

# NATIONAL VITILIGO FOUNDATION, INC.



## 2010 ANNUAL REPORT



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## A WORD FROM THE PRESIDENT



2010 has been quite a year of turmoil for many of us. Challenges we are facing these days include economic instability, political wavering, war continuation, and weather unpredictability. Fortunately, the vitiligo Community in general and the National Vitiligo Foundation, Inc. (NVFI) in specific have had a strong, steady year thanks in part by the support and involvement of our members. **Thank you.** National awareness of vitiligo is dramatically increasing and the subject of vitiligo is more frequently in the news. Several months ago we attended the very First Vitiligo World

Congress (VWC 2010), held in Milano, Italy. This was a hallmark event where 200 Researchers and Clinicians plus hundreds of patients gathered with enthusiasm and passion. The main focus for many of us attending was how to efficiently and coordinately advance in the understanding of and therapy for vitiligo; a true renaissance of a meeting.

Also most exciting this year is the scientific advances that have occurred in research on vitiligo. Several logical genes associated with vitiligo have been identified by various researchers this year. Some of these candidate genes regulate the immune system and some influence the behavior of the melanocyte. This is quite logically when considering the multiple and complex nature of the disease. For the first time we now have clues to the causative factors for vitiligo. These clues will be key for understanding how vitiligo occurs, developing more effective therapies, and ultimately finding a cure. It is still going to take more time, manpower, and money to achieve these goals; however that should be readily achievable. The National Vitiligo Foundation is committed to facilitating this achievement by providing grant support for researchers and clinicians working on the frontiers of vitiligo. To do this we need your help with our annual fund-raising campaign. And to use a cliché, "every bit helps tremendously".

My best wishes and thank you again for your support,

A handwritten signature in black ink that reads "Raymond E. Boissy". The signature is written in a cursive, flowing style.

Raymond E. Boissy, PhD  
President

## THOUGHTS FROM THE EXECUTIVE DIRECTOR

*“When you set out on a journey and night covers the road, you don’t conclude the road has vanished but instead look up to the stars to illuminate your way.”*



I want to **THANK YOU** for placing your trust in me as I begin my journey as the new Executive Director of the National Vitiligo Foundation (NVF). I am thrilled to be entrusted with such a noble challenge and thankful to be surrounded by the many “stars” I have found in the membership, illuminating my way.

While the NVF road is strong and steady, we still have additional work to do. We have to bring our team together and work comprehensively to accomplish our mission which is to educate and help the world understand and accept vitiligo with love and respect; while also helping the medical professions find additional treatment options and ultimately a cure. Under my guidance, NVF will continue to provide prompt and courteous service to our customers and offer complete vitiligo education and patient support.

Forthcoming activities include the redesign of the NVF website, establishing support groups in various communities, increasing sponsorship, engaging policymakers in advocating for the vitiligo patient, raising public awareness and securing funding for research.

I hope you will JOIN me as we unite our collective voices towards new uncharted territories. Even though there are many endeavors upon us, I am confident that together we will succeed in accomplishing our goals.

In the coming months, I will reach out to you for your ideas, comments and help as our journey unfolds keeping you informed every step of the way.

Again **THANK YOU** for allowing me to come along for the ride!

With the warmest regards,

*Mary M. Cleveland*

Mary McAlister Cleveland, B.B.A., J.D.  
Executive Director

VITILIGO: A NATIONAL HEALTH ISSUE

Vitiligo is a relatively common disease, with about 1 to 2% of the world's population affected, which means anywhere from 50 to 100 million people are affected. 100 million people is roughly the population of California, New York, Illinois, Florida and Texas combined.

Vitiligo is a multifactorial skin depigmenting disease with an etiology (the cause and progress of the disease) not well understood. With loss of skin pigmentation, vitiligo patients may become susceptible to skin cancer and skin aging. Frequently vitiligo patients develop other autoimmune diseases concurrent with their vitiligo. Most devastating for the patient with vitiligo are the social, psychological, and sexual ramifications of this disfiguring disease.

The current therapy for vitiligo focuses on halting the progression of the depigmentation with topical immunomodulators and encouraging repigmentation with phototherapy. However, success rates of these therapies is dramatically low, variable, and not permanent. Therefore, new therapeutic approaches are

warranted. With many vitiligo patients responding poorly to the current therapies, more focus should also be directed to improve non-medical consequences of vitiligo that include, make-ups & camouflages, self-image support, public awareness, better insurance coverage, to name a few.

The National Vitiligo Foundation advocates for patients by uniting our collective voices to “**SAI**” (pronounced say) with purpose our mission:

- [1] Support research on Vitiligo,
- [2] Advocate for people with Vitiligo, and
- [3] Increase awareness of Vitiligo worldwide.



Research to find a cure

## YEAR IN REVIEW (1)

*To determine where we are headed, we must review where we have been...  
And what a wonderful journey it's been!*

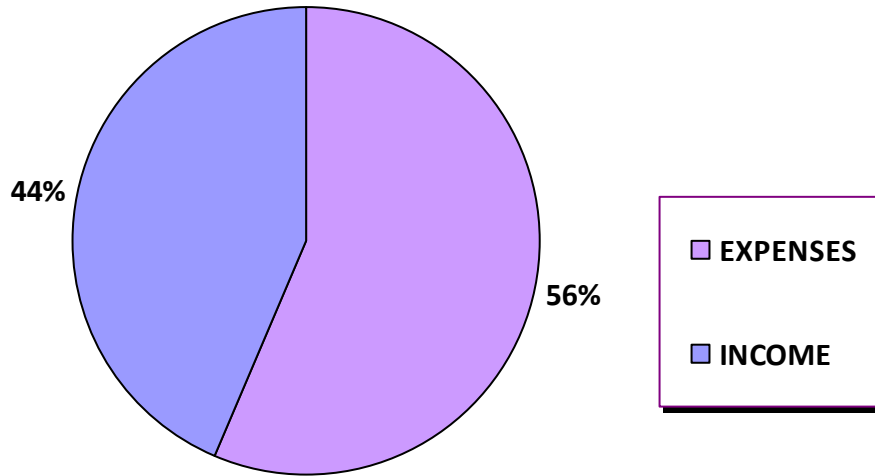
Over the past few years, the NVFI has worked diligently to create a solid foundation to align with our mission. We have defined our goals and through our accomplishments, we have grown steadily. In 2010 we saw a flurry of activity, much with a specified objective...to increase our collective voice to spur resources for continued research and awareness campaigns. Take a look at some of our many endeavors in 2010.

- [Dr. Charles Collins](#), joined our Board of Directors. He is the Associate Professor of Clinical Psychiatry, Sr. Vice Chair & Director of Clinical Operations; Department of Psychiatry and Behavioral Neuroscience at the University of Cincinnati Academic Health Center.
- Participated in the First Vitiligo World Congress (VWC 2010), held in Milano, Italy
- ABC News Story posted to our Media page - [Like Father, Like Son? Prince Michael Appears to Have Vitiligo](#) (updated July 2010).
- The NVF has created an opportunity with [Cover FX](#), which makes corrective makeup for vitiligo and other skin conditions. NVF members receive 10% off Cover FX's Vitiligo Coverage Kit. The Foundation receives 10% of sales to help fund research on treatments and a cure (updated July 2010).
- An outstanding new book on vitiligo (edited by M. Picardo and A. Taieb) is [available on the NVFI Publications page](#) (updated July 2010).
- A [bibliography list](#) of recently published articles on vitiligo is available online (updated July 2010).
- A [media information section](#) is available online (updated July 2010).
- A [Vitiligo Road Map](#) showing the location of, and providing information about, the global centers of vitiligo research is available online (updated June 2010).
- Mary McAlister Cleveland joined the NVFI as the new Executive Director.

## YEAR IN REVIEW (2)

- The NVF partnered with [Vitiligo Friends](#), an on-line support group for individuals in the vitiligo community.
- The [PanAmerican Society for Pigment Cell Research \(PASPCR\)](#) is a scientific organization devoted to researchers interested in various aspects of pigment cells. The society is a very interactive one, meeting on an annual basis, and is composed of clinicians, developmental biologists, biochemists, immunologists, cell biologists, molecular biologists, chemists and physicists, among other disciplines. PASPCR endorsed the NVF with a donation to the foundation to be used in support of research grants.
- The [Dermatology Nurses' Association \(DNA\)](#) welcomed the National Vitiligo Foundation at the DNA national convention. Over 1000 dermatology nurses nationally and internationally were present and had the opportunity to learn about the clinical manifestation and treatment options for vitiligo as well as the role of the NVF in supporting individuals living with this disease.
- The Clemson University ETV Radio, a NPR station had a live broadcast on vitiligo for its "Your Day" segment on July 8th. This report featured The National Vitiligo Foundation and can be found at [Clemson Report](#).
- The [Vitiligo Support and Awareness Foundation of West Africa \(VITSAF\)](#) centered in Lagos, Nigeria held their Inaugural Launch & Seminar Conference entitled "Understanding Vitiligo in Africa" on April 29, 2010.
- A significant article was published last week in the New England Journal of Medicine from the lab of Dr. Richard Spritz that presents amazing information on several genes associated with vitiligo. In the study presented, a genomewide association analysis in 1514 patients with generalized vitiligo was performed that demonstrated significant association between vitiligo and several genes that participate in autoimmune diseases (particularly MHC class I & II molecules) plus the gene that encodes tyrosinase, the primary enzyme responsible for the production of pigment by the melanocyte. This is critical information because it links for the first time a mechanism that explains a possible way the immune system can selectively attack the pigment system. This opens a new avenue of research that will unveil the molecular and cellular mechanisms regulating vitiligo and ultimately better therapy.
- [NVF STORE](#) was added. It can also be found from the opening page of our web site at [www.nvfi.org](http://www.nvfi.org). Help us build awareness for this largest unknown skin disease. Money raised supports vitiligo research.

FINANCIAL STATEMENT



Income	
Donations	\$20,213.27
Advertisers	\$ 5,700.00
Earned Interest	\$ <u>80.03</u>
Total	\$ 25,993.30
Expenses	
Office	\$ 4,582.32
Personnel	\$16,448.13
Accounting	\$ 2,575.00
Fees	\$ 1,432.80
Travel	\$ 2,563.59
Promotion	<u>\$ 6,100.29</u>
Total	\$33,702.13
Assets	\$22,157.48
Liabilities	\$ 0.00

Note: Data as of November 17, 2010

OUR DONORS

THE GENEROSITY OF OUR DONORS PAVES THE WAY FOR THE IMPORTANT WORK AHEAD!

*THANK YOU!*

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LOOKING AHEAD TO 2011

Our goal is to unite our collective voices to "SAI" (pronounced say) with purpose our mission:

- [1] **S**upport research on Vitiligo,
- [2] **A**dvocate for people with Vitiligo, and
- [3] **I**ncrease awareness of Vitiligo worldwide.

JOIN OUR EFFORTS!

We have a very busy year planned for 2011! In addition to providing assistance to customers via email and phone calls from around the world and keeping the vitiligo community aware of the latest research news and treatments, with the support of our membership NVF will also:

Redesign and update the NVF website to include:

Vitiligo Basics improved access

Frequently Asked Questions and Answers

An updated Physicians list

A comprehensive menu of on-line Vitiligo resources

Treatment and Choice Options

Search engines to quickly access Vitiligo Articles, Tips and More

Introduce a National Spokesperson Campaign

Participation in community efforts - Nationwide

Establish vitiligo support groups in various communities

Fundraising Campaigns

Events for Vitiligo Awareness

Critical – Our ability to serve is measured by the contributions we receive

Increase Member Donations

Create a Physician Leadership Program

Secure grant funding

Increase Corporate Sponsors and Partners

Revise the NVF Brochure

Introduce

A Pulse Report, Patient2Patient Mentoring Program, a Student Corner, the Donors Club and a Volunteer Connection program



NATIONAL VITILIGO FOUNDATION  
***THINKING OUTSIDE THE BOX***

JOIN US!