INVESTIGATE HOPE

DISCOVER

Annual Report for the Fiscal Year Ending December 31, 2010
Dear Friends,

We begin this annual letter to you by highlighting the most exciting discovery in the history of alopecia areata. The National Alopecia Areata Foundation (NAAF) used your generous donations to INVESTIGATE every possible avenue that might lead to a breakthrough in the understanding and treatment of this disease, and after 13 years of investments in genetics research, we DISCOVER there are eight genes related to alopecia areata. These same genes are associated with many other autoimmune diseases. Through our research program, NAAF has given HOPE to generations of people affected by alopecia areata.

Scientists throughout the world know about this finding since it was published in the prestigious medical journal, Nature. Medical professionals, including dermatologists, have contacted NAAF to praise us regarding this discovery. Patients and families who have supported NAAF for many years know that their commitment has been worthwhile. At the same time, we all realize we must continue to take steps toward the next discovery in our quest to find an effective treatment and end to this disease.

While we celebrate this breakthrough in research, we also want to remember the other two parts of our mission—awareness and support—which are so important for people living today with alopecia areata. Through our support network, the National Alopecia Areata Foundation makes a difference in the lives of those families and individuals. We continue to investigate and discover new ways of helping people. We offer hope on a daily basis through our website, message boards and social media, informational materials, DVDs, electronic and print newsletters, the Ascot Fund, and the Alopecia Areata Marketplace.

The National Alopecia Areata Foundation strives to communicate the facts about alopecia areata to as many people as possible. Each day we discover new ways to reach more people. Through awareness and advocacy programs we educate the community so that they, in turn, are more compassionate and considerate of people with alopecia areata. We thank NBA player Charlie Villanueva and Miss Delaware, Kayla Martell, who promote awareness through their appearances.

We thank you again for your support. We hope you are pleased with the report of activities and accomplishments from 2010.

Brian Ter Haar, Chair, Board of Directors, 2011

Vicki Kalabokes, President and Chief Executive Officer
SUPPORT: People DISCOVER every day that the National Alopecia Areata Foundation offers the Emotional Cure through its Support Network.

- NAAF held its 25th Annual International Patient Conference in Indianapolis, Indiana, in the summer of 2010, drawing 655 participants from 32 states and 3 foreign countries. The conference is the key to all of NAAF’s support efforts, empowering those affected by alopecia areata to raise awareness and help others in their own communities.
- 86 Conference Scholarships were awarded to people in need, enabling them to attend the conference. A total of 1,121 scholarships have been awarded since the inception of our conference scholarship program.
- Our Children’s Conference Camp, which has been held in tandem with the patient conference since 1988, drew 225 children and teens.
- We continue to expand NAAF’s website to serve you better. It is more interactive to help more people in real time.
- We have hosted NAAF Webinars to educate everyone on topics you have requested such as Advocacy, Research, and Children Returning to School. Our most popular Webinar last year featured Dr. Cristiano reporting on her genetic findings.
- Our NAAF Electronic News (Beneath the Surface) quickly conveys important information to everyone.
- NAAF’s Facebook and Twitter pages encourage even more interaction among our alopecia areata family.
- The Ascot Fund provided financial grants to 65 men, women, and children so they could purchase hair prostheses. These grants truly make a difference in the lives of people. A total of 414 people have been aided by grants from this fund since it was established in 2004.
- Alopecia areata kids have many NAAF resources to help them! We offer a nine-minute DVD/video that kids can share with family, friends, and schoolmates; a school packet for use by parents and teachers; a NAAF bibliography of books for kids with alopecia areata; children’s support groups; our Children’s Conference Camp; our Pen Pals program; secure and private message boards for children and teens; a special KidNet section of the NAAF Newsletter; and brochures for both kids and their parents.
- The Alopecia Areata Marketplace helps people with alopecia areata access hard-to-find and much-needed products to ease their daily life. It now features 54 different merchants. The variety and quality of the products are exceptional.
- Our International Support Network includes 130 loyal volunteers in 111 cities worldwide, organizing local support groups and providing telephone support. NAAF has started highlighting its support volunteers in each quarterly newsletter.
- Our Pen Pal program now has over 1,300 participants, including adults as well as children.
- NAAF responds to thousands of emails, phone calls, and fax requests for information.
- NAAF is able to help more people because of the help we receive from thousands of volunteers nationwide and internationally.
- Our quarterly award-winning NAAF Newsletter continues to be recognized as a model for patient newsletters.
- Our NAAF brochures continue to help those with alopecia areata and educate the public.
AWARENESS: People DISCOVER every day what alopecia areata is and its effects on people through National Alopecia Areata Foundation’s awareness efforts especially our grassroots volunteers around the world.

- Kayla Martell has been a spokesperson for NAAF. She was crowned Miss Delaware, and the National Alopecia Areata Foundation was chosen as her platform to promote alopecia areata awareness. We had millions of media impressions from the numerous media outlets that covered her reign as Miss Delaware. She eventually advanced to the top ten in the Miss American Pageant. We are so proud of her!

- Kristen Wells, host of HGTV’s Smart Fix has also been a spokesperson for NAAF. Kristen contacted NAAF with a burning desire to give back. She wants to add HOPE because her hair did grow back and she has been patch-free ever since.

- NBA player Charlie Villanueva continues to “Meet & Greet” and inspire children and adults affected by alopecia areata, but Charlie says the reverse is true: he says these Meet & Greets really inspire him. The Charlie’s Angels Program has had over 4,500 children and adults participate during the past five years.

- NAAF and the National Coalition of Autoimmune Patient Groups (NCAPG) worked together to produce two video Public Service Announcements (PSAs), one for all autoimmune diseases and one for alopecia areata. Charlie Villanueva was among the people featured. This was a very productive collaboration.


- Over 500 NAAF Conference participants attended an Indianapolis Indians Minor League baseball game to raise awareness of alopecia areata and cheer on Harrison Goldberg, who threw the ceremonial first pitch.

- The Tortoise & Hair™ run/walk is growing into NAAF’s premier nationwide awareness and fundraising event. Held during our annual patient conference in Indianapolis, this event drew over 470 runners and raised over $20,000.

- Volunteers like Heidi Bratt in Massachusetts continue to fight at the state level for insurance coverage for alopecia areata.

“I feel when you educate and make others feel comfortable about alopecia areata by talking about it openly it helps avoid misunderstandings and promotes awareness.”
— Maritza Stern

“Beauty comes in all different kinds of packages. You can be a beauty queen and not have hair.”
— Kayla Martell

“I see alopecia areata as the coolest disease ever because it’s not deadly, you get to go to conferences, meet new kids with alopecia areata too and you get to meet the coolest basketball player ever . . . Charlie Villanueva.”
— A NAAF Kid

“I fought my insurance company for six months and I won! A small victory, yet an important one. Insurance companies need to know that alopecia areata is an autoimmune disease, it is a real disease, it affects people greatly, and that people with alopecia areata have the right to recognition and treatment.”
— Cynthia Klein
INVESTIGATE  HOPE  DISCOVER

- NAAF continued its fight for insurance coverage on the Federal level.
- NAAF volunteers hosted fundraising and awareness events around the world, generating almost $223,400 for NAAF. All of these events are listed by state or province in this annual report. We offer our thanks to all the individuals and families who hosted—or participated in—these fantastic events!
- NAAF now has an official song: “Bald is Best” by Tyree Glenn Jr., the ambassador of Rhythm and Blues. The song gets everyone dancing and singing. Tyree Glenn Jr. has over 20 years of experience on New York’s Broadway, concert tours, and television and radio shows in Italy, Portugal, England, and Germany.
- NAAF, working with the Coalition of Skin Diseases, has continued to advocate for the importance of skin disease research so that all skin diseases in the coalition benefit.
- NAAF takes a very active role in educating medical professionals about alopecia areata, 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.

NAAF gratefully acknowledges all of the AWESOME individuals and families that raised money and spread awareness on our behalf during 2010. Total Raised: $223,400!

CALIFORNIA
Jillian Halloran Family & Friends
Trish Kotal Family & Friends
Friends at Luso-American Life Insurance
Friends of the Marin Human Race
San Francisco Support Group

CONNECTICUT
Connecticut Support Group
Adriene & Robert Guerin Family & Friends
Holly McDonald’s Family & Friends
Jacob O’Rifer Family & Friends
Katy Swede-Taillon Family & Friends

DELWARE
Deborah Pellicano Family & Friends

FLORIDA
Amish & Berna Parikh Family & Friends

ILLINOIS
Ken & Jennifer Anderson Family & Friends
Baumgart/Beckman Family & Friends
Rogers Elementary School

INDIANA
Friends of Northwood Elementary School
Olivia Rusk Family & Friends
NAAF Supporters of Tortoise & Hair™ Indianapolis

IOWA
Friends of Aplington/Parkersburg School District

KENTUCKY
Kelly Fineman Family & Friends
Ruthy Mayfield Family & Friends

LOUISIANA
Abby Ter Haar Family & Friends

MARYLAND
Mark Sayan Family & Friends

MASSACHUSETTS
Friends of Westminster Elementary School

MICHIGAN
Mallory Crowner Friends & Family
Cassie McElwain Family & Friends

MISSOURI
Michelle & Kurt Busse Family & Friends

NEW JERSEY
Tom & Laura Conklin Family & Friends
Liliana Hakim Family & Friends
Christopher Passarella Family & Friends
Carole Rogers Family & Friends

NEW YORK
Harrison Goldberg Family & Friends
Jack Keogh Family & Friends
Lord & Taylor Do Good Campaign
Erica Meilhede Family & Friends
Friends of Northside School
Friends of Reuben Gittelman
Hebrew Day School

NORTH CAROLINA
Alexandra Dest Family & Friends
Samuel Lanning Family & Friends

OHIO
Sara Kluener Family & Friends
Paige Collins Family & Friends

 PENNSYLVANIA
Beth Breslow Family & Friends
Nikola Cao Family & Friends
Friends of Hallowell Elementary School
Diane Gormley Family & Friends
Friends of the Philadelphia, PA Support Group
Emma Robbins Family & Friends
Friends of the Philadelphia 76’ers

SOUTH CAROLINA
Cindy Bondio Family & Friends

TENNESSEE
Shannon O’Neill Family & Friends

TEXAS
Jose Charqueno Family & Friends
Manuel Espino Family & Friends
Michael & Lise Maddux Family & Friends

VIRGINIA
Jeff & Sherene Gravatte Family & Friends

WISCONSIN
Kaycee & Kiah Lang Family & Friends
Friends of Wedgewood Park School
RESEARCH: The National Alopecia Areata Foundation spends a tremendous amount of its resources to INVESTIGATE alopecia areata to DISCOVER as much scientific knowledge as possible and to give HOPE to all those affected by alopecia areata.

- NAAF’s funding of Dr. Angela Christiano at Columbia University over the past 13 years has paid off with the discovery of eight genes that contribute to alopecia areata, one of which has a possible role in the onset of the disease. Many of the genes found to be associated with alopecia areata are also associated with other autoimmune diseases with pre-existing treatments. This discovery is expected to lead to effective clinical trials. NAAF thanks the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for continuing Dr. Christiano’s studies and awarding her the resources to be able to make this discovery.

- NAAF has now initiated an Alopecia Areata Treatment Development Program to find a successful treatment as rapidly as possible. This program, which is a direct result of recommendations from the Alopecia Areata Immunology Summit and Dr. Christiano’s discoveries is strategic and focused. We know exactly what we need to do to accomplish our goals. We have a comprehensive budget and timeline.

The program focuses our efforts in two directions: Basic Immunology Research to find a treatment in the long term and Clinical Studies to find a treatment in the short term, NAAF acts much like a concierge, bringing together players from science, industry, government and patients to find a treatment.

“Thank you so much for the email about Dr. Christiano’s discovery of the genes implicated in alopecia areata and the publicity. I understand there is no cure yet but this puts HOPE in the hearts of millions.”
— Shawn Lintz

“Finally we have the possibility of developing drugs that specifically target the mechanism behind the disease.”
— Angela Christiano, PhD

“Dr. Christiano has definitely been working on this for a very long time. I’m glad her research is finally bearing fruit. Dedication like hers is rare.”
— Nick Kypriotakis

“Thank you very much for such interesting news, which give us additional hopes of attaining our targets against alopecia areata”
— Jorge Sulegui Gil

“Wow, this is what I have been waiting for! As an immunologist who has been following the research in the field of alopecia areata for over 25 years, it was enlightening to hear the results of the work presented by Dr. Christiano at the NAAF conference in 2010. The rigorous population genetics data derived from the National Alopecia Areata Registry provides the focus for new targeted immunologic, therapeutic and clinical studies.”
— Howard B. Fleit, PhD.
BASIC IMMUNOLOGY RESEARCH:
NAAF has funded two research grants in Basic Immunology to date—one to find the autoantibodies involved in alopecia areata and another to determine if infectious agents are involved. These studies are ongoing and should be completed in late 2011.
1. The George Eisenbarth Laboratory, located in the Barbara Davis Center for Childhood Diabetes at the University of Colorado Denver School of Medicine, is a state-of-the-art facility focused on researching the immunology and autoimmunity of Type 1 Diabetes. We believe we can benefit from all the advances and technology the diabetes community has invested in studying their disease to learn more about our own.

NAAF is funding Dr. Li Zhang, a postdoctoral fellow in the Eisenbarth Laboratory, to Develop Molecular Assays for Alopecia Areata–Associated Autoantibodies.

Much autoimmunity research now focuses on discovering the specificity of the immune response—in other words, the specific target that the immune response is attacking.

The specificity of the immune response is determined by either antibodies or T-cell receptors. Antibodies are soluble proteins that circulate through the body, seeking foreign antigens to bind and target. T-cell receptors are located on the surface of T cells, which migrate through the body seeking antigens to attack. In alopecia areata, it appears that specific T cells are attacking specific antigens in the hair follicle.

Once antibody specificities are identified in alopecia areata, additional studies on the role of these antibodies in alopecia areata will be designed, and studies on T-cell specificities will be organized to determine if T cells share the same specificities as antibodies.

2. Yehuda Shoenfeld, MD, FRCP, is also studying infectious agents in alopecia areata. Shoenfeld is head of the Department of Medicine B and the Zabludowicz Center for Autoimmune Diseases at Sheba Medical Center (affiliated with Tel-Aviv University) in Israel and Incumbent of the Laura Schwarz-Kipp Chair for Research of Autoimmune Diseases on the Sackler Faculty of Medicine at Tel-Aviv University, Israel.

An increased prevalence of celiac autoantibodies has been found in the sera of alopecia universalis patients compared to controls. They suggest an association between anti-celiac antibodies and anti-TPO with alopecia universalis and patchy alopecia areata. The exact role of these autoantibodies and their associations with different forms of alopecia areata and other autoimmune diseases will continue to be studied.

CLINICAL STUDIES:
1. NAAF has formed the Corporate Leadership Council to convince companies that there is a market for drugs that may be able to be used to treat alopecia areata.
2. NAAF funded a grant to Dr. Jenna O’Neill at Wake Forest University to research the 235 drugs being developed for other autoimmune diseases and to produce a spreadsheet of all pertinent information, including what stage of study the drug is in.
3. NAAF held an Alopecia Areata Clinical Summit to set priorities to advance clinical studies of alopecia areata.
4. NAAF is negotiating with several companies to partner on clinical studies.
5. NAAF is coordinating investigators to develop a uniform protocol for alopecia areata clinical studies.

6. NAAF is pursuing Quality of Life Studies so we will be prepared to appear before the Food and Drug Administration if we are successful in finding a viable treatment.
7. NAAF is also pursuing current prevalence and incidence studies to present to the Food and Drug Administration.
8. NAAF is coordinating alopecia areata–related grant applications to the National Institutes of Health so there aren’t competing applications.
9. NAAF is pursuing the publication of the biomarkers involved in alopecia areata to advance the clinical studies.

- NAAF has spent the year preparing to take over the National Alopecia Areata Registry, which was established at NAAF’s urging and funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the National Institutes of Health. Dr. Cristiano used 1,054 samples from the Registry for her important discoveries. We hope to change the Registry’s name to the Alopecia Areata Clinical Trials Registry since it will become a major part of the Alopecia Areata Treatment Development Program.

By the end of 2010, over 9,000 people had completed the initial registration questionnaire. Over 3,100 of these people had also completed the second phase of registration, providing blood samples and undergoing a medical exam. The more people we have in the registry, the more we learn about alopecia areata and the more clues we gain to find a possible cure.
INVESTIGATE
HOPE
DISCOVER

STATEMENT OF ACTIVITIES FOR THE YEAR ENDED
DECEMBER 31, 2010

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<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>2010 Total</th>
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<td>REVENUES:</td>
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<tr>
<td>Donations—general</td>
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<tr>
<td>Donations—stock and major donors</td>
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<td>Restricted grants and donations</td>
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<td>Conference</td>
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<td>Special events—Links for Locks and Tortoise &amp; Hair™</td>
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<td>Prior year grant reimbursements</td>
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<td>Awareness campaign</td>
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<td>Alopecia Areata Marketplace</td>
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<td>Brochures and videos</td>
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<td>Interest and dividend income</td>
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<td>Net realized and unrealized gains (losses) on marketable securities</td>
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<td>Net assets released from restrictions</td>
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<td>Total revenues</td>
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EXPENSES

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<td>Research</td>
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<td>Education and support</td>
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<td>Support services:</td>
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<td>Fundraising</td>
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<td>Management and general</td>
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<td>Net assets, end of period</td>
<td>$1,152,136</td>
<td>$35,174 $1,187,310</td>
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The National Alopecia Areata Foundation 2010 Annual Report

The Statement of Financial Position of the National Alopecia Areata Foundation as of December 31, 2010, 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

INCOME FOR FISCAL YEARS 1981-2010

SPENDING PERCENTAGE

80% PROGRAM
Support, Research and Awareness

13% FUNDRAISING

7% MANAGEMENT
INVESTIGATE  
HOPE  
DISCOVER

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Hair Research Center
University of California, San Francisco
San Francisco, California

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Lisa Butler
Vice President Communications

Laura Ralph
Resource and Information Specialist

Mary Cosgrove
Website and Database Specialist

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Legal and Financial Advisor

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President and Chief Executive Officer, NAAF

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MD Anderson Cancer Center
Houston, Texas

Marc Glashofer, MD
Island Dermatology
Long Beach, New York

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Wake Forest University
Winston-Salem, North Carolina

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George Washington University
Washington DC

Sigfrid A. Muller, MD
Las Vegas Skin and Cancer Clinic
Las Vegas, Nevada

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Duke University
Medical Center
Durham, North Carolina

Anthony Oro, MD
Stanford University
Medical Center
Palo Alto, California

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Uniformed Services University
Bethesda, Maryland

Richard Strick, MD
UCLA School of Medicine
Los Angeles, California

John Sundberg, DVM, PhD
The Jackson Laboratory
Bar Harbor, Maine

David A. Whiting, MD
Baylor Hair Research & Treatment Center
University of Texas
Southwestern Medical Center
Dallas, Texas

Members of the NAAF Volunteer Board of Directors at the January Planning Meeting. Front, left to right: Jay Bokulic, Harris Barer, Brian Ter Haar. Rear, left to right: Alan Pallie, Maureen McGettigan, Richard Dest, Donna Hakim, Gary Gordon, Hoy Lanning Jr., and Bob Flint (missing is Bruce Fiscus).
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.

14 Mitchell Boulevard
San Rafael, CA 94903
Phone: 415-472-3780
Fax: 415-472-5343
Email: info@naaf.org
Website: www.naaf.org

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