

VITILIGO VIEWS



“Embracing Diversity”

The Newsletter of the
American Vitiligo
Research Foundation

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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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PRESIDENTS MESSAGE

Welcome AVRF Members,

The AVRF is looking forward to 2006 and our calendar is already being filled; but first let us take a moment to look back at 2005.

2005 was a truly wonderful year for the AVRF. We held our 10-year anniversary celebration in June and what a celebration it was! Shelton Quarles from the Tampa Bay Buccaneers was our guest of honor. The children spent time with the Buc's Mascot, Captain Fear, and Buccaneer Cheerleaders, Dawnyale and Lauren. As usual, the children were our biggest celebrities. They entertained us with a beautiful song written by NaDajiah. The food was excellent, and the guests and festivities made this a very special anniversary. All in all, the evening was one to be remembered.

Among our guests were Drs. Kiran and Pallavi Patel. Drs. Patel invited the AVRF to be among the charities for their 2006 Cultural Carousel Ball, which will take place in Tampa on April 1, 2006. We are elated to be able to share in this evening of awareness and international cultural celebrations. I would like to thank all the individuals who have financially supported the AVRF in order to make our attendance possible.

It was through the help and sponsorship of our members and friends that we were able to achieve so much in 2005; and with your continued support, we can achieve even more in 2006! Thank you for taking the time to visit our website and read our electronic newsletter. In closing, I wish for each of you a very happy 2006.

God Bless,
Stella Pavlides



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American Vitiligo Research Foundation

VITILIGO VIEWS

NAACP PARTNERSHIP LETTER



NATIONAL ASSOCIATION FOR THE ADVANCEMENT OF COLORED PEOPLE

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BRUCE S. GORDON

President & Chief Executive Officer

JULIAN BOND

Chairman, Board of Directors

Greetings:

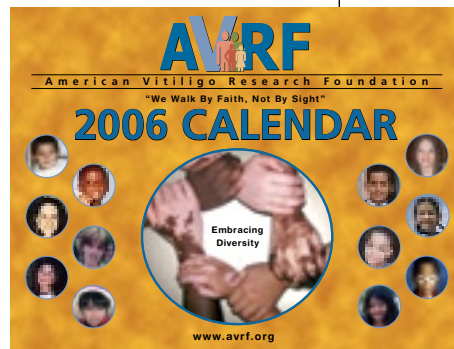
It is with great pleasure and enthusiasm that I take this opportunity to congratulate the American Vitiligo Research Foundation, Inc., on the 2006 Embracing Diversity Calendar.

The children featured in this calendar represent the millions of people around the world affected with vitiligo from every age group, sex, and ethnicity. They are incredible survivors of a disorder that often causes them to feel the effects of extreme alienation and the harsh perceptions of others. As you can see from their photographs and their stories, these young people are strong, intelligent, vibrant and beautiful. They have the power to inspire the world with their ability to triumph over adversity and claim the happiness we all desire in life.

I salute each and every person profiled in the 2006 Embracing Diversity Calendar. My heart goes out to the millions of people with vitiligo as I have been sensitized to their struggles and challenges and those of their families. I am profoundly grateful to Ms. Stella Pavlides, President of AVRF, and all the sponsors and supporters who helped to make this calendar possible. Your labor of love has truly enhanced my life, thank you.

Sincerely,

Lucille C. Norville Perez, M.D.
Director, Health Advocacy Division



OUR EXPERIENCE AT THE 10th ANNUAL AVRF CONFERENCE By Janet Farmer

This past summer our family took the opportunity to attend the AVRF's 10th Anniversary Conference. Our 11-year-old daughter and I attended the 9th annual meeting the previous summer and had a great time. Our daughter, Gabrielle, has been affected by vitiligo for most of her life. We looked far and wide for an opportunity to meet other children with vitiligo and to learn more about this depigmentation disorder.

This past summer's conference was rich with information. The general session included seminars given by scientists and medical doctors about the latest findings on vitiligo. It was fascinating to hear all that is going on in the area of vitiligo research. The doctors answered all our questions very patiently and stayed long after the session was over to explain more. The attendees learned about the work of Dr. Karin Schallreuter, a dermatologist from Europe with patients with vitiligo from all over the world. Some parents had a chance to have their children examined by the doctor and to schedule some possible future treatment.



Vendors, who make everything from sunscreen, to cosmetics, to lights to treat patients with vitiligo, made presentations to the group. Afterward, they had a room set up so attendees could individually discuss their needs and even purchase these special materials.

The part of the weekend we all enjoyed the most was the sharing of meals and casual conversation about our common interest, vitiligo. Almost all the families affected by vitiligo have had similar experiences with physicians who are not very helpful and who offer no hope. We have also seen our children suffer the stares of strangers and incessant curiosity while walking through a mall or



airport. Parents bonded over coffee and made promises to keep in contact with each other.

The children had a great time with all of the activities Stella and Marilyn had planned for them. The kids played at the Build-A-Bear Store, went on a shopping trip, and finally enjoyed a picnic at the beach. Most fun perhaps was the nightly trip to the pool, which included horseplay and lots of noise and splashing! Many of the kids had never seen another child with vitiligo and others who have hadn't had the chance to play or communicate with each other since the previous summer. This is why we came.

While the kids were playing at the pool, the parents talked at pool-side about their experiences. They shared concerns and problems about their children and plans for future treatment and plans that didn't include treatment. It is really quite magical to be able to bond with someone you have so much in common with. Our family looks forward to the next time we can see our friends. ■

A RARE DISORDER, A MOTHER'S MISSION By John Sheppard, Editor

South Florida mom Barb Medosch is on a mission.

Her daughter, eight-year-old Cydney, a student at McNeil Elementary, has been diagnosed with vitiligo, a disorder that affects about one to two percent of the world's population. Vitiligo causes the cells that make pigment in the skin, and sometimes the eyes, to be destroyed. White patches of skin appear on the affected parts of the body.

"It started on her knees," says Medosch. "Then it spread. Cydney's losing pigment in her eye, the left one."

Vitiligo is not contagious, nor is it fatal, but the emotional effects on the person suffering from it can be devastating. "It's not life-threatening, but it is humiliating," says Medosch. "People do stare. Adults are much less sensitive than kids. Sometimes they'll say, 'Oh my gosh! Were you in a fire?'"

The mother of three has taken her daughter to specialists all over the country, including one doctor in Ohio who has done much good for young Cydney. "There are very few doctors who specialize in this," says Medosch.

Dermatologist Rob Finkelstein, D.O., of the Center for Skin Wellness here is carrying on Cydney's treatments, which can be effective but do not constitute a cure.

"Dr. Rob's been great," says Medosch.

Now Riverwalk Oaks resident Medosch, as chairperson of the Manatee-Sarasota chapter of the American Vitiligo Research Foundation (AVRF), is spreading the word about the disorder and the AVRF, so that those who suffer from vitiligo do not have to go it alone.

"If I can help another mother and another child out, that would be great," says Medosch. "The AVRF has been a godsend to us."

WHAT IS VITILIGO?

According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMSD), a part of the National Institutes of Health, "The cause of vitiligo is not known, but doctors and researchers have several different theories. One theory is that people develop antibodies that destroy the melanocytes in their own bodies. Another theory is that melanocytes destroy themselves. Finally, some people have reported that a single event such as sunburn or



Cydney Parker

emotional distress triggered vitiligo, however, these events have not been scientifically proven to cause vitiligo."

Worldwide, according to NIAMSD, 40 to 50 million people have vitiligo. In this country, two to five million people suffer from it. The disorder affects all races and both sexes equally. Vitiligo may also run in families. The disorder is usually progressive, and over time the white patches will spread. For some people, vitiligo spreads slowly, for others, quickly. Some have reported additional depigmentation following periods of physical or emotional stress. Some people who have vitiligo feel embarrassed, ashamed, depressed, or worried about how others will react.

SUPPORT FOR A CURE

"AVRF has been the greatest thing for Cydney," Medosch says. "You meet these kids year after year at the seminars in June and they all have the same problem. Through the AVRF, Cydney's developed self-esteem and confidence."

"If there's another mother that can come to this and talk to other mothers and know that we're out there," says Medosch. "We'll certainly understand any question you have because we've all asked them." ■

Visit the website: www.AVRF.org

MORE ON THE SUBJECT OF VITILIGO, SUN AND SKIN

**A commentary by Professor KU Schallreuter MD PhD
Clinical Director of the Institute for Pigmentary Disorders in
association with E.M. Arndt University of Greifswald/Germany
and University of Bradford/UK**



WHAT IS VITILIGO?

This seems like a redundant question. However, it seems important to recognise that **vitiligo is a disease according to the World Health Organisation.**

VITILIGO IS NEITHER A CONDITION NOR A SYMPTOM

The characteristics of this disease are the acquired sudden loss of the inherited skin colour. Despite its long recognition, the cause of this disease is still unknown. The loss of the skin colour yields white patches of various sizes, which can be localised anywhere on the body. The disease affects all races, men and women and all age groups. Approximately 1 in 200 of the world population develops vitiligo. The affected individual shows often-severe disfigurement, particularly when the face and the hands are involved.

However, not all white skin patches are vitiligo. There are other conditions and diseases that are associated with white skin. A long time ago the term leucoderma has been introduced. This word originates from the Greek language and means white skin. Clearly it seems mandatory to make the correct diagnose. This can be done by Wood's light. Vitiligo shows a very characteristic fluorescence under this condition which is absent in other leucodermas (Schallreuter et al, Science (1994))

SUTTON NEVUS (HALO-NEVUS) IS NOT VITILIGO

Leukodermas of other origin are for example the Sutton Nevus also called Halo-Nevus. Despite both vitiligo and Sutton nevus can occur together at the skin of the same individual, it has been shown that these are two very different diseases (Schallreuter KU et al Arch Dermatol Res (2004) Future work needs to show why both vitiligo and Halo-Nevi frequently occur together.

SKIN COLOUR AND SUN PROTECTION

For decades it was believed that skin colour with its pigment (melanin) content fosters sun protection. However, the sun protection factor (SPF) is only between 2-3 for the brown / black melanin (eumelanin), while the red pheomelanin hardly protects at all, it is even photoactive and generates reactive oxygen species (ROS) (Chedeckel MR and Zeise L, Lipids (1998), Johnson BE et al Nat New Biol (1972)). It is becoming evident that besides melanin formation many other mechanisms and factors are in place to

defend the human body against environmental reactive oxygen species (ROS) formation (Schallreuter KU and Wood JM Photobiology (2001)). ROS can also be generated by ultraviolet light directly inducing a plethora of signalling and defence mechanisms.

In vitiligo patches the pigment is mostly completely absent, but not all individuals suffer from sunburn despite sun exposure (Schallreuter KU et al, Dermatology (2002)).

Moreover, it has been documented at least in 2 major studies that vitiligo per se does not necessarily coincide with increased sun sensitivity (Calanchini-Postizzi E and Frenk E Dermatologica (1987); Schallreuter KU et al (2002))

SKIN AGING AND VITILIGO

Interestingly, the skin of vitiligo sufferers does not age with the same speed compared to age and sex matched healthy people who do not have vitiligo (Schallreuter KU et al (2002)). The results stem from a clinical study of patients with vitiligo who did not avoid sun exposure completely. Hence, it would be of great value to understand this phenomenon. This observation clearly indicates that some other protective mechanisms must be in place to yield this result.

However, it is also beyond any doubt that excessive sun exposure over time can induce non melanoma skin cancer (NMSC) in general in susceptible individuals.

The development depends on the genetic background and on the accumulation of sun exposure times / sunburns over time. In this context it is noteworthy that fair skin people who always burn and never tan are much more prone to develop skin cancer compared to good tanners and dark skin coloured individuals. But there are also exceptions. Even dark skin people can occasionally

VITILIGO AND MELANOMA

Malignant Melanoma (MM) is another skin cancer which can be very dangerous if not recognised early. There are many reports linking this malignancy with altitudes and excessive periodic sun exposure.

People with very fair skin (those who never tan or only very slightly) do have a higher risk to develop melanoma compared to dark skin

MORE ON THE SUBJECT OF VITILIGO, SUN AND SKIN Cont.

people at any body site regardless of sun exposure or not. These tumours can develop in existing moles but they can also arise totally new as pigmented as well as non-pigmented tumours. Early recognition and excision are important for the outcome.

The observation that melanoma is more frequent in patients with vitiligo originates from a study which included 623 Caucasian patients with melanoma of the Oncology Clinic at the Department of Dermatology at the University of Hamburg/Germany (Schallreuter KU et al, *Dermatologica* (1991)).

In this study 11/623 patients with melanoma had a true vitiligo long before their melanoma was diagnosed. Considering that 1 in 200 has vitiligo and 1 in 12,000 develops melanoma, these results suggested a significantly higher risk to develop melanoma for patients with vitiligo and fair skin (Schallreuter KU et al, *Dermatologica* (1991)).

In our Institute for Pigmentary Disorders we have indeed found in 2 Caucasian patients with vitiligo melanoma in a patient group of 1800 Caucasian patients with vitiligo supporting the above findings (Schallreuter KU, unpublished results).

Based on the above results the take home message and recommendation is that patients who have vitiligo should undergo an annual total body examination at their Dermatologists in order to recognise a possible melanoma as early as possible.

MELANOMA ASSOCIATED LEUCODERMA

Some individuals with melanoma develop patches of white skin in the vicinity of their melanoma or after their tumour had been excised. In this context it seems important that these white patches are not vitiligo. This skin shows a very different molecular biology and biochemistry compared to true vitiligo (Kothari, S PhD Thesis U of Bradford 2005). Therefore the term melanoma associated leucoderma seems more appropriate as already suggested earlier by the late Fitzpatrick.

Are white skin patches associated with melanoma beneficial for the outcome ?

The development of white patches anywhere on the skin in association with melanoma was interpreted to be a beneficial sign in the outcome for survival time. There is still an ongoing debate whether the development of such leucoderma associated with melanoma is of true value for the individual's outcome or not (Lerner AB, Nordlund JJ *Arch Dermatol* (1977); Nordlund JJ, Lerner AB *Arch Dermatol* (1979); Nordlund JJ et al *J Am Acad Dermatol* (1983)). This

author feels that there is at the present time not enough evidence to support this statement. Larger patient groups are needed in order to conclude. Therefore, it is simply not correct to advise patients with vitiligo that they have a decreased risk to develop melanoma and that they are well protected against this tumour.

The development depends on the genetic background and on the accumulation of sun exposure times / sunburns over time. In this context it is noteworthy that fair skin people who always burn and never tan are much more prone to develop skin cancer compared to good tanners and dark skin coloured individuals. But there are also exceptions. Even dark skin people can occasionally be very sun sensitive.

VITILIGO AND SKIN CANCER

The result of two major studies showed that patients with vitiligo do not have a higher risk to develop sun induced skin cancer (Calanchini-Postizzi E and Frenk E (1987) , Schallreuter KU et al (2002)).

In the recent past an issue was put forward that PUVA therapy which is a frequently used treatment modality for vitiligo could be of potential risk to enhance the risk of skin cancer and their precursors (actinic keratosis) in these patients (Halder RM et al *Arch Dermatol*(1995)). Considering the amount of rays, which these individuals receive, it seemed reasonable to question the possible side effects. However, until now there is no documentation in the literature about a true coincidence. (Westerhof W and Schallreuter KU *Clin Exp Dermatol* (1997)). A recent publication by Grimes states that there is also no enhanced risk after the use of narrowband UVB exposure which is a treatment modality utilised as mono therapy with increasing doses 2-3x per week in adults and even in children (Grimes P, *JAMA* (2005)).

VITILIGO AND MELANOMA

Malignant Melanoma (MM) is another skin cancer which can be very dangerous if not recognised early. There are many reports linking this malignancy with altitudes and excessive periodic sun exposure. People with very fair skin (those who never tan or only very slightly) do have a higher risk to develop melanoma compared to dark skin people at any body site regardless of sun exposure or not. These tumours can develop in existing moles but they can also arise totally new as pigmented as well as non-pigmented tumours. Early recognition and excision are important for the outcome. ■

**NAACP TRIP:
By Helon Hammond**

We (Helon, Cree, Kathy, and NaDajiah) had the pleasure of attending the 2005 NAACP conference to represent the AVRF.

The response and impact of the AVRF presence were both welcomed and needed. The children were very comfortable and outspoken on vitiligo, to both adults and children. NaDajiah and Cree were so comfortable that they went out into the crowds seeking anyone that would listen to pass out literature and sell their bracelets. They reminded me of little Stellas!

It was amazing that most everyone that visited our table or came in contact with the children knew someone that had vitiligo, but didn't know the clinical name for it, and wanted to know more! They were eager to know if there was a particular cause or a cure in sight. One question that was asked quite often was "Does it affect people of all colors?" In addition to the information provided, the TV production of our children spoke volumes; everyone stopped to view our children on the big screen.

The response of the public made it evident that awareness is definitely the key to making a difference! The acceptance of the NAACP, other vendors, and Dr. Lucille Perez, was overwhelming to say the least. We had an awesome experience and look forward to attending many other events, with forums such as these, to continue putting faces and voices to vitiligo! ■



AVRF booth, NAACP Convention

There were a few attendees with vitiligo in attendance who shared their stories as well. One of them was so elated at the sight of vitiligo being made visible, he was literally in tears. Another lady shared her story with the children as to how she explains her skin condition, which was pretty amazing to say the least. She told the children, with such confidence, that God thought she was SO special that he wanted her to be different from most people, which is why she has vitiligo. The children were definitely encouraged by her story.



NAACP Convention



NAACP Convention

AAD CONVENTION HIGHLIGHTS By Anthony Benigno

The 2005 American Academy of Dermatology (AAD) convention was held in New Orleans the third week of February. The Earnest T. Morial Convention Center exhibition hall was filled with everything dermatological, from expensive laser equipment, surgical supply vendors, makers of creams and lotions, nail care products and the American Vitiligo Research Foundation awareness booth.

Our AVRF Booth #3025 was well-placed in a good traffic area. The backdrop featured the AVRF banner and many 8 1/2 x 11 photographs of our calendar children. A television monitor continuously ran a PowerPoint presentation about the activities of the AVRF. Calendars, brochures and other Vitiligo-related literature were available at the booth as well.

In addition to the dermatologists from the United States who stopped by the booth, there were doctors from China, Eastern

Europe, England, India, Pakistan, Central and South America and Islands in the Caribbean. Most were interested in the literature that they could give to their patients.

A very encouraging sign for Vitiligo care was the number of young dermatologists and dermatology residents who stopped by, and one researcher in the field of dermatology who was truly interested in learning about updates in research of which we might be aware.

When dermatologists stopped by the booth, they were asked if they wanted to be part of a database of dermatologists who treat Vitiligo. We explained to them that quite often the AVRF gets calls asking for referrals to dermatologists who know about and who treat Vitiligo. We gathered their addresses, phone numbers and e-mail information to add to our database. Most were happy to add their names and seemed very willing to treat Vitiligo patients. ■

AVRF GOLF TOURNAMENT



Job well done!
The AVRF extends a special "Thank You" to Janet, Ashton & Dylan for an extremely successful Golf Tournament!

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO, 23 SEPT 2005, RESTON, VIRGINIA

This one-day symposium was sponsored by the International Federation of Pigment Cell Societies (IFPCS), and organised by Alain Taïeb and Mauro Picardo who are currently chairing the special interest group on Vitiligo of the IFPCS. Vince Hearing, the organizer of the 19th IPCC, was very kind to help the logistics of this satellite meeting.

The main objective of the meeting was to foster cooperation within the international community of clinicians and scientists present at the meeting around this common but poorly understood disease that causes much distress especially in dark-skinned communities. Patients' support organisations from all over the world had also been invited to attend and to speak. Maxine Whitton, from the UK vitiligo Society, who could not attend, sent a very thought-provoking paper to the organizers, which helped to shape the discussion on topics ranging from classification of vitiligo and its possible implications for treatment, nature of depigmentation, epidemiology, sunlight and UVB, to basic science and treatment.

The symposium programme took into consideration the IPCC main programme which had already covered a broad range of topics, with two plenary lectures, Raymond Boissy on contact depigmentation and Richard Spritz on the genetics of non-segmental vitiligo, as well as several oral communications and posters (see list in Appendix 1). It was decided to give some extra time for the discussion of posters from the main meeting corresponding to the focuses of the satellite sessions, after a summary presentation by the authors.

SESSION 1: DEFINITION OF DISEASE ASSESSMENT AND OUTCOME MEASURES

Chairs: M Picardo and A Taïeb

1. Alain Taïeb (Bordeaux, France) presented the work done on this topic by the Vitiligo European Task force (VETF). Alain Taïeb mentioned that he wanted to build on his previous fruitful collaborative work for atopic dermatitis, which, through the European Task Force on Atopic Dermatitis (ETFAD), has produced over the last 15 years a widely accepted scoring system (SCORAD), a standardisation of atopy patch tests, and position papers on this disease. His presentation gave a special emphasis on the assessment workshop held in Rome on January 16, 2005 (IPCC Poster 051, PCR 18, suppl 1, p 68-9). The VETF was created in 2003 during the ESPCR in Ghent organized by Jean Marie Naeyaert (Fig 1) to design tools for clinical research in vitiligo and promote collaborative studies.

Two subsequent workshops were held in Paris in 2004 with the aim to design a common evaluation/scoring form which was tested at 11 European clinical centres on 180 patients included in a common database managed in Rome by the San Gallicano Group's statisti-

can, Mario Pellicciotta.



The VETF has chosen to use the simplified classification of vitiligo, following Koga's 1977 paper distinguishing segmental and non-segmental forms of disease, but based more on pragmatic than on pathophysiological grounds. However the VETF data collected allows a more accurate classification if needed (including focal, mucosal, acrofacial, common generalised, universal and even more subgroups) since the topography of lesions is reported in the assessment form. The VETF consensus definition for non-segmental vitiligo is as follows: an acquired, chronic, pigmentation disorder, characterised by white patches, often symmetrical, usually increasing in size with time, and which are due to a substantial loss of functioning epidermal and /or hair follicle melanocytes. The counterpart of this consensus definition is a list of disorders to exclude, namely piebaldism and other monogenic hypomelanoses, including tuberous sclerosis; post inflammatory depigmentation, including mycosis fungoides; post infectious depigmentation such as that seen in pityriasis versicolor, leprosy; post traumatic leucoderma; melanoma-associated leucoderma; melasma; toxic and drug-induced depigmentation (topical and systemic).

The Rome San Gallicano Dermatological Institute (SGDI) workshop was presented to the audience. Its objective was (1) to further test how practical is the VETF evaluation system (Appendix 2) which includes 3 main items related to extent, spreading, and staging, and (2) to assess inter-observer variations in scoring patients. 10 dermatologists from 9 European centres could examine 13 patients (8 NSV, 5 SV). For each patient a patch to be assessed was chosen by the organising SGDI team in order to reduce the duration of the session. The patient's opinion about the progression of the selected patch was recorded separately and did not influence the investigators. The dermatologists did not communicate during the session. 130 evaluations of the 3 scoring items were collected and analysed vs standardized colour and black and white UV photographs (pro-

On behalf of VETF members: A Alomar (Barceona), D Bennett (London), M Böhm (Münster), Y Gauthier (Bordeaux), D Gawkrödger (Sheffield), S Moretti (Florence), T Passeron (Nice), G Leone and M Picardo (Rome), M Olsson (Uppsala), G Orecchia (Pavia), K Ongenae, N van Geel, JM Naeyaert (Ghent), W Westerhof and JP Wietze van der Veen (Amsterdam),

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO Cont.

totype instrument, Deka, Florence, Italy). The workshop validated the clinical use of the assessment form proposed and showed an overall good concordance among panelists. It however raised several problems, e.g. staging since colour of the selected patch is not homogeneous especially in segmental vitiligo. Staging chosen by investigators reflected generally the worst stage. This poses problems when a few white hairs are present in association with skin repigmentation. A proposal was made for simplifying the staging system (stage 4 deleted). Another difficulty was related to the need to magnify the lesions to assess hairs, especially vellus hairs. Wood's lamp equipment for vitiligo assessment should include a magnifying lens. Analysis of spreading (progressive/stable/regressive) was the most difficult item in a blind (not patient influenced) test. Surprisingly, the investigator's opinion was right in the majority of cases if the patient's opinion was chosen as the gold standard. Overall, it was felt that this item should be graded more accurately using the patient's opinion.

Alain Taieb summarized his most important points: (1) The SGDI workshop validated a simple clinical assessment system of vitiligo, which can be easily handled in clinical practice. (2) Proposals for simplification of the tested EVTF assessment system were made for the grading grid. (3) Scorer profiles underscore the need of training to decrease inter-observer variability. He delineated desirable further steps, namely (1) including staging and spreading in the initial assessment of patients, in order to build a global index, most important for therapeutic indications and prognosis, which could be understood as an equivalent of the TNM system for cancer; (2) further large scale tests are needed in clinical trials (to check reproducibility, and sensitivity), and refinements using automated devices should be encouraged for special purposes, as well as teaching tools, which could be posted on an internet site, such as the ESPCR website. (3) An international agreement for classifying, staging and scoring vitiligo could be set as a main objective of the IFPCS special interest group on Vitiligo.

2. Ilt Hamzavi (Detroit, USA) presented the work he published recently with his colleagues while at the University of British Columbia in Vancouver which uses a quantitative parametric score, named the VASI score for Vitiligo Area Scoring Index, which is conceptually derived from the PASI score widely used for psoriasis. He made the point that many vitiligo treatments have typically been analysed using nominal binary scales in which the proportion of treated patients who either do or do not achieve a specified degree of repigmentation is reported and compared by nonparametric statistical approaches. The degree of repigmentation that defines success has often been set previously somewhat arbitrarily at 50% to 75% repigmentation based largely on the global impression of the overall response. Quantitative methods provide data that are generally more intuitive and meaningful to patients and physicians, while at the same time being more sensitive for detecting significant subtle

treatment effects. In addition, a quantitative method for measuring vitiligo severity would allow more studies to be compared across a range of data sets. A simple quantitative technique could standardize vitiligo outcome measurements and allow more studies to be included in meta-analyses.

In VASI, the body is divided into 5 separate and mutually exclusive regions: hands, upper extremities (excluding hands), trunk, lower extremities (excluding the feet), and feet. The axillary and inguinal regions are included with the upper and lower extremities, respectively, while the buttocks are included with the lower extremities. The face and neck areas are not included in the overall evaluation. One hand unit, which encompasses the palm plus the volar surface of all the digits, is approximately 1% of the total body surface area and is used as a guide to estimate the baseline percentage of vitiligo involvement of each body region. Depigmentation within each area was estimated to the nearest of 1 of the following percentages: 0, 10%, 25%, 50%, 75%, 90%, or 100% (Figure 2)

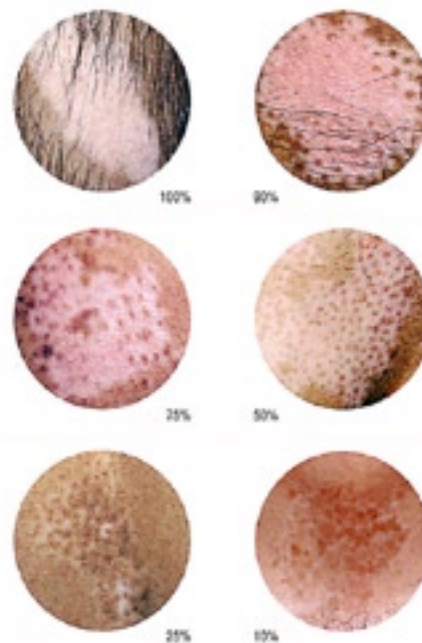


Figure 2: % depigmentation visual scale

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO Cont.

For each body region, the VASI is determined by the product of the area of vitiligo in hand units (which was set at 1% per unit) and the extent of depigmentation within each hand unit—measured patch (possible values of 0, 10%, 25%, 50%, 75%, 90%, or 100%). The total body VASI is then calculated using the following formula by considering the contributions of all body regions (possible range, 0-100):

$$\text{VASI} = \text{S (all body sites) (hand units) } \times \text{ (depigmentation)}$$

Dr Hamzavi stressed that using quantitative scales can more easily capture sequential trends in response by time or treatment number. Although such data for vitiligo are currently unavailable, they are nevertheless important because at the present time patients with vitiligo are asked to commit to treatment for a year or more based largely on knowing only the probability of achieving a certain specific degree of repigmentation at the end of therapy without any actual data on the expected rate of response over time. The VASI provides a sensitive method for detecting treatment responses, as evidenced by the demonstration of a significant difference between NB-UV-B and control within 2 months of treatment. If the Archives' published study had used a nonparametric method to evaluate response and chosen the usual 75% repigmentation threshold as representing treatment success, the trial would have shown a non-significant result ($P = .50$ by the McNemar test) instead of the highly significant difference found using the VASI ($P < .001$). Also, the VASI provides information over a range of time points rather than an arbitrarily set end point. When compared, the correlation with the VASI was lower for patient assessment than for physician assessment but was still statistically significant. The difference may be owing to a wider variation in what patients perceive to represent improvement. Dr Hamzavi said that it was important for other investigators to evaluate the validity of this technique, and he believes it is a quick and reliable tool, which can be applied to any setting and treatment.

3. Other papers of this session were presented by David Gawkrödger (Sheffield, UK) and A.J. Kanwar (Chandigarh, India).

Dr Gawkrödger presented a classification of vitiligo according to clinical pattern and disease association, based on the prospective evaluation of 41 adult patients, stressing the importance of a careful clinical evaluation. He found a 18% family history of vitiligo, 34% of patients had autoimmune thyroid disease, and 33% a family history of endocrine autoimmune disease.

Dr Kanwar examined 212 patients with onset of vitiligo after 50 years of age. Associated endocrine autoimmune disorders were present in 21.4% and 15.9% had a family history of vitiligo. Segmental vitiligo is rare in this age group (5.4%).

Discussion:

Dr M Ramam (New Delhi, India), suggested using the Lund Browder chart to score extent, because its advantage over the "rule of nines" is that the denominator is smaller for many body areas. As pointed out during Dr Taïeb's presentation, the difficulty in assessing surface area involvement is greatest when the denominator is large as on the legs. He further suggested that studies reporting on the response to treatment in vitiligo mention how many patients have achieved complete (100%) repigmentation. He said that this information is usually pooled together with those who have more than 75% repigmentation. However, for patients and those treating vitiligo, the difference between 100% repigmentation and 90% repigmentation is great.



Fig 3: Figure of the Lung and Browder chart reproduced from Hettiaratchy, S. et al. *BMJ* 2004;329:101-103

Another point was made concerning Dr Hamzavi's presentation by Dr Taïeb, indicating that multiplying extent by lesional score as in PASI is a potential source of error and increased variability between investigators, which has been avoided in other scales such as SCORAD which is an additive index combining extent, intensity and subjective signs.

Among questions taken from Maxine Whitton's list: Prevalence of vitiligo: experts in the audience agreed on a population based prevalence around 1% or less, but this figure might be increased in particular ethnic backgrounds.

Location of disease and resistance to treatment: Dr Nordlund (Cincinnati, USA) replied to the question of differential responses to treatment according to location of disease, by emphasizing the role of the reservoir of melanocytes which is found in hair follicles and absent on mucosal and glabrous skin such as the hands, and the role of precipitating/ environmental factors, especially trauma (Koebner's phenomenon).

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Segmental and non segmental vitiligo, a different disease or just a type of vitiligo? The hypothesis of a mosaicism for a major predisposing gene especially in stemness genes was already proposed but not yet investigated, and there are cases associating NSV and SV which point to applications of the concept of type II mosaicism in multigenic diseases, corresponding in the segmental lesion to a possible double dosing of the major predisposing gene, and a more recalcitrant form of vitiligo in the corresponding area (Dr Nordlund, Dr Taïeb).

SESSION II: EVIDENCE-BASED THERAPY AND FUTURE TRENDS

**Chairs: W Westerhof (Amsterdam, NL),
J Nordlund (Cincinnati, USA), Y Gauthier
(Bordeaux, France)**

There were four invited presentations, made by Dr Davinder Parsad (Chandigarh, India) on medical treatments, Dr Mats Olsson (Uppsala, Sweden), on surgical treatments, Dr Pearl Grimes (Los Angeles, USA), on combined therapies, and Dr H Lim who could not join the meeting was replaced by Dr Hamzavi (Detroit, USA) on phototherapies.

A Cochrane systematic review of interventions for vitiligo is currently in press as mentioned in her presentation sent to the organizers by Maxine Whitton who worked on this review with Dr Urba Gonzales from Barcelona and Darren Ashcroft, statistician from

Manchester. This review could assess 19 randomised controlled trials (RCT) with an overall poor methodology, since the method of randomisation was rarely described, and that only 9 studies were double blinded. There was overall weak evidence for the effectiveness of interventions for vitiligo, including alternative and experimental. All measures of outcome related to re-pigmentation, while none considered depigmentation, cosmetic camouflage, or psychological interventions. No pooling was possible since no two trials compared the same intervention. The design was different between studies (left/right comparison, individual patches assessed, or comparisons between groups). Interestingly, placebo effects seemed limited, since in many trials none of the patients who received placebo improved. The relative risks and confidence intervals were large, inducing a high level of uncertainty. Important observations were made in this review: 1. There are large variations in methods for scoring repigmentation 2. There are no reliable data on patient-centred outcomes or quality of life measures. 3. There is a lack of any reliable measure of outcome. 4. Trials are too short to assess effectiveness or adverse effects. 5. Few studies are done in children. 6. Age, duration, type (segmental responds best to surgery), and choice of site (face versus limb extremities) could affect outcome. 7. Lack of consensus about a cause leads to a multiplicity of treatments. 8. No clear clinical guidance emerged from the review, but some implications for research priorities: there is a need for more basic research on causes; agreement on classification and standardised measurement of outcome; translational research from scientific discovery to RCT, and more research into psychological interventions. Patient-centred outcomes would improve study designs.

Most of these difficulties outlined in the review were considered in the invited oral presentations given at the meeting. Dr Parsad emphasised also the various effects of treatments on repigmentation patterns and stability. Diffuse repigmentation is the least stable. Psoralens predominantly exhibit a perifollicular pattern of repigmentation and steroids (topical/systemic), a diffuse type. The speed of repigmentation is much faster when initial repigmentation is of the diffuse type as compared with follicular repigmentation. Marginal and perifollicular repigmentation are more stable than the diffuse type of repigmentation. Dr Olsson made remarks on the selection of patients for surgical procedures and specific transplantation methods. Dr Hemzavi indicated that the evidence for effectiveness of UVBTL01 was the best following the pioneering

Taieb A. Intrinsic and extrinsic pathomechanisms in vitiligo. *Pigment Cell Res.* 2000;13 Suppl 8:41-7.

Poblete-Gutierrez P, Wiederholt T, König A, Jugert FK, Marquardt Y, Rubben A, Merk HF, Happle R, Frank J. Allelic loss underlies type 2 segmental Hailey-Hailey disease, providing molecular confirmation of a novel genetic concept. *J Clin Invest.* 2004 Nov;114(10):1467-74.

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Cont.**

work of Dr Westerhof in Amsterdam, both for adults and children . Targeted phototherapy using excimer 308 xenon-chloride laser or monochromatic excimer light (MEL) are promising for some locations and limited disease. Combination with tacrolimus is synergistic. Dr Grimes emphasised the role of calcineurin inhibitors (tacrolimus, pimecrolimus), which are immunosuppressive, in combination with surgical and phototherapy interventions. A summary of the current approaches to treatment can be found in the following Table.

Type of Vitiligo	Usual management
Segmental (includes focal and mucosal)	<p>First line: Avoidance of triggering factors, local therapies (corticosteroids, calcineurin inhibitors). Second line: Localized UVB therapy, especially Excimer lamp or laser.</p> <p>Third line: Consider surgical techniques if repigmentation cosmetically unsatisfactory.</p>
Non segmental (including acrofacial)	<p>First line: Stabilization with UVB TL01 therapy, at least 4 months. Combination with systemic/ topical therapies, including reinforcement with localized UVB therapy, possible.</p> <p>Second line: Consider surgical techniques in non responding areas especially with high cosmetic impact. However, Koebner phenomenon limits the persistence of grafts. Relative contra-indication in areas such as dorsum of hands.</p>

Parsad D, Pandhi R, Dogra S, Kumar B. Clinical study of repigmentation patterns with different treatment modalities and their correlation with speed and stability of repigmentation in 352 vitiliginous patches. *J Am Acad Dermatol.* 2004;50:63-7.

Olsson MJ, Juhlin L. Long-term follow-up of leucoderma patients treated with transplants of autologous cultured melanocytes, ultrathin epidermal sheets and basal cell layer suspension. *Br J Dermatol.* 2002;147:893-904.

Westerhof W, Nieuweboer-Krobotova L. Treatment of vitiligo with UV-B radiation vs topical psoralen plus UV-A. *Arch Dermatol.* 1997;133:1525-8. ; Njoo MD, Bos JD, Westerhof W. Treatment of generalized vitiligo in children with narrow-band (TL-01) UVB radiation therapy. *J Am Acad Dermatol.* 2000;42(2 Pt 1):245-53.

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO Cont.

TABLE 1: GENERAL OUTLINE OF MANAGEMENT FOR VITILIGO (adapted from Taieb, 2005, in press)

Five short presentations were given on tissue culture techniques (S Mac Neil, Sheffield, UK, and DN Hu, New York, USA), physical treatments namely Excimer Laser (A Overbeck, Madrid, Spain) and low energy helium-neon laser (CS Wu, Taipei, Taiwan), and adjuvant growth factor therapy (A. Ramaiah, Hyderabad, India). Dr Mac Neil presented the data (PP053, OP 120) which are promising in terms of delivering to distant centres melanocytes grown on a chemically defined surface (acid and amine plasma polymers) which have been transferred successfully to an in vitro model of human dermis. Dr Dan-Ning Hu showed an update of a study using pure autologous melanocytes in 150 vitiligo patients Taiwan, with better results in segmental and stable generalised cases. Dr Wu (PP046), working on the assumption that SV results from the dysfunction of sympathetic nerves in the affected areas, expanded his earlier observations in an updated series of 40 patients, indicating that low energy helium-neon laser 632.8nm can repair nerve injury and improve SV. Dr Overbeck shared his experience with the excimer laser and showed encouraging results with a combined blister graft plus excimer laser technique. Dr Ramaiah (OP 118) indicated that his bFGF peptide lotion which is marketed in India can be used in combinatorial protocols.

Discussion:

Indications for surgical treatment: Several panellists warned against such therapies in patients who are not clearly stabilized. Surgery on hands needs immobilization which is not easy to obtain in practice. Non melanoma and melanoma skin cancer and UV exposure in vitiligo patients. There is no demonstrated increased risk from UV in vitiliginous skin (and the contrary is suggested based on anecdotal reports in tropical countries) and UVBTL01 treatment is considered as a safe first-line therapy in vitiligo. There is no need to avoid natural sunlight, since UVB boosts melanocyte division and migration. UVA may act indirectly on the melanocyte environment, through growth factor production by epidermal and dermal cells, promoting melanocyte survival and pigmentation. A moderate suberythral exposure (that is, less exposure than leads to sunburn) is advised to enhance repigmentation, followed by sun protection if further exposure cannot be avoided (summary of various panellists' answers). It is often assumed that skin is protected against sunburn predominantly by melanin. However, Dr Westerhof mentioned a difference in burning capacity of white patches between vitiligo individuals with different skin types. With UVB 311 nm lamps, he irradiated both lesional and non-lesional skin with increasing doses in 33

patients with vitiligo, divided into 5 groups according to skin type (II-VI). Twenty-four hours later he assessed the minimal erythral dose and found a correlation between skin type and UV sensitivity in both lesional skin and normal skin. He suggests that there must be a protection mechanism, other than that offered by melanin pigmentation. Antioxidant status may play a role in this phenomenon.

UV treatments in children: The benefit/risk ratio is frequently evaluated with a strong negative bias in children because the potential side effects of treatments are overemphasized. However, the benefit of an early stabilizing treatment is currently considered more important than the risk of UV irradiation. The limiting factor is the practical management of UVBTL01 therapy in a child, which is generally possible only around the age of 6-7 or older.

SESSION III: NEW DIRECTIONS FOR RESEARCH (Interface between clinical and basic research)

Chairs: C Goding (Oxford, UK), A Taieb (Bordeaux, France)
Panelists: L Larue (Orsay, France), D Bennett (London, UK), P Das (Amsterdam, NL), R Spritz (Denver, USA)

Non immune and immune pathomechanisms were respectively introduced by Mauro Picardo (Rome, Italy) and Caroline LePoole (Chicago, USA).

Dr Picardo reviewed primary cellular defects and alterations of the melanocyte microenvironment that can lead to the disappearance

Chen YF, Yang PY, Hu DN, Kuo FS, Hung CS, Hung CM. Treatment of vitiligo by transplantation of cultured pure melanocyte suspension: analysis of 120 cases. *J Am Acad Dermatol.* 2004;51:68-74.

Yu HS, Wu CS, Yu CL, Kao YH, Chiou MH. Helium-neon laser irradiation stimulates migration and proliferation in melanocytes and induces repigmentation in segmental-type vitiligo. *J Invest Dermatol.* 2003;120:56-64.

Caron-Schreinemachers AL, Kingswijk MM, Bos JD, Westerhof W. UVB 311 nm tolerance of vitiligo skin increases with skin phototype. *Acta Derm Venereol.* 2005;85:24-6.

Atherton DJ, Cohen BL, Knobler E, Garzon M, Morelli JG, Tay YK, Weston WL, Taieb A, Morison WL, Rasmussen JE. Phototherapy for children. *Pediatr Dermatol.* 1996;13:415-26.

Gauthier Y, Cario Andre M, Taieb A. A critical appraisal of vitiligo etiologic theories. Is melanocyte loss a melanocytorrhagy? *Pigment Cell Res.* 2003;16:322-32.

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of functional melanocytes, and considered auto-immune phenomena as secondary. He made the point that vitiligo is probably not a single disease and that it may correspond to multiple causes. He examined neural, metabolic, genetic, redox and adhesion dependent (melanocytorrhagic) mechanisms. Melanogenic and extra-melanogenic metabolism, including for the latter catecholamines, calcium, antioxidant, and pterins, have all been shown to be altered to some extent in vivo or in vitro. A clear genetic basis for these alterations is not yet at hand. He made the hypothesis that altered gene expression could affect the amount or the correct folding of proteins involved in the synthesis of melanin or in the detoxifying process, with subsequent increased melanocyte vulnerability. He emphasized the current evidence for a compromised intracellular redox status due to both impaired antioxidant defence and increased free radical production. The detachment of melanocytes could be the net effect of convergent pathways altering melanocyte survival and give rise to secondary autoimmune responses.

Dr LePoole stated that in vitiligo depigmentation is accompanied by T cell influx to the skin in the vast majority of patients, in an entity she designated as "auto-immune vitiligo". A minority of such infiltrating T cells are type 1 proinflammatory cytokine-secreting cells reactive with melanocyte-specific antigen. Melanoma research has shown that differentiation antigens, also expressed by normal melanocytes, can be immunogenic when expressed in the melanosomal compartment of the cell. Similar reactivity to melanosomal antigens is apparent for T cells infiltrating vitiligo skin. Stress may be a precipitating factor of the immune response inadequately modulated by regulatory T cells. T cells are recruited to the skin as a function of dendritic cell activation and dendritic cells are likely activated at sites of epidermal trauma as a consequence of stress proteins such as HSP that spill over into the microenvironment. Stress proteins chaperoning antigens representative of the cells from which they were derived are then processed by dendritic cells and contribute to their activation. Activated dendritic cells not only migrate to draining lymph nodes to recruit T cells but may execute cytotoxic effector functions as well. The contribution of the effector functions to actual depigmentation of the skin remains to be investigated.

A first debate was launched based on these two reviews and on the list of questions from the UK Vitiligo Society summarized by Maxine Whitton.

Colin Goding speculated on a common stress signalling pathway hypothesis which may reconcile immune and non-immune pathomechanisms, acting on both keratinocytes which provide survival and growth promoting factors for melanocytes, and of course melanocytes, as well as on various dermal cells which can influence melanocyte behaviour. Another hypothesis concerns alterations in stem cells that could also be influenced by stressor factors. He also underlined the role of the transcription factor MITF in the loss of

melanocytes and in depigmentation. The relevance of this mechanism is supported by in vivo (mouse with vit gene deletion) and in vitro studies. The mitogen-activated kinase (MAPK) p38 has been shown to transduce a variety of stress stimuli including UV, mechanical and hormonal stress into cellular responses by phosphorelay cascades, which are possible research targets. One possibility raised is that melanocytes from vitiligo patients are intrinsically more sensitive to stress signalling via the p38 pathway.

In conclusion of this debate, Colin Goding summarized his views as follows: vitiligo appears to be a complex disease in which melanocytes are intrinsically stress sensitive, leading most likely to melanocyte death in response to various kinds of stress - mechanical, viral, even emotional. This would then lead to vitiligo only in those patients who also have genetic predisposition to an auto-immune reaction against melanocyte antigens.

Further questions from Maxine Whitton were addressed:

Is there an agreement on the nature of pigment loss? Are all the melanocytes in vitiliginous skin dead, or do some survive in the white patches, which can be stimulated to divide and multiply? This question refers to the staging of the disease and has important therapeutic consequences. However, the panellists present were not enthusiastic to answer it, because there are more opinions than facts on this matter. Repigmentation can occur from hair follicles and sometimes focally on glabrous skin such as lips - so surely most would agree that sometimes melanocytes or their precursors are still present within the patches in this case. We just don't know if they always are. Further research is obviously needed.

Why does vitiligo appears on particular parts of the body? What is different in those parts of the skin or underlying tissues that predisposes one part to manifest depigmentation and not another? The panellists agreed upon the role of environmental/triggering factors especially trauma causing Koebner's phenomenon, but there are probably other unknown factors. Another point was made by Dr Lionel Larue (Orsay, France) who speculated about the role of melanocyte migration, which makes it take longer for the precursor cells to reach the extremities, so that fewer cells arrive in these areas. This may affect the susceptibility of melanocytes in acral locations. Prof Bennett commented that there was also speculation on a role for neurotransmitters, since some of the susceptible areas (e.g. around the eyes and mouth and the fingers) have a rich nerve supply.

Some people report itching in their vitiligo patches, often it is the precursor to a new white spot. For others the white patches are more sensitive to products such as soap and shampoo. If itching is an inflammatory response then all people with vitiligo should experience it (cf eczema, acne).

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO Cont.

Has any research been done on itching in vitiligo?

Dr Taieb replied that so-called “inflammatory vitiligo” is a known but rare event and that pruritus is rarely mentioned spontaneously by patients visiting our clinics. This point was agreed upon by other clinical experts. Pruritus would be indeed a good argument for the autoimmune or auto-inflammatory theory of vitiligo. However, it appears important to obtain this information more systematically when taking the patient’s history and even to use a pruritus scale in this disease. The VETF should include this item in the updated version of its vitiligo evaluation form.

Five short presentations were discussed in this session. Dr Thomas Tüting (Bonn, Germany) presented a mouse model using C57BL/6 mice which indicates that CD4 T cell help and local inflammation are required to circumvent peripheral CD8 tolerance against melanocytic antigens. Using two different genetic methods for the induction of cellular immunity *in vivo*, gene gun bombardment of the skin and injection of recombinant adenovirus, his group has shown that peripheral tolerance of CD8+ T cells recognizing a single TRP2-derived H2-Kb-binding peptide is regulated in two steps. In the induction phase, stimulation and expansion of TRP2-specific CD8+ T cells *in vivo* depend on CD4+ T cell help. In the effector phase, autoimmune destruction of melanocytes in the skin depends on local inflammation. He suggests that accidental stimulation of CD8+ CTL recognizing major histocompatibility complex class I-binding peptides derived from melanocytic proteins in the context of an inflammatory skin disease may play an important role in the pathophysiology of vitiligo.

This paper raises an issue in line with one of the above questions, and would suggest a more thorough look at inflammatory premises of vitiligo which are so far not clear in most patients.

Dr Silvia Moretti (Florence, Italy), pursuing her previous work on done using immunohistochemistry of cytokine expression described modifications in cytokine transcripts for ET1, SCF, GM-CSF, bFGF and TNF α in 12 patients with active NS vitiligo. ET1 and SCF were more expressed in perilesional than lesional skin, whereas GM-CSF and bFGF were more present in lesional than perilesional skin. TNF α , which has an inhibiting effect on melanocyte growth and differentiation, was highly expressed in both perilesional and lesional skin, but not detectable in normal control skin. Similar data for TNF α transcripts have been reported by Dr Grimes and colleagues. During the discussion Dr Taieb mentioned that if this finding is relevant, it was surprising that in the large number of patients treated with anti-TNF agents, no cure of vitiligo has been so far mentioned. One case of infliximab related vitiligo has even been published. Dr Grimes mentioned that a study of anti-TNF α in vitiligo is under consideration at her institution.

Dr Paola Grammatico (Rome, Italy) took the candidate gene ap-

proach for NS vitiligo. She looked at CDKN2C, a tumor suppressor gene located in the AIS1 region recognized as a vitiligo susceptibility locus, at the microphthalmia (MITF) gene which encodes a transcription factor important for melanocyte survival, and at the angiotensin converting gene (ACE) I/D polymorphisms recently reported in the Korean population in vitiligo patients. The results were negative when using Italian control samples. Dr Richard Spritz commented that candidate gene approaches should not be performed in multigenic disease given their very low yield of positive results. He has developed linkage studies that have been more fruitful.

However, Dr Taieb pointed out that other complex diseases benefited from the candidate gene approach, when a monogenic disorder is highly associated with the considered phenotype, quoting the example of Netherton syndrome and atopic dermatitis.

Dr Muriel Cario-André (Bordeaux, France) summarized the prize winning IPCC poster (PP 050) which demonstrates a strong dermal influence on human epidermal pigmentation. Using epidermal reconstructions seeded on various types of dermis, *in vitro* and *in vivo* with xenografts on tolerant Swiss nu/nu mice, she showed that dermal fibroblast density/activity influences melanocyte migration and proliferation and possibly melanin distribution and degradation. How this applies to vitiligo and other skin disorders remains elusive but the findings suggest consideration of the dermal influence on the epidermal melanin unit as more important than previously envisaged.

SESSION IV: BURDEN OF DISEASE/INTERACTION WITH PATIENTS’ SUPPORT GROUPS

Chair: Alida de Pase (ASNPV, Italy)

Alida de Pase has reported on this Satellite in a separate paper. The interaction of patients’ support groups with the medical and scientific community has already been fruitful as communicated by Richard Spritz at the IPCC, since major predisposing genes have been detected in the families contacted in the UK and North America by patient support groups. It was also important to have the personal account of the patients and they deputized brilliant speakers at the satellite meeting. Randy Salter from Vitiligo Support International reported on his personal experience, and how difficult it was in general to find doctors with an interest in vitiligo patients. A dePase also made a practical point during the meeting concerning paediatric patients, who should be seen in separate clinics because of losing all hope when mixed up with affected adults in the same waiting room. The AVRF (American Vitiligo Research Foundation) deputized Roxanne Knight and Marilyn Giordano who presented slides of severely affected children, bringing home to the audience the message of how urgent it was for the medical/scientific community to address the problem of vitiligo.

REPORT ON THE 19th IPCC SATELLITE SYMPOSIUM ON VITILIGO Cont.

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Conclusions

Mauro Picardo and Alain Taieb expressed their thanks to all the speakers and participants and delineated some future steps. The Special Interest Group on Vitiligo of the IFPCS should have a mailing list to communicate more easily on the internet, and receive messages concerning future initiatives. A specific website would be helpful. A vitiligo meeting will be held at the next ESPCR meeting in Barcelona organized by Luis Montoliu (24-27 Sept 2006) and at the next IPCC in Sapporo, Japan, May 7-12, 2008. Exchanges should be improved to promote an international agreement on such basic issues as assessment tools and outcome measures in clinical trials. Fostering exchanges between the clinical and scientific communities around vitiligo will be a priority and research projects could be set up based on some ideas debated at this Symposium. Fund raising for research is another important issue and the help of patient support groups is expected. ■

SATELLITE SYMPOSIUM ON VITILIGO By Roxanne

On September 23, 2005, Alida De Pase invited the AVRF to Reston, Virginia to attend the "Satellite Symposium on Vitiligo" as representatives of a vitiligo patient advisory group. AVRF celebrated its 10th Anniversary in 2005 and we had a lot of accomplishments/goals to share with the physicians and researchers that were in attendance. We covered the AVRF's milestones of the past 10 years and spoke volumes with our pictures and testimonials of children and vitiligo patients that have been impacted through the years because of our Foundation. Everyone knew we appreciated their interest and support and we pledged our commitment to continue with our mission. I found the response from the brilliant doctors in attendance to be heartwarming.

After the symposium, I traveled to Washington DC to see some relatives, as well as to take in the new WWII Memorial among other sites. It was the weekend of many organized protests in the capital; and I couldn't help but feel a huge sense of patriotism at what a great nation we have with diversity at every corner, much like the AVRF's mission to celebrate diversity. We, the patient advisory organizations (much like Democrats and Republicans), may not always agree on the methodology, but we are all moving our cause forward by taking action. ■



**Mount Sinai School of Medicine, Winter Symposium.
Stella Pavlides, AVRF President & AVRF Medical Advisory
Board member, Dr. Brickell Quarles, Ph.D.**

CHOOSE FOODS THAT COULD PROTECT YOUR COLOR By Audrey VanStockum

Did you know that your choice could affect your vitiligo?

Research shows that people with vitiligo frequently have shortages in Vitamins B-12 and C, folic acid and pantothenic acid. They also need copper and zinc to make those vitamins work properly. These studies found that vitamin supplementation can help stabilize and restore color. However, dosages showing best results in adults are excessive for younger teen-agers.

The exception: Teen-agers who are vegan – vegetarians who don't eat dairy or eggs – may need a B-12 supplement because it's tough to get adequate supplies from animal-free sources unless you are willing to eat lots of seaweed. Ask your doctor or dietician if you take B-12, and if so, how much you need.

Eating well can improve your vitamin levels while minimizing the chance of getting too much of a good thing.

Back to the cafeteria line. The hamburger and pizza may be a fatty, but the meat and cheese offer much-needed B-12. If you're lucky, the bread and pizza crust will be whole-grain. Ask the cafeteria manager, preferably when it's calmed down after lunch.

The salad is OK, and the deeper the shade of green, the better. However, if the lettuce is iceberg – that almost-white lettuce – the suspicious veggie may be better, provided it isn't cooked beyond recognition. (Do you really blame the vitamins for leaving once the veggie turns that tantalizing shade of greige?) Peas, spinach and even corn – not a vegetable, no matter what the menu says – provide useful vitamins and minerals.

Broccoli and cheese have more nutritional punch than sour cream and butter. Eat the potato skins; that's where the best stuff hides. And surely you know that French fries are a poor choice.

Sour cream, ice cream and super-sweetened yogurt are dairy products, which have some value, but high sugar and fat contents make them "sometimes" foods. Cake offers nothing useful, and gelatin is nothing more than jiggly Kool-Aid.

Of course, you can eat the orange, which is chock-full of Vitamin C.

If your school doesn't offer palatable healthy choices, pack your lunch.

Whole-grain breads, wraps, pita pockets and tortillas will add folic acid and pantothenic acid. The nutrition label of your best choices.

Studies show that some vitamins can stabilize and sometimes restore pigment. You're in the lunch line at school. You have these choices:

1. Hamburger
2. Sausage and pepperoni pizza
3. Salad
4. Some vegetable of suspicious origins
5. Baked potato with broccoli and cheese
6. Baked potato with sour cream and butter
7. French fries
8. Ice cream
9. Yogurt
10. Cake
11. Gelatin
12. Fresh orange

Whole-grain breads, wraps, pita pockets and tortillas will add folic acid and pantothenic acid. The nutrition label of your best choices will say "whole wheat" or "whole grain" and not just "wheat." Meat, fish, cheese and eggs provide B-12.

Because folic acid consumption prevents birth defects, food companies enrich many breads and cereals with this vitamin. Get B-12, too, because these vitamins work together.

Don't forget snacks. Again, bypass frou-frou foods and turn to convenient foods such as cheese (B-12), fresh fruits (C) and enriched breads and cereals, even in such munchie forms as homemade Chex mix (folic acid, plus copper if you add cashews, sunflower seeds or almonds.) Drink some hot chocolate; even the mix-with-water stuff has copper.

Will diet cure vitiligo? Unfortunately, no. But eating well may help improve the odds that your coloring will stabilize until someone does find a cure.

will say "whole wheat" or "whole grain" and not just "wheat." Meat, fish, cheese and eggs provide B-12.

Because folic acid consumption prevents birth defects, food companies enrich many breads and cereals with this vitamin. Get B-12, too, because these vitamins work together.

CHOOSE FOODS THAT COULD PROTECT YOUR COLOR Cont.

Don't forget snacks. Again, bypass frou-frou foods and turn to convenient foods such as cheese (B-12), fresh fruits (C) and enriched breads and cereals, even in such munchie forms as homemade Chex mix (folic acid, plus copper if you add cashews, sunflower seeds or almonds.) Drink some hot chocolate; even the mix-with-water stuff has copper.

Will diet cure vitiligo? Unfortunately, no. But eating well may help improve the odds that your coloring will stabilize until someone does find a cure.

BIO:

Audrey VanStockum is the president of Supernatural Health, Inc., a company founded for the purpose of delivering safe, effective natural remedies. Audrey, a vitiligo sufferer, was tired of hearing there was no natural treatment. She was supervising a team of business analysts for a telecommunications company when she began reading everything she could find down to the most obscure footnote, finding how the body produces pigment. The result was Recoleur, the natural product containing the vitamins and minerals often lacking in those with vitiligo. ■

Visit the website: www.Recouleur.com

REID: PARENT SEMINAR SUMMARY

My son, Josiah, weighed slightly less than two pounds when he was born ten weeks early in December 1999. He spent several weeks in a neonatal intensive care unit and then joined our family as a foster child. During his first year, he had heart surgery and was hospitalized for a severe kidney infection. He was diagnosed with mild cerebral palsy, developmental delays, and autoimmune neutropenia (a life-threatening blood disorder). His first vitiligo spots appeared when he was fifteen months old after he recovered from scarlet fever. He'd had a red rash (scarletina) on his chest and, as it faded, the places where it had been were white and did not repigment. The vitiligo spread rapidly all over his body while we searched first for a diagnosis and then for an effective treatment.

By the Fall of 2004 Joey had become our adopted son. By then, the white spots around his eyes had become so large that it looked like he was wearing a mask. People stared at him and some even made comments. Joey started to realize that he looked different from other children and he became reluctant to go out in public.

Then we were fortunate to be able to attend the AVRF seminar in Florida in June 2005. Everyone was so welcoming and there were all kinds of fun activities. Joey met other children with vitiligo and saw how happy and normal they were. I, as a parent, was able to learn so much about vitiligo both from the experts and from other parents whose problems were so similar to mine. I even learned about a slightly different way to adjust Joey's light therapy treatment that resulted in an almost total repigmentation of the awful circles around his eyes. This year our whole family (Mom, Dad, Joey, and at least two siblings) plans to attend the seminar. Joey can't wait and neither can I. ■



UNIVERSITY OF FLORIDA VITILIGO RESEARCH By Wayne McCormack, Ph.D



Wayne McCormack, Ph.D

The University of Florida College of Medicine is pleased to announce the addition of two researchers to the vitiligo research program: Dr. Peggy Wallace and Deborah Herbstman. A professor of molecular genetics and microbiology, Dr. Wallace's lab focuses on genetic mapping, cloning, mutation and functional analysis of human disease genes for a variety of human genetic diseases, including neurofibromatosis type 1, hereditary heart defects, cardiomyopathy, and pain sensitivity. Deborah Herbstman

is a graduate student in the Interdisciplinary Program in Biomedical Sciences, and is performing her doctoral dissertation research under the direction of Dr. Wallace and Dr. Wayne McCormack, with vitiligo research as the focus of her Ph.D. work.

Deborah's previous work in biomedical research has involved both the basic and clinical sciences, including MRI research, immunohistochemistry, and pediatric psychiatric research. Deborah will be working with human DNA samples previously donated from vitiligo patients and healthy volunteers. She will focus on the genet-

ics of vitiligo, looking at how different genes may contribute to an individual's susceptibility to the disease. Deborah will be applying a number of newer genetic analysis tools and techniques being used in Dr. Wallace's lab to the vitiligo research program at the University of Florida. Buying reagents for this work is expensive, and we are very grateful to the American Vitiligo Research Foundation for their continuing support of this important research. The more that we know about the genetics of vitiligo, the closer we may come to understanding the causes of the disease, and hopefully making progress towards prevention and treatments.

Deborah is very excited to meet the families and supporters of the AVRF at the upcoming meeting this summer. She enjoys talking to both scientists and non-scientists about her research, and looks forward to presenting an update of her work to the AVRF. Deborah is involved in teaching fellow students in her graduate program, and she works as a tutor in her local community. She has been an active member of the College of Medicine's Graduate Student Organization, where she is currently in her second year of serving as the group's Community Service Co-Chair. A former National Merit Scholar and member of the national honor society, Mortar Board, Deborah is currently the recipient of the University of Florida College of Medicine's prestigious Grinter Fellowship. ■

THE PERFECT ENDING TO A FAN-TASTIC WEEKEND! By Christine D.



Driving up to the AVRF seminar in Clearwater that first morning, my 11-year-old son, Francisco, and I were unsure what to expect. Would there be huge conference rooms and complicated scientific presentations given by experts? Was our case "normal," unique, too severe or too mild? Were we doing everything we could in regard to the treatment of vitiligo? Questions many first-timers must have run through their heads en route to the American Vitiligo Research Foundation's Annual Conference.

It was silly to have worried. Five minutes after entering the hotel lobby where the conference was being held, we were put completely at ease. We were greeted warmly by Marilyn and ushered to tables full of our favorite foods. We were surrounded by kids of

all ages also diagnosed with vitiligo, and immediately started up a conversation with Ryan and his mom (Ryan and Francisco are the same age). We were well on our way to an awesome weekend!

Seeing Francisco so much at ease that weekend was incredible for me as a parent. He often seems to forget about his skin but with that group of kids, that weekend, jumping in that pool, it was "What vitiligo????"

Everything that had been planned was perfect – from meeting Shelton Quarles and the Buc's cheerleaders at the dinner, the Build-A-Bear and pizza workshops, Stella's generous spirit with the kids and trip to the dollar store, the valuable information exchanged and gained at the conference, the discussions with other parents, and friendships formed in our concern for our children's well-being – it was exactly what we needed. It was so much more than we expected. We belonged. And to top it all off, Francisco won the raffle and took home the autographed football signed by Buccaneer's head coach, Jon Gruden. Wow, what a finish! ■

“HUMBLED BY SMILES OF JOY AND PAIN”

By Dr. Brickell Quarles

Clinical Psychologist-AVRF Medical Advisory Board Member

Last June I had one of the most humbling experiences of my life. I attended the AVRF Annual Convention in Clearwater, Florida. It was my first time in attendance and an experience I have not forgotten. It is one thing to hear from Stella about the misfortunes and tribulations one suffers from having vitiligo, but it is another thing to witness it and see its effects.

Overall, the weekend was wonderful. For the adults it provided an opportunity to gather the latest research data on, and treatment options for, vitiligo. It also gave them a chance to build supportive relationships, and to offer insights to others about their personal experiences with vitiligo. For the kids, with whom I spent most of the weekend, it was all about having fun. And this they did! It was great seeing the children being celebrated for just being themselves. They seemed truly excited about being together again and meeting new friends. The weekend provided them with several moments of escape from the prolonged stares, disrespectful comments, and at times downright rude and insulting demeanors of the uneducated [about vitiligo]. On the other hand, it also made for educational opportunities for people with questions about vitiligo – but what a cross to bear, having to explain your humanity to others just to feel accepted! Life for one with vitiligo is hard, especially given the image conscious society we live in.

Although there were smiles of joy on the kids' faces, there was also an underlying sadness evident at times. A sadness that seemed in silence to say “Why me?” What is one to do when he/she has minimal to no control over his/her worse secret being exposed? The daily vulnerability experienced by individuals, especially kids, with vitiligo is unimaginable, and at times seemed overwhelming. It takes a tremendous amount of bravery and strength to face society in such a vulnerable state.

By embracing diversity, and individuals and a society knowledgeable about vitiligo, we can move from discrimination to acceptance, from hate to love. As a member of the AVRF Medical Advisory Board, I hope to shed light on the emotional and psychological effects of vitiligo, and to identify potential individual and family resiliency factors that can help to make having vitiligo more manageable. ■



**Mount Sinai School of Medicine, Winter Symposium.
Stella Pavlides, AVRF President & AVRF Medical Advisory
Board member, Dr. Brickell Quarles, Ph.D.**

AVRF ANNIVERSARY SEMINAR WEEKEND By Roxanne

2005 marked the 10th Anniversary for the AVRF and there was a great deal to celebrate. True to style, AVRF ensured guests received four days of information, fun, and celebration. Once again, we were able to promote awareness and raise money while doing so.

Thursday began at dinner with an informal meet and greet for all of the attendees.

Friday night was the AVRF anniversary dinner with Shelton Quarles, Captain Fear, and two beautiful Tampa Bay cheerleaders (Dawnyale and Lauren) to help the Foundation celebrate. Also in attendance to honor Stella's contributions were the AVRF Board of Directors, members of the AVRF Medical Advisory Board and National Chapters. Stella was presented with a few special gifts, including flowers and a book filled with congratulations from across the world. There was no shortage of happy tears, pride, and admiration in that ballroom!

The AVRF "Firsts" were celebrated. The list of "First" accomplishments is notable for a mere ten years.

With Stella's great leadership the AVRF has:

- Been recognized in the Congressional Record
- Had vitiligo month Proclamations for "April is Vitiligo Awareness Month"
- Held Seminars for patients, families, and friends since 2001
- Held Walk-a-thons and Skate-a-thons to raise awareness
- Had a story in The New York Times
- Produced an e-newsletter and informational brochures
- Funded research programs in the USA, England, and Germany
- Produced a 30-second and a 60-second Public Service Announcement (PSA) for Florida and Cablevision
- Initiated a "Dream" program, allowing two children to meet their "dream" celebrity (Whoopi Goldberg and Torii Hunter were gracious to the children)
- Produced over 25 billboards to display in Florida throughout April to raise vitiligo awareness
- Established over 25 chapters nationwide, as well as chapters in Kenya, the Philippines, and Jordan
- Held the 1st International Researchers Conference in 2004
- Visited Nairobi, Kenya to educate and raise awareness
- Partnered with the NAACP

This is just the start; the AVRF will continue to move forward and, as always, work to find a cure for vitiligo.



Saturday was filled with seminar presentations from Dr. Sinha, Professor Schallreuter, and representatives from Blue Lizard Sunscreen, UVBioTek and CoverBlend.

True to her commitment and love for the kids, Stella loaded up all the kids on a bus and took them all to Build-A-Bear to build their own new friend, California Pizza Kitchen to learn to make pizzas, and then off to the Dollar Store for a handful of goodies!

Sunday we made our way to the beautiful Clearwater Beach for our Walk-a-thon to raise awareness. Best was the good old-fashioned barbecue with an opportunity to win some really great raffle prizes.

My son learned that weekend what it is to be discriminated against for "not being different." You see, he felt he didn't fit in because he doesn't have vitiligo. As a parent, I cannot always teach embracing diversity and why it is so important to accept all people; but in that one weekend, actions spoke louder than my words. The only thing is my son, Cameron, seems to believe all people with vitiligo live in FL! ■

THE AVRF GOES TO AFRICA
By Loretta Cooper



The American Vitiligo Research Foundation (AVRF) sponsored trip to Nairobi started very early for me on Wednesday, November 9, 2005. I left for the airport at five o'clock in the morning for a seven o'clock flight to Miami, Florida. By seven-thirty, I was settled comfortably on the plane as it made its way down the runway. I arrived in Miami at about three o'clock in the afternoon and followed the signs to the British Airways (BA) terminal where I was to meet Stella. Our flight from Miami to London was scheduled to leave at about five o'clock. As I trekked from the American Airlines gate to BA I was encouraged by the signs along the way that advised me how many minutes it would take to travel from each point to reach my destination. I tested these calculations for a few minutes to determine adjusted timeframes as I accelerated or slowed my pace. My mind soon wandered from this mental quiz, and I turned my attention again to reading signs as I continued through the various terminals at a faster pace.

I arrived at the BA terminal only slightly out of breath and settled into a seat that would allow me a view of other arriving passengers. It was not long before I spotted Stella and we greeted each other and briefly discussed the details and agenda for the seminar and our trip. During this conversation, Stella shared with me information about the bombings in Jordan that were reported in the news that morning. Unfortunately, lives and property were senselessly lost.

We checked in at the terminal counter to make sure that all was in order with our boarding passes and seat assignments. It wasn't long before we were boarding Flight 206 to Heathrow in London. The more than ten-hour long flight would arrive in London on the morning of November 10 at about six-twenty.

In our haste and excitement to begin this leg of our trip, Stella and I

mistakenly sat in the wrong seats. This was brought to our attention by a gentleman who was just a little put out that two adult women were unable to find their assigned seats and who thought that this little mix-up was quite humorous and certainly not cause for much concern. We were not so far removed from our assigned places, at least we were in the correct row. Stella, at my direction, sat at the window which was correctly assigned to our distraught co-passenger. After making things right we buckled up and made preparations for the long flight to England.

Upon boarding, we found on our seats several packets of items encased in individual plastic pouches. Among them were the customary pillow and blanket, a set of earphones, a pair of socks, a sleep mask, travel toothbrush, and tooth paste for the personal use of each passenger. All items were intended to make our flight more comfortable. I'm thinking, "This is definitely the way to fly."

As dinner was being served I made a few general comments to the passenger seated at the window. He was in better spirits by this time, food will help do that. Introductions followed and we learned that passenger Drum is an 82-year old retired pilot who shared some interesting facts about flying and airlines in general. One interesting point he shared is that BA is subsidized by the British government, hence the superb food and superior service.

As we continued to enjoy our meal and converse, we also learned that Mr. Drum is a published author. He offered to send us a copy of his book, *That's the Way it Was*. We exchanged email addresses and he promised to contact us once he returned from his cruise which was sailing from Spain.



After arriving in London, we parted ways with Mr. Drum and wished him well. Stella and I then made our way to the terminal to board the flight that would take us to our final destination. It required taking a tram from one terminal to another. Although we had about four hours before our flight

left we wanted to first locate the boarding area. Once we arrived at the boarding area, we took time to refresh ourselves in preparation for the next leg of our trip. It will come as no surprise that we were equipped with our own washcloths, toothbrush and tooth paste.

THE AVRF GOES TO AFRICA Cont.

At about 10:05 a.m. on November 10, Stella and I boarded the plane to Nairobi. Again passengers were provided the familiar packet of amenities. We were served a delicious meal complete with entrée, salad, desert, snack, mineral water, and beverage of choice.

The aircraft was equipped with individual TV screens that allowed passengers to view a variety of movies and other offerings as well as a virtual map of the flight. At any given time the user was able to access the map and determine the location of the aircraft, the altitude, the outside temperature, the time in the departing city and the destination, and remaining travel time. In making our way to Kenya we flew over Milan, Athens, and the Sahara Desert.

About seven hours into the flight and more than three hours before landing in Kenya we were served tea. Similar to the tea served on our earlier flight we enjoyed miniature sandwiches, English biscuits, fruit, desert, and choice of beverage. Unlike other airlines I have flown, all beverages, alcoholic and non, are served without charge and there is no fee for earphones. Another perk of flying BA style.

Some time after tea and about an hour or so before landing in Nairobi an announcement was made that "Entry Declaration Form for the Republic of Kenya" was to be completed by all passengers prior to landing. Passengers who did not have a visa for Kenya were also required to complete the visa form.

Once the forms were completed, we began to assemble our belongings for an efficient and quick deplaning. Books went back into our carry-ons, final notes made in journals and itineraries, double-checked passports and entry documents, secured seat belts, and settled back for the landing. The excitement of arriving in Nairobi was at its apex. All of our preconceived notions and mental images of Africa were about to be confirmed or disproved.

After going through customs, which consisted of a passport and visa check, and submitting the "Declaration," we made our way to the terminal exit of the Jomo Kenyatta International airport. We were met by Francis Ngundu, our Nairobi Chapter President. Our Swahili lessons began immediately as he greeted us Kenyan style with a hearty Karibu (welcome). He tutored us on the appropriate response which is Asante (thank you). In addition to Swahili (Kiswahili), the sounds of Kikuyu, English, Dholuo, and Seng, a fast-growing Creole language of rappers, filter through conversations in restaurants, businesses, and on the street.

We were ushered outside to meet Bridgette with whom Francis had made arrangements for our car and driver. Before leaving for the hotel, we decided to exchange our currency while Francis was with us in case we needed any translation assistance. All went well as

we exchanged our dollars for Kenyan Schillings.

Although darkness had long settled over the city, we were able to glimpse distinguishing landscapes, landmark buildings, and other sites of interest. During the 20 km trip to the hotel, Francis used this opportunity to share with us some interesting facts about Kenya. He quizzed us on the meaning of "nyrobi" and I quickly responded that it was the Masai word for cool water. I was pleased that my research on Kenya had afforded me this opportunity to share my newfound knowledge.

Francis cautioned us to avoid using the matatu, minibuses which are the common means of transportation for locals. Often distinguished by body parts of passengers protruding from windows and doors and horns blaring as they dart in and out of traffic, the matatu is not considered a safe means of transportation for the novice or the faint of heart.

We were soon introduced to driving Nairobi style. The drive from the airport to the hotel was quite a harrowing experience. Unknown



to Stella and me at the time, it would become the norm. Only two main intersections in this capital city have traffic lights. There are quite a few roundabouts and the most aggressive and daring driver goes first. This was the first of many "white knuckle" excursions complete with closed-eyes, alarmed gasps, and palpitating hearts... Stella's and mine.

We arrived safely at the Holiday Inn at about 10:55 p.m. Francis remained with us throughout the check-in process and promised to get in touch with us the next day. As we made our way to our rooms, we saw a couple from the plane, Sal and Linda. After

THE AVRF GOES TO AFRICA Cont.

headed to our rooms and departed company for a well-deserved rest. The heavy security at the Inn was present at the entrance, on the grounds, and throughout the hallways on every floor. It was both comforting and yet unsettling that this level of security was necessary.

Although very tired, I unpacked and washed off the travel dust and then went to bed. Sleep was elusive. I turned on the television and watched a world news update. There were continuing reports of the bombings in Jordan. The current number of lives lost was at fifty-six. The racial rioting in France was in its second week and Liberia elected its first female head of state. My eyelids became heavy and the last sound I heard before succumbing to sleep was the serenade of croaking frogs coming from the pond outside my window.

It is Friday, November 11, 2005, and it is raining in Nairobi. My first call of the day is from Stella who shared with me that she had an early morning call from my husband, Bill, who was concerned that he had not heard from me. This explains the "dream" I had about the telephone ringing at three o'clock in the morning which I thought was a wrong number. Before ending our call, we made plans to meet for breakfast and begin finalizing plans for tomorrow's seminar.

Over a delicious breakfast of local fresh fruits, roasted plum tomatoes, muffins, eggs and tea, we plotted the activities for the day. We were scheduled to meet a local businessman and his wife for lunch to share with them the goals and accomplishments of the AVRF.

The next and most immediate item on our "to do" list was to meet with Joy, the hotel event planner. Once we located her office, we confirmed meeting room set-up, number of expected attendees, meals, and video equipment needs. Moving down the list we went to the Business Centre to rent a computer to send emails and cre-

ate documents needed for the seminar. This time was also used to advise loved ones of our safe arrival. Unfortunately, this news was just a little late for Bill.

Our luncheon hosts called for us at the hotel at eleven that morning. The drive to their home in the Westland's was about twenty minutes from the Inn. Most of the homes were protected behind high concrete walls with sentry-like attendants at the entrances. The home of our hosts was typical of the others we had seen. The driver honked the horn and the security gate opened and closed immediately once the car cleared the entrance.

To access the living quarters we took an elevator to the second



floor where our hosts provided us with tea and assorted finger foods. While their chef was preparing lunch we discussed several issues related to Vitiligo. We were soon escorted to a lavish dining room where we enjoyed a meal of curried vegetables, samosas, mint rice, tea, and assorted sweets. After several hours of enlightened conversation, we bade them farewell and their driver delivered us back to the Inn.

It rained most of the day. Francis met us in the afternoon and helped us with the

final touches for the seminar. By the time we arrived, the meeting room had been arranged to our specifications. A few minor amendments were requested and made. With all things in order for the seminar, we scheduled a few hours to shop and sightsee.

It's Saturday! Seminar Day! I have shared many wonderful, meaningful, and humorous details of our trip but the seminar is the milestone event – the purpose and focus of our journey. The seminar was scheduled to start at nine in the morning and Stella and I arrived at the meeting room early to do a final walkthrough and test the audio/visual equipment once again. We were both so excited. Although not mentioned between the two of us, we were also a little nervous. Would people really come and would it be meaningful to

THE AVRF GOES TO AFRICA Cont.

Francis arrived with his wife, Lisper, their children, Ann and Bruce, and his brother-in-law, Patrick. Stella, Francis and I greeted the seminar guests as they arrived and directed them to the table where tea, coffee, assorted baked breads, and other offerings were assembled. While waiting for the arrival of other guests, we mingled and got to know one another a little better. We learned that some had challenges getting to the seminar because of the lack of adequate transportation and the need to travel long distances. But they came!

Following a very long “get-acquainted” period, Stella officially opened the seminar. She introduced herself again and shared details of how and why the AVRF came to Nairobi. Each participant was asked to introduce himself or herself and share a little about their experiences. The introductions went well but not much personal information came forth.

Francis shared information about the Nairobi Chapter of the AVRF, and Stella presented more details about Vitiligo, what it is and what it is not. The attention of the participants was very focused and they clung to every word. After the video presentation the floor was open for questions. Some were raised and answered but not as many as we expected. It was a good time to break for lunch.

We all paraded to the restaurant at the Inn where we enjoyed a wonderful buffet lunch. I discovered what has become my favorite vegetable, sukuma wiki, a wonderful preparation of kale and spices which was a great accompaniment for the mashed potatoes and steamed rice. Other offerings included local fresh fruits and vegetables, salads, chicken, beef, and pork dishes. The beverage offerings were unique to Stella and me, Sparletta, Stoney Tangawizi, and Fanta.

The conversations at lunch created an ease between us which was evident when we returned to the meeting and reconvened the seminar. Lynette, a young university student, encouraged the other participants to take advantage of this learning opportunity. She inspired them to ask questions and share openly how Vitiligo has affected their lives and the lives of their loved ones. What followed were candid and emotional accounts of living with Vitiligo in Africa.

We heard the all too familiar chronicles of relationships that were severed or stymied because of Vitiligo. Incidents were related of passengers on public transportation who avoided sitting next to someone with this condition. Details were shared of experiences with co-workers who keep their distance. The devastating social alienation experienced when living with Vitiligo was also shared. Accounts of the stares were shared, always the stares.

Information on the effect of Vitiligo on children is complicated by child trafficking, child killings, and cults that prey on children. As a



result, parents are reluctant to publicly expose children with Vitiligo. Also, parents do not readily seek medical attention for their children because of the fear that Vitiligo is a caste disease.

Kenyans living with Vitiligo experience the same ignorance and alienation that many of us with Vitiligo do. However, there is the added challenge of living in a culture where many believe that people with Vitiligo carry the AIDS virus. Vitiligo is also believed to be a curse and, as such, there is nothing one can do about it. It was evident that all who attended the seminar are hungry for any information we have to share. And they all want a cure! This confirmed for Stella and me that it is imperative that the AVRF continue to raise issues of awareness, diversity, and education at every available opportunity.

We did in Nairobi exactly what we set out to do. We raised awareness and we educated. By the end of our journey every employee at the Inn, without exception, had been introduced to Vitiligo or gained more awareness about it. Each employee proudly donned the blue AVRF awareness bracelet. We had an impact on numerous others as well – other travelers, airline personnel, vendors, and hotel guests. It is clear that we must strengthen our mission in Kenya.

What we accomplished in Nairobi pales in comparison to what we gained. The people of Kenya are kind, gentle, gracious, and hospitable. They treated us like family. Some offered their homes and cars to us while we were there. Stella and I will miss them and their country. And the hugs we received and the tears that were shed as we departed were evident that they will miss us too. Kwa herini (good-bye). ■



American Vitiligo Research Foundation

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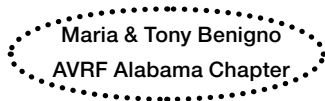


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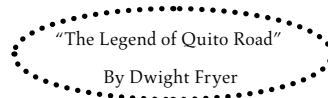
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American Vitiligo Research Foundation

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