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# Feature article: Pia Miranda's story

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By Tia Fijalkowski and Lauren Jimmieson



Hi, I'm Pia and I was diagnosed with vitiligo at age 46 which was just over a year ago. I was born in Melbourne, Australia. This is where I currently live although I spent some of my childhood in Darwin and Canberra. I grew up as a ballet dancer but transitioned to acting in my late teens. I studied at Victoria University and at The Atlantic Theatre company in New York City and I have been working as an actor and voice over artist since then, somewhat sporadically because most actors spend a lot of time out of work!

My heritage is half Italian/half Australian. My family on my Australian side have a history of autoimmune conditions with my mother and aunt both having alopecia, and my grandmother having psoriasis. I guess I always thought that I too may get alopecia,

so being diagnosed with vitiligo wasn't a huge surprise to me, although I do still worry about alopecia as I know sometimes the two co-exist.

I developed vitiligo whilst playing Survivor which makes sense as the mental and physical challenges are extreme. Dealing with the elements, feeling cold, sleeping in the dirt combined with the mental anguish that it creates is probably a perfect storm for an autoimmune condition. It was weird because we had no access to mirrors, so I didn't see it happening in real time. I was told about it and got to see it eventually near the end of my time there. I just thought it must have been a fungus or something from sleeping in the dirt. I remember thinking how odd it was that I suddenly had grey eyebrows, but I didn't connect the two at the time.



When I came home I went straight to a Dermatologist who referred me to Michelle at Chroma Dermatology. She put me on a mix of tacrolimus and narrowband UVB therapy 3 times a week. I was getting pretty aggressive flare ups for the 2 months that I was back but

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as my body started to settle and it began to slow down. The treatment was pretty exhausting, but I stuck with it and I'm glad I did, although I felt like a fried chicken nugget when it was over!



I saw a Naturopath for my gut, did yoga and acupuncture which made me feel more settled. I know that doesn't work for everyone, but it calmed me down as I was dealing with a lot of stress and anxiety. I felt like I was on a train I couldn't get off and googling made me feel worse. I couldn't stop because I was looking for answers. It was the worst. Also, as Survivor was screening I was watching reliving it all... it was like

watching the old me disappear and a new me appear, all on TV in front of an audience. I felt like I went through a mourning process watching it and initially I was embarrassed and ashamed, because everyone else looked fine out there and I felt abnormal. I felt sad that I didn't get the time to deal with it in private but once I went public with it, I was so heartened by the support I received. So many people came forward and shared their personal stories of vitiligo with me and everyone was so kind and supportive, so instead of feeling shame, I actually felt inspired. I was also grateful that my eyes had been opened to a new awareness of beauty and privilege.

I had spent so long in an industry that perpetuates a narrow-minded view of beauty and is so dismissive of people who don't fit the mould. I had spent most of my career trying to fit into this unattainable imagery and I was so busy trying to conform to it that I was oblivious to how this attitude affected the wider community. Now I feel I can truthfully be a voice of change, as I have first-hand seen the amazing people that are disregarded because they don't fit a prototype. I think the more our children grow up seeing differences as something to embrace, the healthier our attitudes will become. We have a pretty unhealthy view of beauty in our society at the moment and I feel like I was complicit in this for a long time by trying to conform to it. I guess being thrust into this in a public arena has helped me mentally, as there was a time when I was worried that my career was over because of vitiligo but now I see vitiligo as a blessing rather than a curse.



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On the subject of treatment, I have had good results and re-pigmented quite a lot, I still have patches, but most have pigment to some degree rather than being completely white. I have a combination of hyperpigmentation and vitiligo so I'm quite patchy but I'm at the

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point now where I don't wear makeup every day and although a lot of that is to do with my treatment results, mostly it's a mental change. I still have days when I'm scared, and I feel alone or I see friends with perfect skin and I feel envious but most of the time I'm OK. I think about my kids and the guilt I will feel if they too get an autoimmune condition, but I'm working through that and hopefully I'll have the tools to be a positive influence if it does happen. I still check my face first thing in the morning and I sometimes panic if I look at myself in a new lighting situation and see something different, but I know that's all part of my journey.

To anyone struggling I would say don't be afraid to reach out. It's been the support of strangers, doctors and new friends that have gotten me through. Every kind word will help. Stories of hope and stories of acceptance will help. I think it's hard because there are no



decisive answers about how it is going to play out and every story is different but getting support from other people with vitiligo helped me a lot. Some days are good some are bad but there is no need to go through this alone. There are support groups available online and please feel free to reach out to me on social media.

Oh and don't google!! I learnt the hard way!



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# Slip! Slop! Slap! Seek! Slide!

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It's summertime again and we can often forget to 'Slip! Slop! Slap! Seek! Slide!' while enjoying our time in the sun. However, it is very important to protect your skin especially in areas with vitiligo which are more prone to burning. Tanning of the skin can also cause the white patches to stand out more due to the contrast of the tanned skin and the depigmented areas.

SunSmart advice from Cancer Council Australia includes:

1. Slip on covering clothing such as long sleeves or collared shirts
  2. Slop on sunscreen – at least SPF30+ broad-spectrum water-resistant sunscreen is ideal. Apply a generous amount at least 20 minutes before going out and re-apply every 2 hours after swimming or excessive sweating.
  3. Slap on a hat
  4. Seek shade
  5. Slide on some sunglasses
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# Camouflage workshop

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The Vitiligo Association of Australia hosted the Camouflage Workshop online this year. The workshops were held over two days on 25<sup>th</sup> July and 1<sup>st</sup> August 2020. We had camouflage experts locally and internationally speak to us including Joanna Blair from the School of Makeup in Australia, Julie Buckley from Colourderma Solutions and Hair and Vanessa Jane Davies from the Skin Camouflage Services in London. We also had company representatives including Polly Gotschi from Oxygenetix, Rae Denman from Veil, Rajja Richani from Kryolan and finally Michelle Weaich who is a nurse from the Skin Hospital in Darlinghurst, spoke to us about Zanderm. We are very grateful from all the speakers of the event who have shared their expertise and knowledge and a special thanks to Cameron who shared his story of vitiligo and camouflage on the night.

There were wonderful discussions and members were able to learn about the history of camouflage, camouflage products available, tips and tricks and the opportunity to ask experts questions. There was a strong message throughout the workshop that camouflage is all about empowering patients and provide the choice to anyone who would like to conceal their vitiligo areas. What matters most is for patients to feel comfortable and beautiful in their own skin. We look forward to continuing the VAA Camouflage Workshop next year so please do join us.



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# VAA Research Grant

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In June this year, the VAA was proud to announce the successful applicants of its first ever research grant of \$2000 to support research that contributes to a better understanding of vitiligo. The grant was open to health professionals and students, including medical or nursing, junior doctors, specialists and allied health professionals. There were two excellent applications and the VAA decided to provide both applicants with a grant towards their research projects. The funds for the grants were raised through the VAA's fundraising activities. The successful applicants and their research project were:

**Dr Brent Doolan (Dermatology Research Fellow, The Skin Hospital, Darlinghurst NSW):**

“Doolan BJ, Weaich M, Gupta M. An analysis of patient satisfaction in a pigmentary disorders clinic from a quaternary referral service. *Australas J Dermatol*, [In Press], doi: 10.1111/ajd.13397.”

Patient satisfaction is the major indicator of quality of care provided by a health facility. In 2012, Australia's first specialised pigmentary disorders clinic was established at The Skin Hospital, Darlinghurst to help manage difficult-to-treat conditions such as vitiligo. We aimed to assess patient satisfaction of this service by identifying areas of dissatisfaction and attempting to further improve the pigmentary disorders clinic. Using a Patient Satisfaction Questionnaire, we were able to ascertain good overall satisfaction with the service, as well as areas to improve. This study highlights the need for a referral service for GPs and dermatologists and the need for a dedicated pigmentary disorders clinic in the Australian setting.

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“A retrospective evaluation of patient profiles and treatment modalities used within an Australian pigmentary disorders clinic”

Currently in Australia, there is limited data on the demographics, quality of life, blood investigations and effective treatments used for patients presenting with pigmentary disorders, especially in the management of vitiligo. Treatment is largely based on data obtained from overseas studies and international clinical trials. We wish to perform a review of over 600 patients with pigmentary disorders from The Skin Hospital, Sydney to better understand this patient group. This landmark study is the first to investigate the profile of pigmentary disorders patients in Australia. The knowledge of clinical characteristics, associations and current treatment modalities may help improve management among this cohort and aid in determining if additional services are required in Australia.

**Dr Jennifer Nguyen (Dermatology Research Fellow, Occupational Dermatology Research and Education Centre, Victorian Melanoma Service, Dermatology Department Alfred Health, Vulval Dermatology Royal Women’s Hospital, Melbourne VIC and Vitiligo Association of Australia Committee Member):**

“Use of Camouflage Therapy in Vitiligo: a survey for Dermatologists and Patients”

Vitiligo is a depigmenting skin condition that can affect any area of the skin. Individuals with vitiligo often experience significant psychological and social impacts. Currently, medical treatments available for vitiligo includes topical or systemic immunosuppressants, phototherapy or surgical grafting though results are often delayed or unsatisfactory. Camouflage therapy involves the use of pigments and dyes to temporarily conceal vitiligo and has been recognised to improve self-esteem and quality of life in adults and children with vitiligo. Despite this, there is limited information regarding camouflaging products for vitiligo and its general use by dermatologists and patients for vitiligo. This project will aim to investigate the current accessibility, usage, perceptions and barriers regarding camouflage products for vitiligo patients and dermatologists around the world. Results of this survey will allow for better understanding into the awareness and attitude to camouflage therapy for vitiligo patients.

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# Recent Research in Vitiligo

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*Thomas KS, Batchelor JM, Akram P et al; UK Dermatology Clinical Trials Network's HI-LIGHT Vitiligo Trial Team. Randomised controlled trial of topical corticosteroid and home-based narrowband UVB for active and limited vitiligo - results of the HI-Light Vitiligo trial. Br J Dermatol. 2020 Oct 2 (United Kingdom)*

A randomised controlled trial with adults and children compared the treatment outcomes of topical corticosteroid alone vs narrow band UVB vs combination of topical corticosteroid and narrow band UVB. Results from 517 participants showed combination therapy with topical corticosteroid and home based handheld narrow band UVB is superior to monotherapy.

*Narayan VS, Uitentuis SE, Luiten RM, Bekkenk MW, Wolkerstorfer A. Patients' perspective on current treatments and demand for novel treatments in vitiligo. J Eur Acad Dermatol Venereol. 2020 Sep 7. (Netherlands)*

A prospective survey was conducted on 325 patients with vitiligo from the

Amsterdam University Medical Centre to assess patient's perspective on current and novel therapies for vitiligo. A majority of patients (94%) believe new and improved treatments are needed and 86% are interested in participating in clinical trials for a new therapy. Approximately 50% of participants were not satisfied with the outcome from current available treatment. Patients with facial lesions and of darker skin types reported greater burden from vitiligo.

*Peterson D, King B. UVL in combination with other therapies for vitiligo: synergy or necessity? J Am Acad Dermatol. 2020 Sep 3:S0190-9622(20)32584-6. (United States)*

This paper suggests ultraviolet light therapy in combination with other therapies such as topical corticosteroid, topical calcineurin inhibitors and systemic therapy is more effective than monotherapy. Ultraviolet light helps to reverse the depigmentation in vitiligo and therefore works synergistically when used with other therapies.

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Nofal A, Fawzy MM, Alakad R. *Trichloroacetic Acid in Different Concentrations: A Promising Treatment Modality for Vitiligo. Dermatol Surg.* 2020 Aug 18. (Egypt)

A prospective study of 100 patients with acral and non-acral stable vitiligo to evaluate the effect of trichloroacetic acid. The trichloroacetic acid was applied every 2 weeks until complete repigmentation (maximum of 6 treatments). Excellent response was observed in 80% of cases of eyelid vitiligo, followed by the face, trunk and limbs. Vitiligo affecting the hands and feet showed the lowest response rate.

Mahajan VK, Verma YR, Mehta KS, et al. *Adults with a more extensive body involvement, moderate to extremely severe vitiligo and a prolonged clinical course have an early onset in childhood in addition to other prognostic factors as compared to individuals with later-onset vitiligo. Australas J Dermatol.* 2020 Aug 18. (India)

This retrospective study reviewed 408 medical records of adults aged 20-75 years old who were diagnosed with vitiligo between January 2016 to December 2019. Results of this study shows that patients with early onset of vitiligo were more likely to be males and had higher body surface area involvement, more severe disease and longer disease duration.

Bishnoi A, Vinay K, Kumaran MS, Parsad D. *Oral mycophenolate mofetil as a stabilizing treatment for progressive non-segmental vitiligo: results from a prospective, randomized, investigator-blinded pilot study. Arch Dermatol Res.* 2020 Jul 31. (India)

This prospective, randomised investigator blinded study of 50 patients with active

vitiligo were randomised to group A (received oral dexamethasone 2.5mg on two successive days a week) and group B (received mycophenolate mofetil for 180 days). Results from this study showed 20 patients in group A and 18 patients in group B had disease activity arrest with treatment. Relapse rate was higher and occurred earlier in group B which received mycophenolate. Both dexamethasone and mycophenolate minimally induced repigmentation.

Rosmarin D, Pandya AG, Lebwohl M et al. *Ruxolitinib cream for treatment of vitiligo: a randomised, controlled, phase 2 trial. Lancet.* 2020 Jul 11;396(10244):110-120. (United States)

A multicentre, randomised, double-blind phase 2 study of 157 patients across 26 US hospitals and medical centres in 18 states assessing the efficacy of ruxolitinib cream compared to placebo in patients with vitiligo. Patients with vitiligo involvement of 0.5% or more of the facial area or 3% or more of the non-facial area were randomly assigned to receive ruxolitinib cream (1.5% twice daily, 1.5% once daily, 0.5% once daily or 0.15% once daily) or the vehicle only. Ruxolitinib cream particularly applied at 1.5% once and twice daily was associated with substantial improvement of vitiligo lesions.

Wen Y, Wu X, Peng H, Li C et al. *Cancer risks in patients with vitiligo: a Mendelian randomization study. J Cancer Res Clin Oncol.* 2020 Aug;146(8):1933-1940. (China)

The association of vitiligo to different cancers was assessed in this Mendelian randomisation study involving 246,706 cases and 1,021,154 controls. Results showed vitiligo is associated with reduced

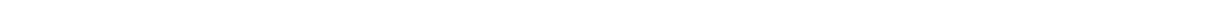
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risks of multiple cancers including lung cancer, breast cancer, ovarian cancer, melanoma, non-melanoma skin cancers, kidney cancer and liver cancer.

*Bassiouny D, Hegazy R, Esmat S et al. Cosmetic camouflage as an adjuvant to vitiligo therapies: Effect on quality of life. J Cosmet Dermatol. 2020 May 13. (Egypt)*

A study using the Dermatology Life Quality Index to assess vitiligo patient's perspective of camouflage as an adjuvant therapy. 100 patients with vitiligo were assessed and 40 patients were randomly chosen and advised how to apply camouflage and followed up one month after regular application. Patients who were showed how to use camouflage showed significant reduction in their Dermatology Life Quality Index score.



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# Would you like to be a part of a support group for children with vitiligo?

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When I was a child, resources and access to support simply did not exist for kids with vitiligo. The Vitiligo Association of Australia is ready to change this. My name is Lauren and I have dedicated my career to working with children through entertainment, play therapy and educational theatre. I also have vitiligo. It's time we join forces and create a support network for kids with vitiligo. Would you like to take part and share your ideas? I'd love to hear from you. To kick start this movement, my partner Anthony and I have used our platform, Story Surprise, to create an episode dedicated to unique kids! A huge thank you to Danielle Wheeler and Nick Davio for granting us permission to use their resources to bring this episode to life. The book and song 'I've got Spots' was featured in the Story Surprise episode being released on YouTube, Instagram and on to the VAA Facebook page on Thursday 25<sup>th</sup> June – World Vitiligo Day! Enjoy!

Instagram – The Lauren and Anthony Gram:

<https://www.instagram.com/the.laurenandanthony.gram/>

YouTube – The Lauren and Anthony Tube:

[https://www.youtube.com/channel/UC6\\_1T-jbpQXSNmQLtRe50MQ](https://www.youtube.com/channel/UC6_1T-jbpQXSNmQLtRe50MQ)

If you would like to chat about bringing the support group for kids to life, please contact me at [lauren.kidsupport@vitiligo.org.au](mailto:lauren.kidsupport@vitiligo.org.au) and we can get the ball rolling!

--Lauren Jimmieson



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# VOLUNTEERS NEEDED

- Are you interested in helping others with vitiligo?
- Are you a good organiser?
- Do you have specific skills that could benefit the VAA?



The VAA needs enthusiastic volunteers to help at a national or local level.  
If you would like to help out, please contact Adrian Mar at [president@vitiligo.org.au](mailto:president@vitiligo.org.au)

***Help to make our association even better!***

## JOIN THE CONVERSATION



Vitiligo Association of Australia



[vitiligo.org.au](http://vitiligo.org.au)