



Vitiligo
Association of
Australia

National Newsletter

Winter 2020



WORLD
VITILIGO
DAY
AUSTRALIA

June 25th 2020

Tia's story

As Lauren Jimmieson shares

Hi there, it's Lauren Jimmieson from *The Jimmie Journal*. To celebrate World Vitiligo Day, I have the privilege of sharing a wonderful tale of finding confidence and embracing the challenges life can throw your way.

I met Tia a year ago. Tia is vivacious and beautiful inside and out! Like me, she developed vitiligo during her childhood. Although the road to acceptance hasn't always been easy, Tia has a powerful vitiligo story to share and a passionate message to inspire others! Tia's experience resonates with me personally and therefore, I'm sure others in the vitiligo community will feel similarly. It's fantastic to see how Tia's mentality has adapted as she has grown, and how this has shifted the perspectives around her. At the end of this feature, I'm sure you'll agree that Tia is a fantastic role model for young people. Not just young people with vitiligo! In fact, reading about Tia's strength will inspire any



young person facing an internal struggle of acceptance. Thank you, Tia, for being so open and candid with me!

It's an honour to help you share your message.

This is Tia's story.

Surprise, you have vitiligo!

At three years old, a small white patch appeared on Tia's wrist and remained unchanged. This didn't cause concern or impact Tia much at all. Things changed when Tia was sixteen. Being a teen can be challenging at the best of times. While facing her year ten studies, the vitiligo spread without warning. Significant patches developed around her eyes and mouth while smaller ones presented on her arms, legs, stomach, ribs, feet and neck. For a teenage girl, Tia describes this as a 'worst nightmare'. This is a feeling I remember all too well. Like myself, Tia found it difficult to accept the change. Her unique skin earned her attention that left Tia outcast and self-conscious.

Haters Back Off!

During her time with vitiligo, Tia has endured hateful and abusive comments and been shamed because of her unique skin. Unfortunately, this experience is shared by so many others with vitiligo. Tia has experienced countless interactions on trains where she has received displeased looks, rude comments and even people shifting to be away from her. People have questioned whether her patches were scars from a chemical burn. She's been asked if she will be stuck this way forever! Although she tries to not let other's uneducated thoughts and opinions get the better of her, inevitably these moments stick with a person and Tia says the negativity plays on her mind during tougher days.

These difficult interactions made Tia feel very self-conscious. She

became reluctant to make new friends, afraid of what they might be thinking. With time, Tia found people her age were fairly quick to accept her unique skin. It was actually people of older generations who were reluctant and more cautiously curious. In Tia's experience, she found adults viewed her vitiligo negatively and she feared these people wouldn't accept her befriending their children.

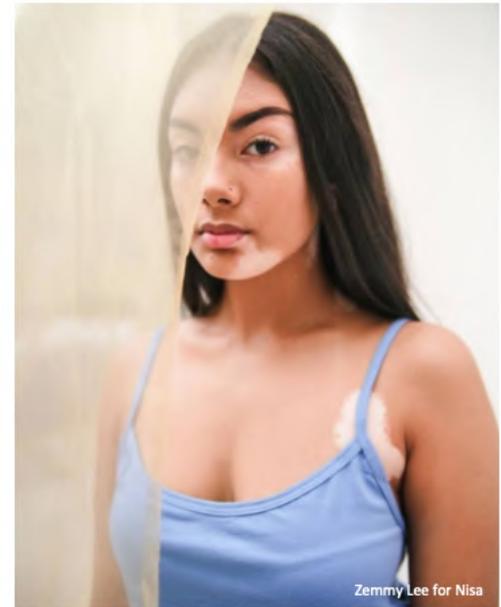
Finding acceptance at home

Tia says that it took her family time to accept her changing appearance. In the early days, Tia says her family strongly encouraged her to seek treatment and to cover her spots. At the time, Tia felt hugely impacted by this. Deep down she didn't want any treatments but felt the pressure to pursue this option so she could feel accepted by society. Extended family would often question Tia's mother about the condition which further planted seeds of self-consciousness in Tia.

"I wanted to make my parent's proud and I felt I never could because of my skin."

In hindsight, you can reflect and understand that questions and conversation instigated by family come from a place of concern and an effort to do everything possible to help that child. However, Tia struggled while she tackled her teens and the mountain of uncertainty that came with her changing skin. She interpreted her family's questions and concerns as a lack of acceptance. For as long as she felt the network around her didn't accept who she

was, it was impossible for Tia to accept herself.



With a little help from friends

When Tia's patches became noticeable, she felt people's eyes watching her and analysing her unique appearance. Most of the time she covered her spots with makeup in an attempt to conceal them from her peers. On one occasion, she woke late for school and was unable to apply her coverage in time. That day, she attended school uncovered. She was anxious about others' reactions and how this may affect her friendships. I can tell you from personal experience that the weight of these worries isn't something any teen should have to add to the mounting pressures of adolescence. This stressful predicament was a blessing in disguise for Tia as it presented an opportunity for her friends to recognise her unique beauty. On that day, Tia's friends showed her just how supportive they could be! Tia says that this moment helped her recognise her beauty,

although it took her a long time to wrap her head around it.



I relate to this experience in Tia's story. The ability to secure a safe support network of understanding, compassionate friends and family can make or break your mental health when times are tough. Sometimes, welcoming this network's support is easier said than done. Tia should be commended for allowing herself to let others in during these more difficult times. That takes great strength!

Shifting your Mindset

In the early days, the sudden development of Tia's vitiligo triggered anxiety and depression. She went to great effort to conceal her skin, became paranoid about other people's opinions and questioned why she was 'cursed'. Tia felt unworthy of happiness. She did not feel beautiful or confident. Tia believed that she could never be accepted as long as she had vitiligo.

"I personally felt that I had let down my family, believing

that no one would want a child or sister looking how I did and feeling as if I had become a burden to my family with constant doctors' appointments and treatments"

Tia befriended a boy at a social dance. Sometimes, Tia socialised with him with her patches uncovered. It took a mammoth effort to surpass the hurdle of fear and anxiety this brought her. The bond she found with this person allowed Tia to feel comfortable in his presence. Finding someone who passionately and openly celebrated her uniqueness helped Tia build her confidence. Although there were still plenty of bad days shadowed with negative thinking, slowly, she started speaking openly about her condition. Over time Tia developed a strong support network. This network included the school councillor who assisted her along the way. This support instigated a shift in Tia.

When Tia began year eleven, she decided to change her attitude and her mindset around vitiligo. Instead of focusing on outside opinions, she zoned in on self-acceptance. Deep down, she felt it was pretty cool to be a part of a special group only affecting 1% of the world.

"Once I began to embrace it and accept this about myself, I saw that others also changed their views on me."

Tia's family noticed this change in her and supported her efforts to embrace her uniqueness. Being a young person with a challenging

condition, Tia saw the opportunity to inspire others. She hopes sharing her story with the Vitiligo Association of Australia will continue to do just that – inspire and motivate you to love the skin you're in.

"Although this condition does not define me, it helped created the person I have become today. My vitiligo brought me a new-found confidence and enabled me to be proud of my looks."



Zemmy Lee for Nisa

Confidence Renewed

At fifteen years old, Tia began modelling. This career path came to a standstill when her vitiligo developed, and her confidence was lost. Her new perspective opened up opportunities. At seventeen years old she stepped back into the spotlight, collaborating with photographers and brands including Kings Cove, GMS X MID, DRMAT to name a few. This year, Tia signed with JR Management. Recently she has worked with Nisa women,

Waxclub and Living Dappled who published her first article on her vitiligo and modelling journey. Tia looks forward to continuing to build her modelling career while she uses her story and positive attitude to influence and inspire young people around the world.

Tia, thank you for being so bold and embracing your spots. By doing so, you have shifted the perspective of those around you and assisted others to broaden their own thoughts on the constructs of what defines beauty. It is the confidence you have within that has encouraged others to let down their walls and change their thinking, behaviour, language and approach. Your openness gives others the freedom to ask questions and be honest, to keep communication free flowing and therefore, to educate the community around you.

I hope Tia's story has brought a smile to your face and ignited a passion in your heart. I know it certainly did for me! What better way to wrap up today's story than with a special message straight from Tia, in her own words...

Tia's Message

"My vitiligo has become one of my favourite features and I now can gladly say that after 3 challenging years I am proud to be classified as unique. It also changed my perception on the world, and I focused less on my own and others physical appearance and began to find beauty in all unique things. Having vitiligo means I have a face someone always remembers. I am transitioning from fitting in to standing out. I won't lie, getting to the stage of accepting my unique skin was not easy and there were a lot of bumps along the way. There are days where I love my skin and still occasionally days where I want to scream. I am at a stage where I want to share it with the world and reach out to others who are struggling to embrace it. Vitiligo turns an ordinary human into a walking piece of artwork. I want to inspire others and help them see the beauty in this condition. I am so blessed to have such a strong support group who helps me further embrace my skin and reminds me that although I am not the standard definition of beauty, I am still beautiful in my own unique way. To this day, I am still challenged by some hurtful comments, but I try to let the positivity I receive from embracing vitiligo outshine the negative. When I see others with vitiligo, I see art, uniqueness, beauty and pure blessings in disguise. I hope

to create a community where everyone can help each other get through the rough times. A small support group for those who need a push when it comes to finding their inner beauty and confidence.



I hope I can inspire others and let them know that they are not alone. They are special, and everyone wants to be special!"

Instagram: @tiafijalkowski

The VAA invites members to submit their story to feature in the newsletter, if you are interested please email secretary@vitiligo.org.au.

We would love to hear from you!

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

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 the VAA Facebook page on Thursday 25th 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

If you would like to chat about bringing the support group for kids to life, please contact the Vitiligo Association of Australia and we can get the ball rolling!

--Lauren Jimmieson



COVID-19 and Vitiligo

The COVID-19 pandemic has raised many health concerns across the globe. An important question that is often asked is: *Does vitiligo increase the risk of contracting COVID-19 or potentially worsen health outcomes?*

Associate Professor John E. Harris, Director of the Vitiligo Clinic and Research Center at the University of Massachusetts Medical School has eloquently addressed these concerns in his recent blog post. The blog post is available from the following link https://www.umassmed.edu/vitiligo/blog/blog-posts/2020/03/coronavirus/?fbclid=IwAR1rLQBuANtPwPgDi5_dQsrUtOWcu0mpiGXWoQ1Fa73ptt1maE22A4KDQcQ.

To summarise his post, from current knowledge on vitiligo and its management the general answer to this question is no. From a disease perspective, vitiligo is an autoimmune condition which causes the focal destruction of melanocytes. For the majority of vitiligo sufferers, the immunity against infections such as COVID-19 should not be affected. Vitiligo sufferers with co-existing Common Variable Immunodeficiency Syndrome can in theory have increased risk of COVID-19, but these cases are tremendously rare. Additionally, in most cases topical and oral management options for vitiligo should also not affect immunity against COVID-19 and it is important to relay your concerns directly to your doctor in regard to specific managements.

Another valuable resource for all patients is the Australasian College of Dermatologists website which is available from the following link <https://www.dermcoll.edu.au/covid19updates/for-patients-and-community/>. The Australasian College of Dermatologists has provided information regarding risks in patients and in specific patients receiving immunosuppressants or biologics as well as links to further information from the government.

We encourage everyone to practice social distancing and adequate hand hygiene to minimise any risk of obtaining the infection. Please do not hesitate to reach out to us and we hope everyone remain safe during this time.

The History of Vitiligo

In view of the recent World Vitiligo Day, we thought to revisit the history of vitiligo.

The word 'vitiligo' is believed to originate from the Latin term 'vitium' which translates to 'blemish'.

Descriptions of 'vitiligo' like lesions date as far back as 1500 years BC in Ancient Egyptian and pre-Hindu Vedic texts. Throughout history, vitiligo is often confused with leprosy which also exhibited pale patches on the skin¹. Due to this, stigmatisation was targeted at vitiligo sufferers. It was not until the end of 19th century, when a Norwegian physician established a distinction between the two diseases with the observation of "small rods in lepre cells" which was absent in vitiligo¹. Further progression in

understanding vitiligo was also made during this time, with Hungarian physician and dermatologist Moriz Kaposi describing the histopathology of vitiligo as a "lack of pigment granules in the deep rete cells". Initial treatments used included plants containing psoralen which were applied to the skin as well as exposure to sunlight, proving conceptually similar to modern day treatment.

Today, there are efforts all over the world to raise awareness for vitiligo. Organisations, support groups and individuals across the globe work together to make a difference to change the stigma that surrounds vitiligo and provide support for vitiligo sufferers. Ongoing studies in vitiligo continues as researchers all over the world further understand the

pathophysiology of vitiligo and aim to develop new targeted treatment.



Recent Research in Vitiligo

Ongoing efforts in understanding vitiligo and its management continues. Below is a summary of some interesting recent published articles in relation to research in vitiligo.

Anbar TS et al. Clinical evaluation of interrupted versus continuous narrowband ultraviolet B phototherapy in non-segmental vitiligo treatment: A prospective randomized comparative study. Dermatol Ther. 2019 Nov;32(6):e13117.

A randomised prospective study comparing the effectiveness of interrupted versus continuous narrowband UVB in 23 patients with non-segmental vitiligo. Results showed that re-pigmentation continued even after ceasing phototherapy and results from the interrupted group was similar to continuous group. This study suggests interrupted NB UVB can provide adequate re-pigmentation and offer benefits such as encourage patient compliance and reduce side effects.

Tkachenko E et al. Patient satisfaction and physician productivity in shared medical appointments for vitiligo. J Am Acad Dermatol. 2019 Nov;81(5):1150-1156.

Share medical appointment (SMA) involves review of multiple patients with a similar diagnosis simultaneously by a medical practitioner. This review approach was well received compared to traditional appointment and allowed more patients to be seen monthly.

Arora CJ et al. The efficacy and safety of tacrolimus as mono and adjunctive therapy for vitiligo: A systematic review of randomised clinical trials. Australas J Dermatol. 2019 Jul

This systematic review and meta-analysis suggest combination therapy with tacrolimus and narrowband ultraviolet B phototherapy produces better repigmentation rates compared to NB-UVB alone. Tacrolimus and steroids also had similar rates of repigmentation. Fractional laser combined with tacrolimus had similar potency with tacrolimus alone.

Rahimi H et al. Hearing status in patients with vitiligo. Clin Cosmet Investig Dermatol. 2019 Jul 21;12:445-450.

A case control study involving 53 patients with vitiligo and 52 age and sex matched control subjects. The aim of the study was to ascertain if there was a difference in pure tone audiometry and distortion product otoacoustic emission. Results showed there was no difference between the two groups and vitiligo patients have normal hearing.

Liu B et al. Home vs hospital narrowband UVB treatment by a hand-held unit for new-onset vitiligo: A pilot randomized controlled study. Photodermatol Photoimmunol Photomed. 2019 July [epub ahead of print].

100 patients with limited new onset vitiligo were involved in comparing home NB-UVB phototherapy versus hospital-based NB-UVB. Results

showed that home phototherapy was as effective as hospital and also offered the benefit of reduction in costs and better compliance. However, education on use and monitoring for adverse events should be advised to ensure safety of the home phototherapy.

Vallerand IA et al. Vitiligo and major depressive disorder: A bidirectional population-based cohort study. J Am Acad Dermatol. 2019 May; 80(5): 1371-1379.

The relationship between major depression disorder (MDD) in precipitating the onset of vitiligo was studied. Results showed that patients with MDD had 64% increase risk of developing vitiligo with the risk reducing with antidepressants. For patients with development of vitiligo, a diagnosis under the age of 30 had 31% increase of developing MDD compared to 22% in patients diagnosed after 30 years of age.

Sawant NS et al. Gender Differences in Depression, Coping, Stigma and Quality of Life in Patients of Vitiligo. Dermatol Res Pract. 2019 April 2;2019:6879412.

100 patients with vitiligo participated a study comparing female and male prevalence of depression, coping, stigma and quality of life. Depression was prevalent in 63.64% females and 42.86% males. Female participants had higher faulty coping style compared to males. There were no significance differences between both genders in stigmatisation, impaired quality of life.

Upcoming Events

July 2020 – Camouflage Workshop

This year's VAA Camouflage Workshop will be held online.

Come and join the online workshop to learn more about different types of camouflage brands.

More details to come!

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

Help to make our association even better!

JOIN THE CONVERSATION



Vitiligo Association of Australia



vitiligo.org.au