



“Embracing Diversity”

The Newsletter of the
American Vitiligo Research
Foundation

Focusing On Children...Our Future

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2004

MISSION STATEMENT:

American Vitiligo Research Foundation Inc. (AVRF) provides public awareness about vitiligo through dedicated work, education and counseling. We seek to make a difference worldwide to those afflicted by the disease, focusing on children and their families.

We embrace diversity and encourage acceptance. AVRF encourages higher ethical standards in research, and therefore supports finding a cure through alternatives to animal testing. AVRF is a tax-exempt charity, regulated by section 501(c)(3) of The Internal Revenue Code



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“We Walk By Faith, Not By Sight”

Looking back...moving forward.

By Stella Pavlides, President

Dear AVRF Members,
Welcome to our first newsletter!
We have decided to share our information with you electronically. This method will allow us to reach more patients and their families worldwide.

For those who did not attend our July 2003 seminar, we have included a summary of the weekend . You will also be able to view photos of the events, the speakers, and our vitiligo awareness walk.

Loretta, one of the AVRF Board Members, will share our visit to Congress and the awareness we raised in our nation’s Capital.

The AVRF is working on new programs that will benefit the entire vitiligo community by raising awareness, educating the public, and funding research. This past year, the AVRF has seen tremendous growth and continues to move forward in a positive direction.

In closing, I would like to thank each of you for supporting the AVRF in its mission to make a difference. Your continued support is vital.



Sincerely,



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American Vitiligo Research Foundation

2003 SEMINAR

Seminar Summary, 2003

By Randy Salter

Administrator~VitiligoSupport.com

Vitiligo Views



Sunday Walkathon Group

Every year I travel from Los Angeles to Florida to spend time with members of the vitiligo community, and with good reason. This year's AVRF Vitiligo Awareness Seminar held in Clearwater, Florida was without a doubt one of the best so far, packed with information, energy, and great time for all who attended.

Many people arrived on Friday, July 25th, and took in the new venue for the event, the Hampton Inn, Clearwater. The hotel had very nice rooms, beautiful gardens, and a great rock waterfall pool and jacuzzi area. Having spent the prior week in South Florida and Orlando visiting friends and relatives, it was a relaxing break.

Friday evening, about 40 of us gathered for dinner in Clearwater, for an informal chance to introduce ourselves and socialize. Many of the doctors and other speakers for Saturday's seminar joined us as well. Later in the evening, many people went out to listen to music or join in karaoke at the city's various clubs.

Saturday morning, we enjoyed the hotel's excellent buffet breakfast, and then moved in to the main conference hall for registration. By far the largest seminar to date, over 120 people attended. U.S. Congressman Todd Tiahrt (R- Kansas) opened the program with a prayer, and remained for the weekend with his family. He is a strong supporter of the effort to find a treatment and cure for vitiligo, and his enthusiasm was obvious. Professor John Wood of the University of Bradford in England (and husband of Dr. Karin Schallreuter) served as M.C. and moderator of the day's program.

Chris Cane of Amjo Corporation joined us again to review the latest options in home UV therapy systems, and this year his wife Cheryl presented some great information about cutting through the red tape of obtaining insurance coverage for UV systems. The

Daavlin Corporation was also present, and had a great display of their products.

Attendees were treated to two cosmetic presentations, by both the Neostrata company, and Fantasy Tans. During the break, the hallways were filled with people trying new coverups, and those getting airbrush sprayed with sunless tanning products.

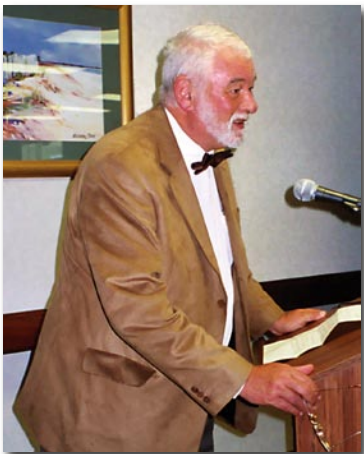
Dr. Lawrence Schachner, M.D., a specialist in pediatric dermatology at the University of Miami, gave an informative Powerpoint presentation that overviewed virtually all of the treatment options currently available for vitiligo. Dr. Karen Mallin, Psy.D, a pediatric psychologist also on staff at the University of Miami, explained various ways to deal with the psychological aspects and issues facing those with vitiligo, especially children. While her focus is on pediatric therapies, I found her program was applicable to almost everyone dealing with these issues.

After lunch at the Carrabbas Grill, we returned to the conference center, and were honored to hear from Dr. Leopold Montes, M.D., who discussed his findings about nutritional deficiencies in those with vitiligo. His research is fascinating for those of us interested in the pathology underlying vitiligo, and I ended up buying a copy of his book, "Vitiligo Nutritional Therapy" which I've since read (and which convinced me to be more diligent in my vitamin regimen).

Wayne McCormack, Ph.D. Associate Dean and Associate Professor at the University of Florida in the Department of Pathology, Immunology and Laboratory Medicine reviewed his latest work and research, and discussed the commonalities that his team was finding for those with vitiligo. His research into the genetics and pathology of vitiligo may eventually make it easier to understand the approach to treating vitiligo.

continued on page 10

The AVRF 2003 Seminar took place July 26th and 27th in Clearwater, Florida. Over 125 patients and family members attended, along with featured speakers including Prof. Karin U. Schallreuter, MD, Wayne T. McCormack, PhD., Leopoldo Montes, MD, Lawrence A. Schachner, MD, Karen Mallin, Psy.D and John M Wood, PhD as moderator. Demonstrations were presented by Daavlin Corporation, Neostrata-CoverBlend, FantasyTans Vitiligo and Amjo Corporation. Program guests included Congressman Todd Tiahrt (KS) and Thomas Paul (district representative for Congressman Michael Bilirakis-FL).





Our Experience at the 2003 AVRF Seminar

By Elizabeth Krohn

My 13 year-old daughter Mallory has had vitiligo since she was five. We have tried almost every treatment option available, some with more success than others. However, one of the best things we have done for Mallory's vitiligo was to attend the AVRF Seminar last summer. While this did little for her skin, it worked wonders for her self-esteem.

Mallory had never been around so many people with vitiligo at once. She felt wonderful being able to be herself, hang out with her new friends, and NOT get stared at. There were so many children there of all ages. Numerous fun activities were planned for the kids while the parents sat in the seminar. The children really bonded and Mallory keeps in touch with four of them on a fairly regular basis. This support group is priceless!

While Mallory was busy with the other kids, I was busy in the seminar. I spoke with other parents who could really understand my concerns. I also have kept in touch with several people I met that weekend. Knowing these other parents has been mutually beneficial. We have shared treatment information, including successes and failures, with each other.

The speakers at the seminar were fantastic. These doctors and professionals really CARE about helping people with vitiligo. They were all very gracious and answered all of our questions. Many of them stayed late to continue discussions, and even went to dinner with us. A great deal of information was shared that weekend.

The absolute best part of the weekend was near the end when Mallory turned to me and said, "Thank you so much for bringing me here, Mom. It's so cool to see that I'm not the only one!" That spoke volumes to me and brought tears to my eyes. Thank you Stella, Marilyn, and the AVRF!!!



Mallory

Vitiligo – What is new in 2003?

By Professor Karin U Schallreuter, MD

From the Institute for Pigmentary Disorders in Association with the Ernst-Moritz-Arndt University Greifswald, Germany, and the University of Bradford, UK

In 2003, the actual cause of vitiligo is still unknown.

There are several hypotheses; however, none can really explain the development of this disease. Over several years an increasing amount of convincing data has shown the accumulation of reactive oxygen species, especially of hydrogen peroxide (H₂O₂), in the epidermis of patients with vitiligo (1).

These results have been obtained using in vivo examinations (directly in the skin of the patients) and in vitro examinations. The latter ones are based on cultures of skin cells growing in the lab in artificial medium or biochemical and microscopic examinations of skin samples of patients and on healthy controls (1,2).

Moreover, computer modelling enables us today to study the direct effects of H₂O₂ on proteins (e.g. enzymes or transcription factors). This helps in understanding the in vivo/in vitro results in more detail.

The accumulation of H₂O₂ in the epidermis of patients with untreated active vitiligo has been well documented (1-3). In addition, it has been reported that treatment with pseudocatalase PC-KUS, which deactivates this H₂O₂, leads to repigmentation in 60% of all patients whereas the progression of the disease is stopped in 95% of the patients (1,5).

Another important evaluation was added to the diagnosis and follow-up of patients. This test allows the detection of patients with a defective metabolism of phenylalanine (6). Phenylalanine is one of the essential amino acids, which have to be supplied in the daily diet. Phenylalanine is converted in the body to tyrosine, which is in turn necessary for the synthesis of the skin pigment melanin (7). This turnover of phenylalanine to tyrosine can be determined in the lab (6). Our results showed a reduced capacity of this turnover in about 40% of the patients with vitiligo(6).

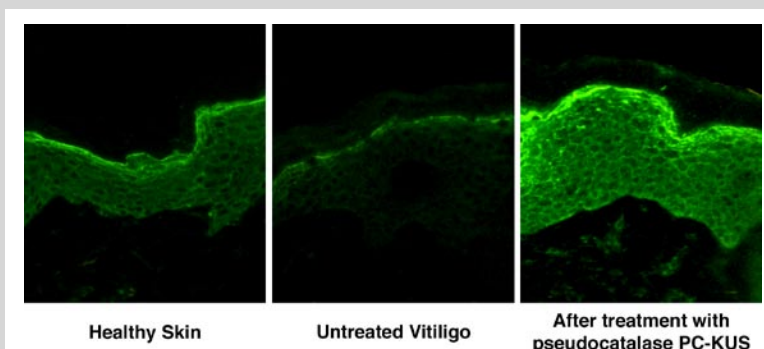
This additional lab test identifies these patients by using an appropriate substitution and it is possible to regain pigmentation in 95% of all patients (KUS, unpublished data).

Recent studies have demonstrated evidence for accumulation of H₂O₂ in the blood of patients with vitiligo besides the high H₂O₂ levels in their skin (4,8,9). Earlier lower activities of catalase and glutathione peroxidase were reported in the blood of these patients. Both enzymes are very important in the removal of H₂O₂ (3,4,10).

Moreover, our group has shown that the total recycling process of the important cofactor 6-tetrahydrobiopterin (6BH₄) is interrupted by H₂O₂ (3,4,10).

Pterin-4a-carbinolamine dehydratase (PCD), the enzyme controlling the rate limiting step of this process, is very low, and in some cases even completely absent (3,11).

Dihydropteridine reductase (DHPR) the enzyme responsible for the 2nd step in the 6BH₄ recycling (12) is also significantly reduced in the blood of patients with vitiligo (4). The activity of both enzymes, PCD and DHPR, recovers after treatment with PC-KUS. These results unmasked for the first time a passage of the H₂O₂ (produced in the epidermis) from the skin into the blood of patients. However, the amounts in the blood are 1000 fold lower than in skin; but, still high enough to produce systemic effects (3). These new results allow for the first time the follow-up and control of the oxidative status of patients with vitiligo by simple lab methods. Therefore, individual monitoring of H₂O₂ stress becomes easier and more objective. More exciting is, that we could show that patients after removal of epidermal H₂O₂ with pseudocatalase PC-KUS are regaining their natural catalase levels in the epidermis.



Catalase expression in the epidermis

The pictures show low catalase in untreated patients compared to healthy controls and the recovery after removal of H₂O₂. This important observation supports the earlier work by Aronoff in 1967, when he described that catalase can be destroyed by its own substrate (13). This result and the findings in vitiligo confirm also that catalase is not per se affected in predisposed individuals. It is the sudden production of high H₂O₂ concentrations which knock the catalase off.

The good news is that endogenous catalase recovers in the repigmented epidermis of patients with vitiligo (see figure), but may get destroyed again if another sudden rise of H₂O₂ levels occurs. Unfortunately this event is at present unpredictable.

It is encouraging that the removal of the H₂O₂ from the millimolar range in vitiligo with PC-KUS leads to a recovery of the complete skin colour in the majority of affected individuals.



However there still remains the cardinal question, whether H₂O₂ is the cause or the consequence of vitiligo. Further research is needed to unravel this disease in the future.

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ADDIN EN.REFLIST

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In Memory of:

Thomas B. Fitzpatrick

MD, PhD

1919-2003

Remembering Thomas B. Fitzpatrick, M.D., Ph.D.

"His leadership is measured not so much by the number of people he led but by the number of leaders he created."

-John A. Parrish, M.D.



L-R: Wayne McCormack, PhD; Stella Pavlides, Prof. K.U. Schallreuter MD
John Wood PhD, Thomas B. Fitzpatrick, MD PhD

DEPARTMENT OF DERMATOLOGY AT HARVARD MEDICAL SCHOOL

Thomas B. Fitzpatrick, M.D., Ph.D., former Professor and Chairman of the Department of Dermatology at Harvard Medical School and Chief of the Massachusetts General Hospital Dermatology Service (1959 to 1987) died on August 16, 2003. Often proclaimed as one of the world's leading dermatologist, during his tenure at Harvard, Fitzpatrick trained many of today's top dermatologists in academia, industry and practice, and is considered a father of modern academic dermatology.

For over 50 years, Fitzpatrick was a major influence in basic and clinical research. His fundamental observations and creative applications of knowledge markedly advance the understanding of pigmentation, aging and disorders of the skin.

Fitzpatrick was most honored and cherished as a teacher. The most powerful components of Fitzpatrick's teaching style were his encyclopedic knowledge, vast experience, relentless problem solving, and his compassionate individualization of treatment. His most contagious traits were his childlike curiosity and his genuine joy of work; wonderful gifts that were spread to dermatologists throughout the world during his half-century of dedicated service.

On a Personal Note

"Not only is this a terrible loss to the future of vitiligo research, but a deep personal loss to me. Doctor Fitzpatrick was not just part of the AVRF Medical Advisory Board, but a dear and respected friend. He was always there to answer a question, support my ideas, and encourage my dream to start the AVRF. I spent many long hours with Doctor Fitzpatrick at Massachusetts General Hospital discussing vitiligo and his research. He always had time for everyone, and never treated anyone with anything other than the utmost respect. He was a true gentleman and a scholar. I was honored to attend his memorial service, meet his family, and share in the tribute to his countless accomplishments. His passing deeply saddens me. I will miss our calls and visits. I have lost a very dear friend."

Stella Pavlides • President of the AVRF



What Causes Vitiligo?

What We Know & What We Don't Know

By Wayne T. McCormack, Ph.D.

* Please note that this is an interactive electronic document. Clicking on the web-links contained within this article will open a separate internet browser window on your screen to allow you to browse additional content. If your internet browser is configured to view PDF documents from within, use the <back> button to return to this document.



This article is adapted from a presentation by Wayne T. McCormack of the Dept. of Pathology, Immunology & Laboratory Medicine at the University of Florida College of Medicine, which was originally created for the 2003 AVRF Symposium (Figure 1). It contains images taken from various web pages. My apologies to those not credited properly for some images. The AVRF is not responsible for the content of this presentation.

What is vitiligo? ([AVRF weblink - Vitiligo Defined](#))

Vitiligo is melanin pigment disorder of the epidermis (skin) and hair follicles, characterized by regions of skin that lose their pigment due to the loss of the pigment-producing cells of the skin (melanocytes). The overall incidence is about 1% in the general population, affecting both sexes and all racial groups. The average age of onset of vitiligo is about 19 years of age. About half of all patients develop vitiligo during childhood or adolescence.

The normal function of melanocytes is to produce melanin pigments in packets inside the cell called melanosomes. These melanosomes are then distributed into the other skin cells, keratinocytes. There the melanin absorbs energy from the sun's ultraviolet (UV) light to protect our skin from UV damage, and provides our skin color. Increased melanin production in response to UV light exposure in tanning.

The loss of pigment predisposes affected skin to UV damage, such as sunburn. Vitiligo is associated with other autoimmune diseases, such as Hashimoto's thyroiditis. Although considered to be a "benign" medical condition, the effects of vitiligo on appearance, especially on the face, sometimes causes psychological problems. This can be especially problematic for children.

([AVRF weblink - Vitiligo FAQ](#))

The standard treatments for vitiligo include PUVA in adults (psoralen + UV-A light treatment), broad-band and narrow-band UV-B light treatment, and topical steroids. Experimental treatments that are not widely available include dermabrasion, skin grafting, transplantation of cultured melanocytes, and pseudocatalase. Nutritional approaches to vitiligo treatment can provide gradual repigmentation. Cosmetics can be used to cover depigmented patches effectively. Patients with extensive depigmentation sometimes opt to permanently depigment their skin using benoquin. There are many other "alternative" treatments for vitiligo, which have not undergone rigorous clinical testing. ([AVRF weblink - Vitiligo Treatments](#))

What Causes Vitiligo?

In some, but not all, vitiligo patients ... there are MELANOCYTE DEFECTS, such as:

- aberrations in the internal structure of the pigment-producing melanocytes
- changes in enzymes involved in pigment production
- poor responses to oxidative stress and other biochemical changes

In some, but not all, vitiligo patients ... there are ENVIRONMENTAL TRIGGERS that may start the disease process in susceptible individuals, such as:

- chemicals found in some cosmetics, hair dyes, germicides, bleaching creams (including phenolic compounds and hydrogen peroxide)
- minor skin injuries (isomorphic responses), such as abrasions, surgery wounds, sunburn
- emotional or psychological stress
- hormones (puberty and pregnancy)
- In a chicken animal model, a specific herpesvirus infection in the feather pulp triggers depigmentation of the feathers

In some, but not all, vitiligo patients ... there are AUTOIMMUNE RESPONSE in which the immune system abnormally recognizes melanocyte proteins and contributes to melanocyte destruction, including:

- infiltration of the dermis and epidermis by lymphocytes, including helper and killer T cells
- abnormal expression of MHC class II molecules by melanocytes
- changes in cytokine expression
- changes in T cell subpopulations
- production of autoantibodies against melanocytes enzymes, e.g. tyrosinase, TRP-2
- susceptibility to some other autoimmune diseases, e.g. Hashimoto's thyroiditis, alopecia, pernicious anemia

In some, but not all, vitiligo patients ... there is GENETIC SUSCEPTIBILITY, meaning that vitiligo sometimes "runs in the family" suggesting that genes may contribute to vitiligo susceptibility

Dr. McCormack's research laboratory at the University of Florida has been doing research to test the hypothesis that genetic susceptibility to vitiligo is a complex genetic trait involving many genes. The experimental approach used is called genetic association. First, candidate genes were examined to determine which ones could be used for genetic testing (genotyping) of vitiligo patients and family members. The frequencies of gene variants were compared between populations of vitiligo patients and control individuals without vitiligo to determine whether the gene variants were more common in patients (a case/control study). More common gene variants may contribute to vitiligo susceptibility.

For genes found to be associated with vitiligo susceptibility, genetic testing of family members was used to determine whether the gene variants were transmitted more often from parents to affected individuals than predicted by random chance. Some genes were subjected to DNA sequencing analysis to look for other changes in the DNA (mutations) that might cause changes in gene activity contributing to vitiligo. The expression and function of some genes is tested in additional experiments.

- candidate vitiligo susceptibility genes included genes encoding proteins involved in:
 - melanocyte biochemistry (pigment production)
 - other melanocyte functions
 - regulation of immune responses

Recent publications:

"Genes of the LMP/TAP cluster are associated with the human autoimmune disease vitiligo"
by Courtney B. Casp, Jin-Xiong She, and Wayne T. McCormack
Genes and Immunity, Volume 4, Number 7, Pages 492-499, 2003 On-line

"Genetic Association of the Catalase Gene (CAT) with vitiligo susceptibility"
by Courtney B. Casp, Jin-Xiong She, and Wayne T. McCormack
Published in Pigment Cell Research, Volume 15, Number 1, Pages 62-66, 2002 On-line

Improved understanding of the genetics of vitiligo susceptibility may lead to:

- future detection of "at risk" individuals
- possible identification of patients who might respond better to specific treatments
- novel treatments for vitiligo (?)

SUMMARY: What Causes Vitiligo?

The cause of vitiligo is complex, and likely to be different for different individuals. Any or all of the following may contribute to the development and progression of vitiligo:

- genetic susceptibility
- biochemical and/or structural defects in melanocytes
- isomorphic responses to chemical exposure or skin injury
- disease progression mediated by an autoimmune response

AVRF weblinks:

[Home Page](#)
[Vitiligo Defined](#)
[Frequently Asked Questions](#)
[Vitiligo Treatments](#)

Kaleah's Dream

In 2003 the AVRF started a program called "Kaleah's Dream" to help raise awareness and educate the public about vitiligo as well as fulfill a dream for a child who suffers from the condition. Our special thanks to Whoopi Goldberg for making this dream a reality for Kaleah.

By Kaleah

In March of 2003 I had the awesome experience of meeting a person I never thought I would. Because of the AVRF and all their hard work, I got to go to New York City and meet Whoopi Goldberg.

She was just like a normal person. People used to make fun of her because she was Dyslexic, but now people wish they were like her.

I wrote a poem for her and she put it up on what she called her "Granny Wall" (where her Grandkids drawings go).

I know I am special because I have a lot of people that believe in me, and now I know I have another friend that lives in NYC.

I got to stay in a great hotel, do lots of sight seeing and I learned how to hail a taxicab.

I met another new friend, Ralph. He has a very important job at the New York Times and I got to go on a tour and have ice cream. It was like a "Dream" trip and I will never forget it!



Whoopi Goldberg & Kaleah

By Shanna

Leah and I had the very best time in NYC. We not only met Ms. Goldberg, but we were treated to a Broadway Play that she was starring in. I'm not sure who was more excited, Leah or I. Whoopi treated us like we were people she had met before. She was extremely interested in Vitiligo and Leah's struggles.

The NY Times tour was a great learning experience for us, as was visiting Ground Zero. I know that Leah will never forget the trip and the positive things she learned. Without Stella's generosity, we could never have had this experience.

The AVRF works tirelessly to make children know they are loved and that all things are possible through faith. Our family has the faith that one day there will be a cure for this disorder. In the meantime, we know that the AVRF is always there for us.

2003 Seminar...continued from page 2

Dr. Karin Schallreuter, M.D., developer of Pseudocatalase, discussed her most recent work and findings, as well as the success stories of many of her patients both in her traditional program, and those who have participated in her Dead Sea clinic in Jordan.

Attendees gathered for dinner at the Durango Grill for great steaks down the road from our hotel and then returned to the conference center where AVRF held a prize raffle, dessert and coffee. By far the highlight of the evening was a Hawaiian song and dance program presented by the children attending the seminar, who had spent a fun-filled day with Polynesian dance instructor, Maria.

Sunday morning, the attendees donned their Vitiligo Awareness t-shirts, and headed off to Busch Gardens for a walkathon around the park, followed by a day of jungle adventures and roller coaster rides.

As we said our goodbyes Sunday afternoon, having made new friends and learned about new areas of research and treatment, the importance of supporting events like the 2003 AVRF Vitiligo Awareness Seminar was not lost on any of us. Hope to see you all in 2004!

AVRF MAILBAG

Hi and Happy Holidays to the AVRF.

Just want to let you know, the calendar is one of the best things to happen to NaDajiah since she had vitiligo. Besides the trip to Florida, she attended a new school this year in a different state so she had to start all over again with people staring and wondering what was wrong with her. I have to say the children at her new school have treated her well. She came home one day and asked me how people looked when they were burned. To make a long story short, all this time the children thought she had been burned. I sent a note to her teacher the first day of school notifying him of her skin disease and the response he might get from the children.

When we received the calendar, she took it to school. Her teachers were very happy to see the calendar and some learned things about vitiligo that they didn't know. All the kids think she is a celebrity. They say NaDajiah is famous. Also the teacher read the back of the calendar to the students and they got to have an open session on vitiligo. Dajiah explained to them what it was; who could get it and that it is not contagious. The teacher was very proud of her and grateful for the calendar. Her Science teacher asked could she bring it back in so she also could read it. NaDajiah's medical doctor is very proud that she is in this calendar. His own son has vitiligo, not a major case but enough to notice. We also met this Indian couple a few days ago and tried to explain to them, what was

wrong with them. The wife said it was an allergy. I tried to explain to her it wasn't and her husband said he was born with it. It is in his family, so he never bothered to see a doctor about it. We have met so many people this year with vitiligo. They seem to strike a bond with NaDajiah. Some have on make up and will say to her, you know I have that same disease. This has given Dajiah a more positive image of herself, and she doesn't treat herself like she has vitiligo. When she looks in the mirror, now she just sees NaDajiah. She doesn't see the girl with the spotted face any more and I have to say that it is thanks to the AVRF Florida seminar and her being in the Vitiligo calendar. You made her famous and she is a star! She doesn't realize she was always our Little Princess and our famous Star.

Thank you AVRF, & happy holidays to you. When she receives mail from you guys her face just lights up. We thank you sincerely from our hearts. You are wonderful people you just don't know the power you have! The gift you give, thank God for you and that you came into our lives.

-Kathy



NaDajiah

AVRF Goes to Washington

By: Loretta Cooper
-AVRF Board Member

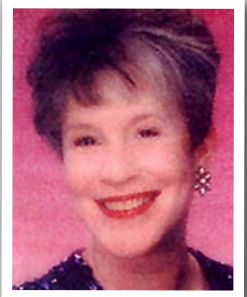
In June 2003, representatives of the AVRF converged on Washington D.C. to spread the word about Vitiligo. Our small but determined group included Stella Pavlides, AVRF President, Loretta Cooper, Board Member, Kaleah Letcher and her mom, Shanna (daughter and wife of Board Member Paul Letcher). From our homes in Florida, California and Nebraska respectively, we traveled to our nation's capital to promote the AVRF's mission to raise awareness, educate and fund research. This two-day, fast paced mission included meetings with distinguished members of Congress and the National Institutes of Health (NIH).

Several impromptu meetings were held in Capitol hallways, on the street, on the Metro, in our hotel lobby, and at airport boarding areas.

This exciting opportunity was the result of an invitation from Congressman Todd Tiahrt and his wife, Vicki. She graciously escorted our small entourage to and from our

various appointments along with Jackie Gardner, Vitiligo Support, who bravely served as navigator. Congressman Tiahrt allowed us to use his Capital offices as our "home base" where we gathered to refresh ourselves and review our strategy. Thanks to Melissa James, Senator Tiahrt's office manager, for scheduling the various meetings and preparing the detailed agenda that helped us to stay focused.

Highlights of the trip included lunch in the members dining room, meetings with representatives of Florida, Kansas, Maryland, Nebraska, Ohio, Texas, Virginia, the Hispanic Caucus and the Chair of the Black Caucus, to name a few. We braved a trip on the Metro Rail to Bethesda, Maryland to meet with NIH Director, Dr. Stephen Katz, Dr. Alan Moshell, Director of NIH Skin Diseases Program and Anita Linde, NIH Senior Program Analyst.



Loretta

My Seminar Experience 2003

By Jessica

In July of 2003 I attended my second AVRF seminar. If you have Vitiligo yourself and attend the seminar, you will feel a sense of belonging and acceptance. I know that each year that this has been held, it becomes better every time.

This year, a new activity was added, which was taking the children miniature golfing. Being a shy person, I usually just stand back and watch things that go on around me. I can tell you that each child felt accepted here and had a smile on their face. To see everyone really having a fun time and not being afraid of what others may think gives you a wonderful feeling. Once you go to these seminars, you bring a new family into your life. This Vitiligo family is loving, compassionate, and never stops working. My favorite part of the seminars is making new friendships, which will last forever and sharing experiences we have all gone through because of Vitiligo. Even though this disease once brought me down, I am truly grateful for all of the experiences it has brought me and I am always looking forward to new friendships at the AVRF seminars.



Having a home NB-UVB unit

By Sharon

Our 16-year-old daughter Jess started treatment for her vitiligo with the narrowband-UVB lamp about 1 1/2 years ago. She has had vitiligo since the age of 6. I couldn't imagine having to visit a doctor's office to use their lamp 2 times a day every day. Knowing that our insurance would not cover the costs of a lamp, we had to weigh the costs of traveling to the doctors everyday. Traveling which meant gas and time lost from work and school, verses buying our own lamp. Twice a day every day, the costs add up quickly. The decision was not hard to make. Pressure and stress was taken off everyone in the family once that decision was made. No more "who is taking her to the doctor, when do we have to go, when can we fit it into our schedule". That is the convenience of having your own lamp. Our daughter can do her treatments around her schedule and in the comfort and privacy of her own room.

Her results from using the [Daavlin](#) narrowband UVB lamp are phenomenal. I'm sure if we did not have our own lamp, we would not see the progress that we have. There would have been missed appointments, which mean fewer treatments. Going from 75% depigmented to 80 % repigmented or more is incredible after years of unsuccessful treatments.

Sacrifices had to be made to be able to afford the lamp, but my daughter's mental and physical health with her vitiligo was more important than the things that were sacrificed. I would recommend to anyone that a purchase of the narrowband-UVB lamp for home treatment be well worth the investment.

A Learning Experience

By Cynthia May

Having a child with Vitiligo has been such a learning experience. Not just for Ryan, his brothers and sister and parents, but also for our extended family. We have opened our eyes to things that we might not have noticed before. We have used Ryan's Vitiligo to help explain other conditions to our children. We have recognized others in our community with Vitiligo and have had the courage to discuss the disease with them. One of the greatest lessons that my children have learned is how to accept themselves for what they are, not what they look like. "Thank you Ryan!" We have been fortunate to see that other children learn what Vitiligo is through our book, "Ryan's Vitiligo."

I would feel lost if it weren't for the American Vitiligo Research Foundation. I have found so much encouragement and kindness in both Board Members and others involved with the AVRF. I love the fact that the AVRF is putting the focus on children. The calendar was a fantastic idea. I can't wait to see all the angels in the next calendar. I say angels, because in my book that's what these kids are!

When Ryan and I attended the Seminar and Walk-a-thon I witnessed the rebirth of Ryan. He became a member of a very special group of kids. He opened up and began to socialize amongst the other children in attendance. It was a very special gift.

I have found hope that there will be a cure. The Seminar lifted my spirits, made me appreciate life and family even more. I want to say "Thank You" to all the speakers and all the wonderful people Ryan and I met. May God Bless You ALL!



"The book is meant to be comforting to a child with vitiligo and instructive to a thoughtless child without."

Donald G. McNeil Jr.

- NYTimes

For more information about the book and how it might help your child at school, please click [here](#)

Congressional Update

Congressional Record



**The Honorable Michael Bilirakis
in the House of Representatives
Commending the American Vitiligo Research Foundation
November 6, 2003**

Mr. Speaker, I rise today to call attention to a little-known but debilitating disease that profoundly impacts its victims.

Vitiligo is an auto-immune disorder which causes the skin to lose its pigmentation, resulting in the development of white patches around the bodies of those afflicted with it. Although its physical effects are neither as severe nor life-threatening as some diseases, vitiligo profoundly impacts the social and psychological well-being of its victims, particularly children and African-Americans.

Vitiligo may physically be painless, but the discrimination it precipitates hurts nonetheless. The more than five million American men, women, and children who have vitiligo know the sting and emotional distress it causes. I have seen it in the eyes and heard it in the voices of those with whom I've met who have it.

I learned about vitiligo from one of my constituents, Stella Pavlides, who is the Founder and President of the American Vitiligo Research Foundation, which is headquartered in my congressional district in Clearwater, Florida. Stella is a tireless advocate who has dedicated her life to finding a cure for vitiligo and ending the hurt it causes. I have pledged to her that I will work with my House colleagues to raise public awareness about vitiligo so that we can make it a disease of the past and not the mystery illness shrouded in ignorance that it is today.

Mr. Speaker, I want to commend our colleague, Congressman Todd Thiart, for taking a leading role in helping me bring this disease to the attention of our colleagues. I hope that all of our colleagues will join us in raising public awareness about vitiligo and dedicating ourselves to helping the medical and scientific communities find a cure for it.

~Thank you, Mr. Speaker



The AVRF would like to extend our heartfelt gratitude to Congressman Todd Tiahrt for his continued support. Congressman Tiahrt was the driving force in procuring a grant for the AVRF. Congressman Tiahrt has taken a leading role in bringing this disease to the attention of the US Congress. The money granted to the AVRF for 2003 from the CDC is being utilized to raise vitiligo awareness worldwide.

*Thank you,
Congressman Tiahrt.
~The AVRF*



REPRESENTATIVE TODD TIAHRT
WASHINGTON, D.C.

July 26, 2003

(Isaiah 40: 28-31) "The everlasting God, the Lord, the Creator of the ends of the earth, fainteth not, neither is he weary. There is no searching of his understanding. He giveth power to the faint; and to them that have no might he increaseth strength. Even the youths shall faint and be weary, and the young men shall utterly fall: But they that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; and they shall walk, and not faint."

Heavenly Father:

We thank you for this glorious day, and we thank you for this gathering.
We pray that this be a time of friendship and of learning.

We ask your blessing on Stella, for her work and all the enthusiasm and love she brings to this cause. We ask for your blessings on all who participate today.

Lord, strengthen those who are devastated by this disease. Give them hope, peace and courage. And, Lord, we pray for a cure.

In the name of our Lord and Savior. Amen.

~Invocation given by Todd Tiahrt, U.S. Representative (4th District Kansas)
American Vitiligo Research Foundation

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