



Greetings NVF Member:

June 2011

The National Vitiligo Foundation (NVF) hopes are ready for summer!! As you know our goal is to [1] support research on Vitiligo, [1] advocate for people with Vitiligo, and [3] increase awareness of Vitiligo worldwide. Towards those efforts we have the following new exciting information.

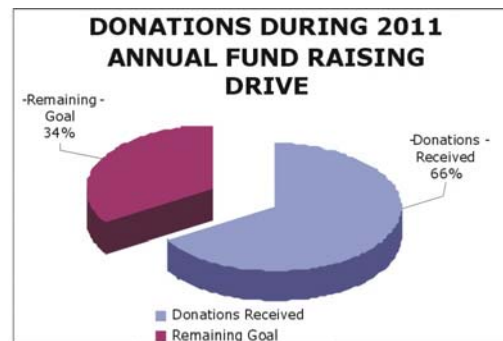
**MEMBER NEWS:** With great pleasure we announce our current NVF VOLUNTEER OF THE YEAR –



**Heather Marsh.** Heather has been volunteering with the National Vitiligo Foundation for several years now. As a volunteer she has spent many hours creating thousands of mailings to keep NVF members informed of Foundation activities and progress, and to help with fundraising for the Foundation.

Heather works as a special education teacher in the greater Cincinnati area. She is very passionate about finding a cure for vitiligo and other skin diseases. She has seen firsthand how skin diseases hurt the self-esteem and psychological well-being of children, close friends, and even her own husband. Stories of children being discarded or abused by parents, or the children committing suicide because of their physical appearance, are part of what motivates her to take action and be involved. Heather believes that until we find a cure, providing support and educating the public to drive awareness will help save many lives and help bring acceptance for millions around the world.

**FOUNDATION NEWS:** We would again like to thank the membership for your overwhelming response to our Annual Fund Raising Drive that began at the first of the year. We sent out our Annual Report to all members with a request to update contact and email addresses and a significant number of members returned the donation envelopes. To date we have reached over two-thirds of our fund raising goal of \$36,000!! This is very encouraging for the staff at NVF as we try to implement our advocacy for our members, the Vitiligo community and the clinicians and scientists trying to find better therapies and a cure. THANK YOU



**RESEARCH NEWS:** Below you will find a Research Update by Dr. Richard A. Spritz, M.D., Professor and Director of Human Medical Genetics Program at the University of Colorado Health Sciences Center. Dr. Spritz has pioneered studies for more than a decade on indentifying the genetic basis for the susceptibility to develop Vitiligo. He has made great strides in this research program but more work and help remains. I encourage you to read his update and to participate in his request for additional questionnaire information. This questionnaire can be found by the link to in on the NVF website homepage or at: [http://nvfi.org/pages/patient\\_studies.php](http://nvfi.org/pages/patient_studies.php) . Thank you for your participation in this valuable research.



## UNIVERSITY OF COLORADO SCHOOL OF MEDICINE

Research Update – Richard A. Spritz, M.D.

It's been a long time since I gave a research update to the NVF. Back in 1997 the NVF helped in our very first vitiligo research, providing funds for a collaborative effort with the Vitiligo Society (United Kingdom) to survey both societies' memberships to learn more about the epidemiology of vitiligo, to invite the NVF membership to participate in genetic studies, and to collect DNA samples and information from some of the larger families.

Genetic research on vitiligo has come a very long way since then, culminating over the past few years in our large-scale “genomewide association study” that involved dozens of collaborating physicians and researchers and thousands of vitiligo patients around the world. The results of that study, the first of its kind, changed understanding of vitiligo forever. It is now clear that typical “non-segmental vitiligo” (which includes generalized vitiligo, acrofacial vitiligo, and vitiligo universalis) is a primary autoimmune disease, and it now appears that even segmental vitiligo may involve autoimmunity as well. As the result, research efforts are now shifting towards more clearly defining the genetic causes and environmental triggers of the autoimmune process, so as to better understand how to halt that process and thus make repigmentation more effective, or even perhaps how to prevent it from ever even starting.

Altogether, we now know of at least 16 genes that underlie susceptibility to vitiligo in Caucasians, though many of these genes seem to play smaller roles in other ethnic groups, in whom the genetic causes of vitiligo remain less clear. We now know that no one of these genes is enough to “cause” vitiligo. Instead, we know that genetic susceptibility to vitiligo involves many of these genes acting in combination, perhaps different combinations in different people. In fact, the genes we have found explain quite a lot. They explain why many patients with vitiligo, or their close relatives, may develop other autoimmune diseases (such as thyroid disease, type 1 diabetes, rheumatoid arthritis, psoriasis, pernicious anemia, lupus, or Addison's disease). The reason is that some of the same genes also underlie genetic susceptibility those other diseases as well. Yet other genes appear to target the immune system to specifically attack pigment cells, leading to vitiligo. Thus, some genes underlie susceptibility to autoimmunity in general, other genes underlie susceptibility to specific autoimmune diseases or groups of diseases, and environmental triggers probably start the process. Unfortunately, we don't yet know what those triggers may be, but research is hot on their trail.

We've come so far that we can now also make some statements about what has not been found. What has not been found is anything that would implicate vitamin deficiency, mineral imbalance, food allergies, or any of the many other widely-held beliefs about environmental triggers or easy home remedies. That is too bad, but that is why we do research. That doesn't mean these couldn't be involved, but with each new piece of the puzzle that falls into place, the bar is set higher and higher regarding proof for pieces that otherwise don't fit.

So, where do we go now? We've identified 16 genes so far, which have already led to remarkable new insights. However, we also know this only scratches the surface. In addition to extending our studies to non-Caucasian populations, our immediate goal is to triple the size of the genomewide study, which we expect will more than triple the number of genes, any of which might provide a key to new treatments or even eventual disease prevention. That means we need to enroll at least 3000 new patients into our study over the next 12 months. Can we do it? I don't know; that depends on you. Twelve years ago many of the NVF membership enrolled in our study; our thanks to all of you who have participated, but we can't include you a second time. However, if you are a more recent NVF member, or didn't enroll back then, or if you enrolled but were never contacted, please consider sending in our Study Entry Questionnaire. Unfortunately, we can only include participants in the USA or Canada, but we thank those of you who live elsewhere for your moral support.

Please fill out the questionnaire completely, including complete contact information (otherwise we can't contact you), return it via mail or email, and we will contact you as soon as we can. Please understand that this study involves many thousands of participants, so we cannot provide individual study participants with personalized reports of data, study progress, genetic risk, advice regarding treatment, or other medical advice. Thanks again to all of you for your help and participation, and to NVF as an organization.

Sincerely,

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Human Medical Genetics Program  
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**YOU CAN ALSO VIEW DR. SPRITZ'S RESEARCH PROGRAM ON THE NVF ROAD MAP**

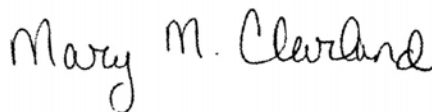
[http://nvfi.org/map/road\\_map.php](http://nvfi.org/map/road_map.php)

These new information and programs highlight the great strides the NVF has accomplished in the past few months. These accomplishments have been successful in part by your generous and sustained support & contributions. I personally wish to thank you.

Sincerely,



Raymond E. Boissy  
President  
National Vitiligo Foundation



Mary Cleveland  
Executive Director  
National Vitiligo Foundation