



President's Report

When it comes to finding information about medical conditions the internet can be both a curse and a blessing. If "treatment for vitiligo" is entered into a search engine the most prominent results are advertisements for products claiming to provide a miracle cure based on unproven "therapies", from food supplements to "natural organic" creams. Many of these can be classified as scams, which prey on the desperation of vitiligo sufferers, giving nothing in return for payment except false hope.

But on the other hand, the internet is a valuable resource that can enable a person with vitiligo to learn about the latest treatment and research developments and even to be more informed about their condition than their doctor. The question is how can one find these reliable professional websites amongst the explosion of information now available to us at the touch of a keyboard.

I think that the best online resource

for vitiligo is the Vitiligo Research (VR) Foundation site based in the USA: www.vrfoundation.org The CEO of the VR Foundation, Mr Yan Valle, is a committed advocate for vitiligo sufferers, having the condition himself. For example, he managed to apply successfully for the VR Foundation to gain membership status of the United Nations Economic and Social Council. The VR Foundation website provides a glimpse into the activities of other advocacy and support groups not just in America but also around the world, and it provides through its newsletter and links up to date information about the state of various treatments and research. Yan himself is writing a "No nonsense guide" to be published online that will help those with vitiligo navigate through the minefield of treatment options. Disappointingly the VR Foundation had intended to publish an evaluation of over-the-counter and self-prescribed therapies, including vitamins, supplements and natural remedies, but were forced to abandon this

effort due to the potential threat of legal action from manufacturers of these products.

I would also like to point members towards the blog site of Dr John Harris, a dedicated vitiligo researcher based at the University of Massachusetts Medical School. Dr Harris is at the forefront of research into finding a targeted immune-based therapy for vitiligo and his research to date is considered ground-breaking by international experts on vitiligo. He is also a lovely fellow who had said that he is constantly thinking about scientific strategies to find a cure for vitiligo. He has recently posted updates on the use of JAK inhibitors and oral simvastatin in treating vitiligo:

www.umassmed.edu/vitiligo/blog

I am delighted to introduce Dr Jennifer Nguyen who is on the VAA Committee and has now taken over the role of the VAA Newsletter Editor, taking over from Dr Michelle Rodrigues who remains very involved with VAA



DONATE TODAY

CONTACTS

Like 2.7K

Follow @vrfoundation



VR Foundation™

VITILIGO RESEARCH FOUNDATION, NON-PROFIT 501(C)3 ORGANIZATION

TYPE TO SEARCH

SEARCH

Foundation

Researchers

Doctors

Patients

World map

How to help



VR FOUNDATION, A CONSULTATIVE MEMBER OF THE UN ECOSOC. DETAILS

SHORTCUTS TO YOUR HEALTH

NEWLY DIAGNOSED

Learn ABC's of Vitiligo.

LIVING WITH VITILIGO

Join our community

FIGHTING VITILIGO

Take part in online study now

DONATE AND SUPPORT

activities. Jennifer is also assisting with the Camouflage Project and she gives a progress report in this issue.

Lastly I would like to remind our readership of World Vitiligo Day, which is held on 25th June each year. This date has become a focus for activities that help to

raise awareness of vitiligo across the globe. I encourage you all to think of ways that we can help to promote public awareness of vitiligo, such as posting references to WVD using social media or getting involved in events organized by local groups to mark the occasion. Maybe you can start up an event yourself! If you are interested in getting involved,

contact the VAA.

I hope you enjoy reading this edition of the VAA newsletter.

Dr Adrian Mar
VAA President



VITILIGO
CLINIC & RESEARCH CENTER

UMASS Medical School
Department of Medicine
Division of Dermatology

Search Search All UMMS



Home

About

Vitiligo Clinic

Treatments

Research

Blog

In the News

Support Vitiligo

Vitiligo Resources

Vitiligo > Blog

"Speaking of Vitiligo..."



I am a physician-scientist who focuses my clinical and research efforts on vitiligo, and therefore I think about this disease a lot – all the time, in fact. Therefore I thought it would be helpful to share my thoughts with others who are interested in vitiligo as well, particularly the patients who suffer from it and their loved ones. I want to make clear that while I am affiliated with many vitiligo organizations, my comments in this blog are my own, and do not reflect the opinions of those organizations. In addition, my research is largely focused on finding new treatments, and ultimately a cure, for vitiligo. This work is supported by a number of sources, including pharmaceutical companies, which by definition creates potential conflicts of interest. In full disclosure, here is a list of our

[vitiligo research supporters](#). Please know that, to the best of my ability, all of my comments are unbiased reflections of my understanding of vitiligo as both a physician and scientist. I do not permit advertisements on my website, and do not endorse companies or products that may advertise on other sites that may be referenced here.



STATE-TO-STATE

REPORTS FROM STATES AROUND AUSTRALIA

WA

Dr Ali Didan

The major VAA events for Perth are the HBF run and the fundraiser dinner which is now held on World Vitiligo Day (25th of June). In last year's HBF run, the VAA team had walked the 4km category with a total of 6 people. It was a refreshing and motivational experience to be able to walk with

thousands of people of all ages. Some were using crutches and others on wheel chairs, but nothing was in their way to stop their determination and courage to completing the event. HBF run is a run for a reason. Our reason was to raise awareness and show support for those affected

by vitiligo. We also raised over six hundred dollars which contributed to a research grant. This year's VAA HBF team is still open for recruitment with details on our Facebook page and website. Currently we have seventeen participants which is the largest group to have participated in the Perth VAA HBF team.



The fundraiser dinner for this year is scheduled on the 25th of June at Allegro Pizza in Claremont. Last year's fundraiser dinner was very successful with at least 90 people attending and over \$2000 fundraised. The night was comprised of speakers on topics about vitiligo, punch grafting and members "Vitiligo Journey" which everyone enjoyed. We also had multiple prizes throughout the night and an auction of a few items. We are hoping to have a similar arrangement for this year's fundraiser dinner.



STATE-TO-STATE

REPORTS FROM STATES AROUND AUSTRALIA

NSW

Dr Monisha Gupta, Dr Richard Wittal, Ms Michelle Weaich

The Skin Hospital, Darlinghurst acquired an excimer lamp in June last year and we have already noticed some encouraging results.

A little over 1200 treatment sessions have been delivered over this period of time for various conditions including vitiligo – 45 patients; psoriasis – 2 patients; en coup de sabre – 1 patient; alopecia aerata – 1 patient; and lichen sclerosus et atrophicus – 1 patient.

Patient satisfaction has been high despite significant out of pocket costs being involved. We would like to push for VAA to advocate for treatment with the excimer lamp to be recognized as another method of phototherapy for Medicare billing and to be subsidised by the government.

Our Nurse, Ms Michelle Weaich, will be presenting on this topic at the upcoming Australian Dermatology Nurses Meeting in Sydney.

We are pleased to note that South Australia will be also offering this service in the near future and we hope to be able to collate an Australia wide experience.

Dr Monisha Gupta recently presented a talk on the topic of “Camouflage – an under utilized therapeutic option in Vitiligo” at the first Vitiligo International Symposium held in Rome, 2-3 September 2016.



THE SKIN HOSPITAL
A DIVISION OF SKIN & CANCER FOUNDATION AUSTRALIA

[Our Specialists](#)

[Services](#)

[Hospital Information](#)

[Mohs Surgery](#)

[Skin Conditions](#)

[Home](#) [Services](#) [Vitiligo & Hyperpigmentary Disorders Clinic](#)

Pigmentary Disorders and Vitiligo Clinic

The Skin Hospital is the first and largest Vitiligo centre in Australia.

Australia is evolving into a multicultural, multi ethnic society with growing numbers of racially pigmented ethnicities. With this increase in numbers we are seeing more cases of Vitiligo and Pigmentary disorders at The Skin Hospital as many people are suffering from conditions where there is a change in the colour of the skin.

Vitiligo is where the individual develops patches of depigmented (white) skin; melasma in which brownish patches develop on the cheeks, forehead and upper lips and post-inflammatory dyschromias where the skin heals with a change in skin colour following injury. In addition, skin diseases like **acne**, **eczema**, **psoriasis** and infections can also result in changes in skin colour. These disorders together are called Pigmentary Skin Disorders.

Along with Vitiligo and Pigmentary patients our Dermatologists also work closely with people with Albinism, offering subsidised consultations, presentations at their conferences and supporting other activities. This provides us with experience in managing two similar appearing conditions with different prognosis and complications.

In addition to a detailed history and examination at the clinic, ready access to pathology services is available so that biopsies and special stains can be performed and assessed quickly. Thereafter, medical treatments are tailored to the patient's needs.

Types of treatment options involved in our Vitiligo and Pigmentary Clinics includes:

- Medical therapies - topical/oral
- Onsite Phototherapy services - whole body cabinet and hand and foot unit.
- Photo documentation to assess progress is performed.
- Camouflage consultation - nurse led clinic available as a one off cosmetic consultation for \$55 and then \$25 for subsequent sessions.
- Laser Targeted UVB therapy
- Camouflage options

Surgical options, such as:

- Miniature Punch Grafting
- Recell
- Autologous Melanocyte Transfer (Westmead only)

In the future, we have planned that we will also be offering tattooing and onsite psychological counselling as well as Excimer Light treatment if we are successful in our current fundraising appeal.

- What is Dermatology
- Specialised Dermatology
- Biologics
- Chronic/Advanced Eczema Clinic
- HIV Skin Clinic
- Hyperhidrosis (Excessive Sweating)
- Female Dermatoses & Vulval Clinic
- Oral Medicine/Pathology Clinic
- Patch Testing Clinic
- Vitiligo & Hyperpigmentary Disorders Clinic**
- Skin Cancer Surgery
- Skin Cancer Surgery
- Plastic and Oculoplastic Surgery
- Corporate Skin Checks
- Corporate Booking
- Cosmetic Services
- Cosmetic Dermatology Services
- Facial Peels
- Muscle Relaxants
- Skin Fillers
- Laser & Light Treatments
- Laser & Light Therapies
- Ablative Laser
- Broadband Light Photorejuvenation
- Excimer UV-Light
- Fractional Laser

STATE-TO-STATE

REPORTS FROM STATES AROUND AUSTRALIA

SA

Dr Sachin Vaidya

A Vitiligo clinic in the Queen Elizabeth hospital was started in July 2016 and is headed by Dermatologist, Dr Sachin Vaidya. Autologous micropunch grafting is available at this clinic. Recently, an excimer lamp was also acquired by the clinic. This service will soon be available for patients with vitiligo.

The first Vitiligo Support Group meeting was held in late September last year in Adelaide. All attendees were updated on recent advances and also the difficulties in managing vitiligo.

Our Vitiligo Support Group is also planning to organise a charity dinner for World Vitiligo Day on 25th June.



VIC

Dr Adrian Mar

The Victorian branch of the VAA has decided to engage in some fund-raising activities at around the time of World Vitiligo Day. A VAA team is being put together to participate in the *Run Melbourne* event which is to be held on 30th July. A fund-raising cocktail party is also being planned, with details to be announced soon. All monies raised will go

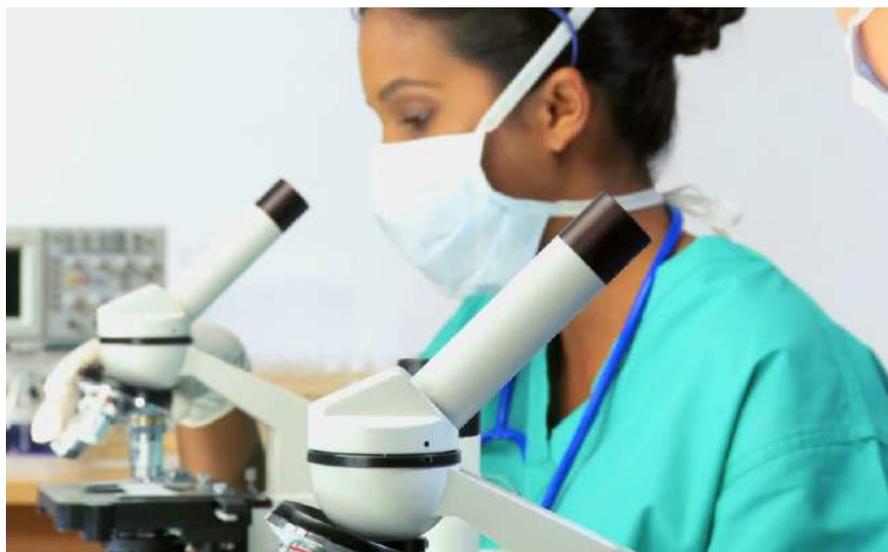
towards the VAA Research Grant project.

Any Victorians interested in joining these activities or helping to organize events with the local support group can contact the VAA at info@vitiligo.org.au



Vitiligo Research Grant

The VAA Committee is excited to announce that a research grant will be established to encourage local research into vitiligo. The grant will be to the value of \$2000 and the winner will be determined by an independent committee of the Australasian College of Dermatologists. The application process for the inaugural award will commence in late 2017 and details about the eligibility of applicants and key dates will appear on the VAA website. It is hoped that the VAA Research Grant will support much needed research within Australia.



Camouflage Road Testing

Camouflage products are useful to disguise skin depigmentation associated with vitiligo. Currently there are many products available for this purpose from everyday commercial cosmetic makeup and tanning lotions to products specifically designed for vitiligo camouflage. Depending on specific skin types and situations, these products when used correctly can provide a natural coverage over depigmented areas.

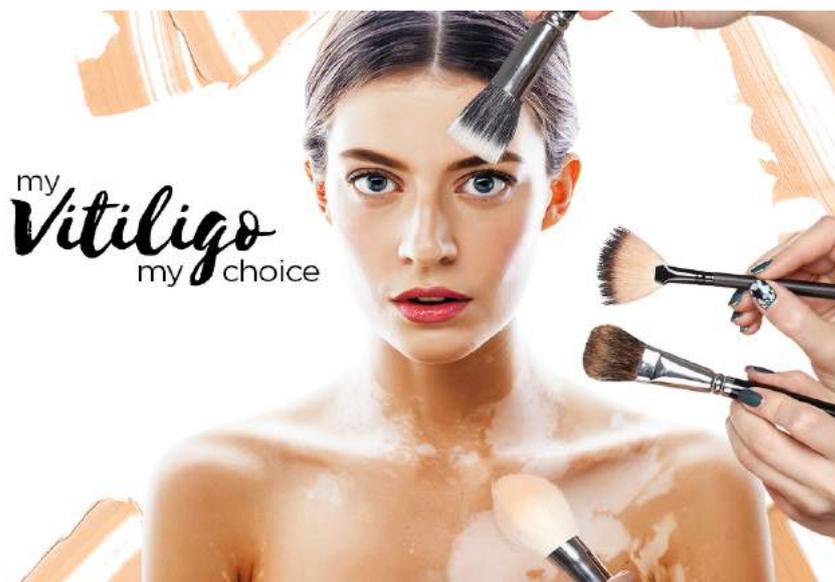
Currently there is very little information readily available which summarises and compares camouflage products used for vitiligo. As a result, choosing the right product is often an overwhelming and expensive task.

The VAA Camouflage Road Testing project aims to assist people with vitiligo to be more informed regarding camouflage products to better find a product that will suit their skin needs.

To achieve this goal, a team of independent advisors including make-up consultants, vitiligo nurses, vitiligo sufferers and doctors are currently working together to systematically assess over 30 camouflage products identified on the market. We are hoping to be able to acquire and test these products and will inform everyone when these results are available. The VAA has also put forth the project (as a proposed website

called "My Vitiligo, My Choice") as an application for the Galderma SkinPact Grant with hopes to acquire additional funding for the project.

Please note the VAA does not endorse any commercial products. If you have further inquiries about this project or if you are interested in being involved, please contact info@vitiligo.org.au



Upcoming events

6-9 May 2017

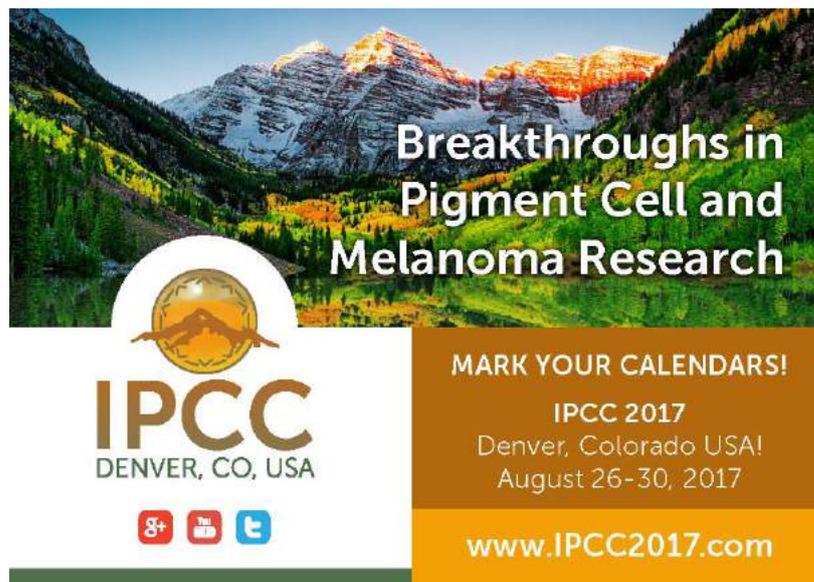
50th Annual Scientific Meeting of the Australasian College of Dermatologists (International Convention Centre, Sydney)

25 June 2017

World Vitiligo Day

26-30 August 2017

International Pigment Cell Conference (IPCC 2017) – “Breakthroughs in Pigment Cell and Melanoma Research” (Denver, Colorado, USA)



Meet the team

VAA Office Bearers

Dr Adrian Mar
(President)

Dr Ali Didan
(Secretary)

Mr Stephen Niederberger
(Treasurer)

A/Prof Prasad Kumarasinghe
(Immediate Past President)

VAA Committee

Ms Lisa Brown
Dr Michelle Rodrigues
Dr Desmond Gan
Dr Jennifer Nguyen
Dr Richard Wittal
Dr Aesha Gupta
Dr Monisha Gupta
Ms Tanya Tyler
Dr Shobhan Manoharan
Dr Sachin Vaidya

Newsletter team

Jennifer Nguyen (Editor)
Adrian Mar

Faye Collay
James Tammesild
James Gilbert

JOIN THE CONVERSATION



Vitiligo Association of Australia



vitiligo.org.au