

VITILIGO ASSOCIATION OF AUSTRALIA

Newsletter

Volume 1, November 2010

Welcome to the first newsletter for the Vitiligo Association of Australia!

On Saturday the 23rd October 2010, the Vitiligo Association of Australia was formed. After being advertised in two newspapers (*The West Australian* and *The Australian*), as well as through the Australasian College of Dermatologists email group and through local dermatology practices, a number of people including health care professionals, patients and relatives attended.

The meeting was held at the Hollywood Medical Centre in Perth and was convened by Dr Prasad Kumarasinghe.

Everyone was given an opportunity to share their ideas and opinions. It was decided that the association is a great means for people with vitiligo or who have an interest in vitiligo to meet and discuss issues related to vitiligo.

The main aims of our association include:

- To educate and support patients and families with vitiligo in Australia
- To promote research to improve understanding of pathophysiology, improve treatments and patient care in vitiligo
- To minimize /eliminate social stigmas
- To increase public awareness
- To have international collaborations in vitiligo research and services

- To represent Australia at international forums on vitiligo
- To assist /advocate in health policy planning / Medicare planning for services for vitiligo patients

Office bearers were appointed:

- President: Prasad Kumarasinghe -WA
- Secretary: Benjamin Daniel-NSW
- Treasurer: - Lisa Brown- WA

Committee:

Dedee Murrell- NSW
Richard Wittal-NSW
Monisha Gupta-NSW
Tanya Tyler -NSW
Jason Wu- QLD
Shobhan Manoharan-QLD
Adrian Mar - VIC
Douglas Gin-VIC
Julie Wesley- SA
Yalda Manafi -WA

Our next meeting will be during the Australasian College of Dermatologists Conference in Perth, tentatively on 15th of May 2011.

Smaller local meetings are encouraged more frequently in different states.

Message from the President

It is a great pleasure to send you this message to the members and the 'members to be' of the Vitiligo Association of Australia

Vitiligo is a disease affecting 1% of the world's population but the attention it receives from medical circles, healthcare policy planners, and research organisations is totally inadequate. One of the reasons for the lack of resource allocation is because many people have wrongly considered it as a 'mere cosmetic problem' rather than a disease with psychologically devastating consequences. Most of the developed countries have had vitiligo support groups, but there has not been an Australia-wide vitiligo support group. A small support group has been functioning in Sydney for a few years. We are happy to have their representation as well in this national effort.

I am very grateful to those present at the meeting held on 23rd October 2010 in Perth, WA to found this vitiligo association. It is very encouraging to have many dermatologists from different states supporting this association. We are hoping to use this National network to collaborate in research as well as improving patient care more uniformly. We also hope to make representations to Medicare about rebates for patients receiving various services for vitiligo. At present targeted light therapy, camouflage and surgical treatments for vitiligo do not have Medicare item numbers or any government concessions. We also hope to emphasize the need to seek the assistance of counsellors or psychologists where necessary in managing vitiligo patients.

I would also like to encourage vitiligo patients across Australia to make our website an interactive information base. We have already established links with the National

Vitiligo Foundation in USA (<http://nvfi.org>), Vitiligo Society of UK (<http://www.vitiligosociety.org.uk/>), Vitiligo European Task Force, Vitiligo Society of South Africa (http://www.vitiligosociety.co.za/Vitiligo_Society) and Shweta Association (India). These groups are also willing to collaborate with us. We are now a part of the World Alliance of Vitiligo Support (WAVS). Their website (www.wavs.eu) will be active from 1st January 2011. I look forward to your active support to make this association grow and prosper. Our aim is to help vitiligo patients all over Australia. We are currently working in restructuring the vitiligoaustralia website. We will keep you updated on our website very soon. We welcome your ideas to improve the services by the association. Please email myself (prasadkumarasinghe@yahoo.com) or Dr Benjamin Daniel (Honorary Secretary) on benjamindaniel1@gmail.com.

I humbly request every dermatologist and medical personnel in the group to try and arrange a patient education/patient interactive meeting at your respective local hospital or private clinic to make people more aware of vitiligo, offer psychological support for vitiligo patients, and discuss treatment options available. Vitiligo should not deter anyone from reaching one's goals in life.

Dr Prasad Kumarasinghe

President Vitiligo Association of Australia

Royal Perth Hospital, Perth, WA



PATIENT'S PERSPECTIVE:

Vitiligo: My Story

By Tanya Tyler, NSW

When I was asked to write a piece for the first newsletter I was honoured but I really didn't know where to start as my journey has been so up and down over the last 20 years. I know if you're reading this you either suffer from Vitiligo or know of someone who suffers from this condition.

If you do suffer from it you know all the negatives associated with it, the good days and the bad days you have, the "Why me" days and the daily dilemma of what to wear to cover up those white patches.

Instead of focusing on the negatives I really wanted to focus on the positives that have come out of suffering with this condition for over 20 years. Some of you are probably thinking positives, there aren't any, is this woman crazy, but when you think about it there are some.

Here is my story:

I developed Vitiligo over 25 years ago and it's really been the last 15 years that it has progressed to over 70% of my body. Vitiligo really has changed my life in so many ways. In the beginning I hated it so much (I still do at times) I couldn't look at myself in the mirror and I would ask "why me!" but my saving grace was that I was bringing up 3 beautiful children so the focus was taken away from my Vitiligo. In a society where looks are everything, Vitiligo is very difficult to handle emotionally. I found the stares people gave me very draining.

Over the years I have realised and maybe this comes with age, that there are positives that come out of every adversity that comes your

way and you have a choice. With Vitiligo you have a choice whether it rules your life or NOT. I have chosen in recent years NOT to let it rule my life as life is too short to let this condition debilitate you. It has taken me quite a few years to get to this stage but I'm so glad I'm here now. There were years that I would cover up and not wear anything pretty as it might draw attention to myself or meet new people as I was terrified of what they would think of me. There were many social gatherings I missed out on because of my Vitiligo, but slowly I've managed to overcome this.

A few years ago I made it a goal of mine to start a support group for Vitiligo sufferers in Sydney and managed to achieve this. I've met some of the loveliest people in this group and I enjoy seeing them whenever we meet. This group has helped others and me in so many ways. We talk about different treatments and what's working and what's not.

I know there is no cure out there but many treatments. Keep trying and don't give up, one day there will be a cure. It's important to acknowledge your feelings associated with Vitiligo and to work through these, maybe with the help of a Counsellor as these feelings can be quite debilitating at times. Vitiligo has encouraged me to study counselling so I can talk and listen to people who have adversities in their lives and just need someone to talk to as life experience really helps in these situations.

Vitiligo has also made me a better person, I accept people for who they are and I'm a lot more understanding than I used to be.

Another positive is that Vitiligo has encouraged me to look after myself. Keep yourself healthy with vitamins, positive affirmations and exercise and anything that

works well for you to keep you healthy on the inside as well as the outside.

My children and husband have really been an inspiration to me, as I want to show them that you have to overcome adversity no matter what it is. Surround yourselves with people who raise you up, not put you down.

Summary of the positive side of Vitiligo:

1. It's NOT life threatening: how lucky are we!
2. I've met so many wonderful people through the support group.
3. I look after myself more.
4. Realised that what a person is like on the inside is more important.
5. Vitiligo is a great radar for meeting genuine people.
6. Has made me a better and more understanding person.
7. Has encouraged me to go back to studying so I can help others.

My advice for anyone out there who has Vitiligo who is feeling down and we all have those days so you're not alone, turn your life around as it starts with you. Make the decision for Vitiligo **NOT** to rule your life. Imagine you don't have Vitiligo for a moment and write down your goals and dreams, what do you want to achieve in your life? Make a plan for each goal and get started! Don't waste anymore time. Remember to start with baby steps, day by day and if you ever need any encouragement please contact me as I would be more than happy to help.

Finally, believe in yourself! Go out there and be yourself- white spots and all!

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Living with Vitiligo

By Lisa Brown, WA

While I was growing up, I never remember experiencing any of the common body image issues that the other girls my age were experiencing. I used to worry about lots of other stuff, like whether the other kids liked me, my parent's divorce, whether I was smart enough....but for some reason I always felt like the body stuff was sorted- one thing I could happily tick off my list of concerns. I knew my body wasn't perfect but I just really felt comfortable in my own skin. I was mainly proud of my tan- people were always commenting that I was brown as a berry and asking me when I had returned from Bali (even though I hadn't been!).

Of course, I wasn't aware that this would all change soon.

I remember Year 9 (age 14) as being a really stressful time. There was a couple of kids bullying me at school, I had gained a few kilos (but nothing I was overly concerned about enough to stop eating junk food!), my parents were going through a sad, messy divorce and I was just feeling generally unhappy with the way things were going. I had also noticed a big white patch had appeared on my knee. I didn't like it but just hoped it would go away. It looked so obvious sitting there in the middle of my olive skin and some of the other kids at school had started commenting on it and asking what it was. Mum took me to a Dermatologist who told me it was vitiligo and there was nothing I could do about it. I felt dismayed on the day but didn't realise the full impact of this diagnosis at first because for years I just had that one patch on my knee. We had been warned that the vitiligo would eventually start spreading and during high school Mum started taking me to two sessions

of light treatment in Fremantle per week. This time commitment became stressful at times and it reminded me that I had vitiligo and was different from my friends. Subsequently, I took a break from the light treatment for a number of years.

To my alarm, as I got older, more chalky white patches rapidly started appearing on my flawless olive skin, patches which seemed impervious to the pigmenting effects of sunlight. During my down days I would just sit there and stare obsessively at every little patch, refusing to look away. My eyes would tear but I would force myself to do this as some kind of strange act of self-torment. I still do this some days but try to exercise a lot more restraint with it. I hated it when people at university, boyfriends, or later on, clients would ask me what the white patches were. I wanted to pretend they weren't there and find some miracle cure so I could go back to feeling great and comfortable about my appearance, instead of avoiding looking at my body's reflection in mirrors or obsessing about whether people were staring at my 'dalmation hands.'

As I have become older, I have found it both harder and easier to deal with vitiligo. Harder, because my vitiligo has spread further and I still get scared sometimes about how bad it will get. But I also find it has gotten easier in some ways. On a surface level, I now use dermablend to cover the really obvious patches, like the ones on my hands and I think a lot of people don't even notice it. I have also become more aware of my personal gifts; including my compassion, warmth and capacity to make others feel comfortable; characteristics which have been enhanced by being a person with vitiligo. I know that others deeply value these characteristics in me and vitiligo does not stop them from being there. It also helps that now I am with a very special

man, who makes me feel beautiful and treasured. He understands what a pain vitiligo is for me but supports me in whatever interventions I try to manage it in a healthy way, often coming up with helpful suggestions himself. He reminds me of all my strengths and how much more important they are than a pigmentation disorder.

I also know that with the help of a good concealer I can still look great in a short dress and I still get wolf whistles from guys passing by when I take my dog for a walk. (;p)

Having vitiligo has made me more conscious about the lifestyle decisions I make, like trying to eat healthily (most of the time), undertake regular exercise, minimise the stress in my life and make time to do things that I find enjoyable and enriching. It has made me become less focussed on external assets and more on internal strengths, in myself and others. It has also reminded me that it is important to have the serenity to accept the things that I cannot change (at least not currently).

Instead of hiding from my vitiligo (other than behind the odd concealer/fake tanner every now and then!), I am now being more proactive in my treatment and open, cheerful (well, sometimes 😊) and frank when people ask me about it. I am even fortunate enough to work next to a hospital so I can conveniently have light treatment there three times a week and at night time I apply the prescribed steroid creams. I am still hoping that together we can find a cure for this one day, or at least a way to significantly reduce it's ability to spread and to affect our physical appearance and self esteems in the process.

My message to all those who have Vitiligo....I can relate with all my heart to how hard it can be some days. I really hope to meet you some

day and share our experience together. But keep doing the things that you love and enjoying spending time with the people you love. Because on your harder days, they are the ones who will remind you of all your special gifts and who you really are (and it's nothing to do with a few white spots). This will increase your courage to face those occasional question-askers, starers and to make a difference in whichever way you chose, no matter whether it's big or small. Together, I would love your support to get some funding behind Vitiligo to help us with this problem. But in the meantime, despite the challenges and occasional sad days, I hope you can have a decent time just being you because I have no doubt you are very worthwhile and likeable just the way you are. I would rather be a dalmation sniffing the flowers and enjoying the scenery than a dalmation with a broken spirit.

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At the inaugural meeting of Vitiligo Association of Australia in October 2010.

Other vitiligo support groups:

Vitiligo Foundation in USA: www.nvfi.org

Vitiligo Society of UK: www.vitiligosociety.org.uk

Vitiligo European Task Force: www.espcr.org/vetf/

Vitiligo Society of South Africa: www.vitiligosociety.co.za

Shweta Association (India): www.aarogya.com/support-groups/vitiligo/4701-shweta-association.html

World Alliance of Vitiligo Support (WAVS): www.wavs.eu (from 1st January 2011)

SOME RECENT PUBLICATIONS ON VITILIGO...

Recent Onset Vitiligo treated with systemic corticosteroid and topical tacrolimus: need for early treatment in vitiligo

J Dermatol. 2010 Dec;37(12):1057-9

This paper presented 2 cases reports of patients with recent onset vitiligo who were successfully treated with oral prednisolone (20mg/day) and topical tacrolimus (0.03%) ointment. Gradual repigmentation and disease progression arrested in both cases. Complete recovery was established in 12 weeks with mild side effects (indigestion and increased appetite).

Cosmetic Camouflage in Vitiligo

Indian J Dermatol. 2010 Jul-Sep;55(3):211-4.

This paper outlines the different products and techniques available to camouflage the areas of skin affected by vitiligo. Various temporary camouflage products such as liquid dyes, remedial cosmetic camouflage and self-tanning products are described.

Depigmentation therapies for normal skin in vitiligo universalis

J Eur Acad Dermatol Venereol. 2010 Nov 4

This article looked at depigmentation methods used in patients with extensive vitiligo. Commonly used agents include monobenzyl ether of hydroquinone (MBEH), monomethyl ether of hydroquinone, 88% phenol solution, laser and cryotherapy. The review found that MBEH is the safest with the least number of side effects. Laser and cryotherapy is associated with pain and potential scarring.

The polymorphism of catalase T/C codon 389 in exon 9 and vitiligo susceptibility: a meta-analysis

J Eur Acad Dermatol Venereol. 2010 Nov 4

This paper reviewed the literature as to whether there was an association between the catalase T/C codon and vitiligo. Though the precise pathophysiology of vitiligo is unknown, oxidative stress has been implicated. Catalase (CAT) is an endogenous antioxidant enzyme which is affected by the CAT gene. This meta-analysis found a correlation between the CAT T/C exon 9 polymorphism and the risk of vitiligo.

Tetrahydrocurcuminoid cream plus targeted narrowband UVB phototherapy for vitiligo: a preliminary randomized controlled study.

Photomed Laser Surg. 2010 Oct;28(5):679-84.

This randomised controlled study compared narrow band UVB (NBUVB) plus topical tetrahydrocurcuminoid with NBUVB alone in ten patients with vitiligo. UVB treatments were twice / week. Both groups of patients had significant repigmentation. Though the combination group (NBUVB + tetrahydrocurciminoid) had a slightly better repigmentation rates at 8 and 12 weeks, this was not statistically significant.

Treatment of stable vitiligo hands by ReCell system: a preliminary report.

Eur Rev Med Pharmacol Sci. 2010 Aug;14(8):691-4.

A patient with stable vitiligo had ReCell system performed on his hands. The ReCell system is an autologous cell harvesting surgical procedure which allows the delivery of melanocytes in cell suspension onto an area of vitiligo. It is quite safe and simple but the downside is the cost. The skin repigmentation result was characterised as "excellent" for this patient.

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