible to see what is happening in living human skin down as far as the hair follicle. This may be useful as we begin to test treatments.

In November, NAAF President and CEO Vicki Kalabokes and CPO Dory Kranz met with NAAF’s friends at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), which is the primary funder of alopecia areata research within the National Institutes of Health (NIH). Vicki and Dory participated in the NIAMS Coalition 2013 Outreach and Education Meeting, a day-long meeting with leaders of other nonprofits like NAAF, where they heard from and gave feedback to key players within the NIH. These included Dr. Francis Collins, the Director of NIH, and Dr. Stephen Katz, the Director of NIAMS, as well as many others.

Senior members of NAAF met with high-level representatives from the NIH Office of Rare Disease Research (ORDR) to discuss the state of alopecia areata research, its future, and the role these organizations can play as they identify research synergies and emerging opportunities. Dr. Stephen Groft, Director of ORDR, Dr. David Eckstein, Deputy Director of ORDR, and other NIH leaders met with NAAF President and CEO Vicki Kalabokes; Leonard Sperling, MD, from NAAF’s Scientific Advisory Council; and Richard Gelula, Director of the Alopecia Areata Treatment Development Program, at the NIH campus in Bethesda, Maryland. Vicki, Richard and Maria Hordinsky, MD and Chair of our Scientific Advisory Council, also attended the National Coalition of Autoimmune Patient Groups Meeting to advance our treatment agenda with leaders of the autoimmune disease community.

Legislative Liaisons met personally with members of Congress to advocate for support in our efforts to increase federal research funding (as described fully under Advocacy).
We Make Targeted Research Investments

- The Alopecia Areata Registry, Biobank & Clinical Trials Network (the Registry) celebrated its first anniversary of NAAF Funding. It was on April 1, 2012, that NAAF assumed sole funding and sponsorship of the Registry, which is a gold mine of information both for our researchers and for those suffering from the disease. At NAAF’s 28th Annual International Conference, over 100 saliva samples were collected for the Registry. More data and samples increase the potential for significant medical breakthroughs.

- The Excimer Laser Protocol received pre-approval from an institutional review board. This board approval of the protocol is a critical early step in the development of a potential treatment. However, progress in launching the Excimer Laser Clinical Trial, which will assess the efficacy and safety of the 308-nm excimer laser in the treatment of scalp alopecia areata, has been challenging. We have a protocol and five sites with trained investigators ready to go, but the study has been delayed by other requirements. Thankfully, we are navigating this learning curve in a device trial, which is many times less expensive than a drug trial. And we believe that NAAF and alopecia areata research will be better for the time and care we are taking to do this right. If successful, the use of the excimer laser could conceivably become the first FDA-approved treatment for alopecia areata.

- On August 15 NAAF investigators met to review and finalize the Core Uniform Alopecia Areata Clinical Trials Protocol. NAAF hopes to accomplish two goals with this protocol: 1) to stimulate the pharmaceutical industry to investigate potential treatments for alopecia areata by providing a pre-approved uniform protocol, and 2) enable us to judge the effectiveness of therapies and compare one therapy to another. The core uniform protocol will be submitted to a central institutional review board for approval. A carefully designed protocol is intended to safeguard the health of the patients as well as answer specific research questions.

- We committed to funding research by Ralf Paus, MD of Munster, Germany, to characterize the receptors of the autoaggressive T-cell clones that are responsible for alopecia areata by isolating CD8+ T cells from alopecia areata skin and characterizing their T-cell receptor chain directly in human skin with alopecia areata lesions. Identification of disease-specific T-cell receptors may serve as a basis for specific alopecia areata immunotherapy and may serve as a prognostic biomarker. If successful, this could lead to the first causal therapy of alopecia areata.
## Clinical Research Infrastructure

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<tr>
<th>Research Project</th>
<th>Purpose</th>
<th>Significance</th>
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<tbody>
<tr>
<td><strong>Alopecia Areata Registry, Biobank &amp; Clinical Trials Network (Registry)</strong>&lt;br&gt;Madeleine Duvic, MD&lt;br&gt;Joyce Osei, MPH, MHA&lt;br&gt;MD Anderson Cancer Center, Houston, TX</td>
<td>Ongoing effort to aggregate patient data, biological samples, and a network of research institutions. At the end of 2013, we had 9,635 first-tier and 3,693 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 related to alopecia areata. We link clinical-trial-ready sites to the patient community and facilitate clinical trial enrollment and feedback.</td>
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<tr>
<td><strong>Excimer Laser Clinical Study</strong>&lt;br&gt;James A. Solomon, MD, PhD&lt;br&gt;Ameriderm Research, Ormond Beach, FL&lt;br&gt;Amy McMichael, MD&lt;br&gt;Wake Forest School of Medicine, Winston-Salem, NC&lt;br&gt;Cheryl Gustafson, MD&lt;br&gt;Emory School of Medicine, Atlanta, GA</td>
<td>Evaluate risk and cost of study designed to assess the efficacy and safety of the 308-nm Excimer laser in the treatment of scalp alopecia areata. Initiate design modifications for smaller initial proof of concept study.</td>
<td>If successful this could be the first FDA-approved treatment for alopecia areata.</td>
</tr>
<tr>
<td><strong>Uniform Clinical Trial Protocol</strong>&lt;br&gt;James A. Solomon, MD, PhD&lt;br&gt;Ameriderm Research, Ormond Beach, FL&lt;br&gt;Natasha Mesinkovska, MD, PhD&lt;br&gt;Cleveland Clinic, Cleveland, OH</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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<td><strong>Biomarker Study</strong>&lt;br&gt;Angela Christiano, PhD&lt;br&gt;Ali Jabbari, MD, PhD&lt;br&gt;Columbia University, NY</td>
<td>NAAF provided skin and blood samples from the Alopecia Areata Registry, Biobank &amp; Clinical Trials Network for investigations to identify genetic biomarkers expressed in alopecia areata as part of the Alopecia Areata Scalp Biopsy Biomarker Study, which aims to develop a set of exploratory biomarkers that can later be validated.</td>
<td>A biomarker is important 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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### DISCOVERING TARGETS AND TESTING POTENTIAL TREATMENT OR CURE HYPOTHESES

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<tr>
<td><strong>Characterize T-Cell Receptor Clones and Identify Related Targets</strong></td>
<td>Characterize the receptors of the autoaggressive T-cell clones that are responsible for alopecia areata by isolating CD8+ T cells from alopecia areata skin and characterizing their T-cell receptor (TCR) chain directly in human skin with alopecia areata lesions.</td>
<td>This may lead to selective elimination of autoaggressive CD8+ T-cell clones and to identification, in a follow-up project, of the self-autoantigens that trigger the attack on the hair follicles and may serve as a basis for alopecia areata immunotherapy and prognostic biomarker(s).</td>
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<tr>
<td>Ralf Paus, MD</td>
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<tr>
<td>University of Münster, Münster, Germany</td>
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### Skin Cell Therapy Study

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<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>Results show the injection of IDO-producing skin cell therapy suppresses the autoimmune response, preventing the progression of alopecia areata. Eighty percent of control mice acquired alopecia areata while none of the IDO cell therapy group was affected.</td>
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<tr>
<td>Aziz Ghahary, MD</td>
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<tr>
<td>University of British Columbia, Canada</td>
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*This data was used to apply for a grant from the Canadian Institute of Health Research to conduct more mechanistic studies and eventually a pilot clinical trial. A grant of $100,000 for two years was received.*

### Parathyroid Hormone Therapy Study

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<td><strong>Parathyroid Hormone Therapy Study</strong></td>
<td>Test the efficacy of PTH-CBD, a compound that stimulates the hair cycle, in stimulating hair growth in the C3H/HeJ engrafted mouse model of alopecia areata.</td>
<td>The final report shows PTH-CBD is a promising therapy for alopecia areata, particularly in conjunction with a mild immune suppressant, such as hydrocortisone cream.</td>
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<td>Robert Gensure, MD</td>
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<td>Tulasi Ponnappakem, PhD</td>
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<td>Ranjitha Katikaneni, MBBS</td>
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<tr>
<td>Children's Hospital at Montefiore, Bronx, New York</td>
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### Indentify Antibody Targets

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<td><strong>Indentify Antibody Targets</strong></td>
<td>Sequence DNA, create libraries and look for candidate targets in alopecia areata blood samples from the Registry. Registry samples were processed at Columbia University and sent to Dr. Dai in November 2013. Dr. Dai will have results to share soon.</td>
<td>This study may identify what the immune system is attacking that results in alopecia areata and point to possible therapy approaches to block the destruction of hair follicles.</td>
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<tr>
<td>Daisy Dai, PhD</td>
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<td>University of Colorado, Denver</td>
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Statement of Financial Position
December 31, 2013

ASSETS 2013

Current assets:
- Cash and cash equivalents: $931,280
- Marketable securities: 3,234,113
- Accounts receivable: 26,981
- Prepaid expenses and other current assets: 119,021
  Total current assets: $4,311,395

Net assets released from restrictions: 669,814
  Total assets: $4,319,519

LIABILITIES AND NET ASSETS 2013

Current liabilities:
- Accounts payable: $2,534
- Accrued vacation payable: 21,957
  Total current liabilities: 24,491

Net assets:
- Unrestricted: 1,082,699
- Temporarily restricted: 3,212,329
  Total net assets: 4,315,028

Net assets, end of period: 4,295,028

Income for Fiscal Years 1981-2013

The Statement of Financial Position of the National Alopecia Areata Foundation as of December 31, 2013, 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, 65 Mitchell Boulevard, Suite 2008, San Rafael, CA 94903, or on the website www.naaf.org.
Donors to NAAF provide critical financial support and represent a growing community that have allowed us to expand our support and education programs and drive research to find a treatment. Donors also strengthen us by introducing NAAF to their communities. We thank you for your support.

**January 1, 2012 – December 31, 2013**

Editor’s note: Some of the donors listed raised all of the money for their donation, or a portion of it, by fundraising.

**GOLD BENEFACTORS —$50,000 AND ABOVE**

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<td>Wendy &amp; Brian Ter Haar Family &amp; Friends</td>
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**Foundations and Organizations**

- Daniel and Janet Mondelau Foundation, Wilmington, DE
- Sunshine Charitable Foundation, Lake Forest, IL

**GRAND BENEFACTORS —$5,000 to $9,999**

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**Family & Friends**

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**In memory of Kathyn Stamilus Brandy**

**BUSINESSES**

- Downtown Chiropractic, New York, NY
- E & J Gallo Winery, Modesto, CA
- Freedom Wigs Ltd., Dunedin, New Zealand
- Johnson & Johnson, Morris Plains, NJ
- Mary Kay, Inc., Addison, TX
- Murray Hill Chiropractic, New York, NY
- Spencer Forrest, Inc., Los Angeles, CA
- Xenopros, Santa Clara, CA

**Foundations and Organizations**

- Barry H Glick Charitable Foundation, Wanaque, NJ

**ESSENTIALS**

- Bessemer Trust, New York, NY
- Delaware Support Group, Wilmington, DE
- Wells Fargo Foundation, Santa Monica, CA
- Maxine & Jack Zarrow Family Foundation, Tulsa, OK

**MAJOR BENEFACTORS —$2,500 to $4,999**

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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.