



NEWSLETTER

April 2011

- ❖ Check out the new Vitiligo Association of Australia website
- ❖ www.vitiligo.org.au

Dates for your Diary

- ❖ ACD meeting date
- ❖ Saturday 14th May:
Perth Convention Centre

Message from the President



Dear Friends,

Recently we had a successful meeting of the WA Group of the Vitiligo Association of Australia in Perth. Much work has been done since the inaugural meeting of the Vitiligo Association of Australia in October 2010. We have managed to officially register the association and the constitution with the Department of Commerce as an Incorporated Association. We have started a newsletter, and have developed links with other vitiligo associations across the world. Now the Vitiligo Association of Australia has its own website (<http://vitiligo.org.au/>) as well. We have already had vitiligo patients contacting us through the contact details given on the website. We would like you to make this website very interactive. We are already a member of the World Alliance for Vitiligo Support (WAVS). We encourage vitiligo patients to participate in Australian research projects on vitiligo where feasible. A limited study on knowledge and attitudes of vitiligo in the community has been completed in Perth and two studies on cellular grafting are being done in Perth and Sydney. Another study on the Quality of Life (dermatology life quality index or DLQI) among vitiligo patients is being done in Perth. It would be useful to have DLQI studies done in other states as well. I think it is reasonable to lobby the authorities to allow psychologically affected vitiligo patients to obtain some topical camouflage preparations at a concessionary rate. But I am aware this is a tough task. If any members of the association have any specific research ideas that they would like to discuss please feel free to contact Ben or myself (prasadkumarasinghe@yahoo.com or benjamindaniell@gmail.com)

Dr Prasad Kumarasinghe

Fast Facts:

- Vitiligo is really common! 1% of the population are affected!

- 20% will have an affected first degree relative

- Did you know? Famous American actress from the hit series "Charmed", Holly Combs has Vitiligo!

- Check out the new Vitiligo Association of Australia website

<http://www.vitiligo.org.au>

"Breaking News"

(research papers)

Br J Dermatol. 2011 Mar 17.

Multivariate analysis of factors associated with early onset segmental and non-segmental Vitiligo: a prospective observational study of 213 patients.

This article explores the difference between segmental and non-segmental vitiligo. It reveals an increased family history of vitiligo and autoimmunity and halo naevi in those with non-segmental vitiligo

Dermatologic Surgery Jan 26 2011
Autologous Noncultured Melanocyte Transplantation for Stable Vitiligo: Can Suspending Autologous Melanocytes in the Patients' Own Serum Improve Repigmentation and Patient Satisfaction

Noncultured autologous melanocyte transplantation is a new and effective surgical treatment for stable vitiligo. This paper compares repigmentation results in stable vitiligo in two groups of patients. In one group, the melanocytes are suspended in normal saline and in the other group, they are suspended in the patient's own serum.

Clin Exp Dermatol. 2011 Apr 20

Noncultured epidermal suspension transplantation for the treatment of stable vitiligo in children and adolescents.

Methods. Noncultured epidermal suspension transplantation was performed in 13 children and adolescents (age 8-17 years), with a total of 19 lesions of stable vitiligo. Patients were followed up for at least 1 year.

Results. Of the 19 lesions, 15 (79%) had > 90% repigmentation at the end of 1 year, and the remaining 4 lesions (21%) had 75-90% repigmentation. Results were not influenced by age, gender, site or size of lesions, type of vitiligo, or duration of stability of disease, although the small sample size makes conclusions tentative. The colour match at the final visit was excellent for 16 of the 19 lesions (84.2%). No major adverse effects were seen except for infection at the recipient site in one patient.

Conclusion. Transplantation of noncultured epidermal suspension is a safe and effective treatment for stable vitiligo in childhood. Considering its good efficacy and safety as a day-care procedure under local anaesthesia, it may be considered one of the treatments of choice for stable vitiligo in children and adolescents, especially for cases resistant to other therapies

"Around the World"

(conference updates)

Dermatologists world-wide are collaborating and sharing ideas about how to best help our patients with Vitiligo....

The American Academy of Dermatology meeting held in New Orleans in February 2011, offered a variety of interesting lectures and forums on Vitiligo, its pathogenesis and exciting therapeutic developments.

A doctor from Washington DC discussed exciting new genes like CAT T/C in patients with vitiligo. He discussed how patients with vitiligo and halo naevi are at decreased risk of having other associated autoimmune conditions and how minocycline was being used with some success in certain stages of vitiligo to scavenge free radicals.

An Indian dermatologist discussed non-cultured epidermal suspension in vitiligo. His presentation concentrated on the practical application of this technique and stressed the importance of only considering such a technique in patients with stable segmental vitiligo. He openly disclosed all his tips and tricks and stayed long after his presentation concluded to answer questions from dermatologists around the world!

Two dermatologists from California discussed the associations of vitiligo. One suggested all children with vitiligo should have blood tests to exclude autoimmune disease given the increased frequency of this in children. Two other dermatologists from Detroit spoke about the importance of developing support groups and scoring systems for assessing vitiligo severity.

So much information was exchanged and so many ideas shared...it is hard to put it all down on paper. It is however, entirely

encouraging and most exciting! This conference undoubtedly fuelled an existing passion to learn more about vitiligo and disorders of pigmentation, to contribute to both the national and local association and to perhaps learn more from experts around the world and bring this knowledge and skill back home to Australia!

Travel tip: If visiting New Orleans, be sure to visit the best jazz bar (in my humble opinion!) on Frenchman street – it is **most** appropriately called "The Spotted Cat"!!! Gotta love that!!!

Dr Michelle Rodrigues

Coping with Vitiligo:
A fragile acceptance of difference
By Yalda Manafi: Counsellor

“I think something my friend said to me was...she said it was still healthy skin. I suppose it is. It just hasn't got any colour in it but yes, I suppose it is healthy. And she sort of saw it in that way...that had an impact on me.”

After being given the privilege to write this article, I started researching common “recommendations” on how to best cope with vitiligo. I am sure that many of you have also done your research and I wonder if you may have reacted similarly to me. It appears that the common advice is “not to let it affect your self-esteem” and statements such as “you are still the same person” and “don't be ashamed” are repeated often. I wonder if many of you who have been told or read these statements also thought that *that's easier said than done*. My aim is therefore to avoid telling you what you already know and instead focus on helping you identify the ways you already cope with vitiligo. Perhaps this approach can help you consider which strategies are helpful to you, which ones are not helpful, and identify those strategies that need improving or changing.

Those who do not suffer from skin problems often do not appreciate the role our skin plays in communication information to others. We communicate; culture, religion, ethnicity, gender, likes and dislikes simply through the colour of our skin, the way we show it, cover it up or decorate it. But what do we do when our skin start to change or sets us apart from “normality”?

Within the psychology literature, coping is commonly defined as various emotional and behavioural strategies that we use to manage stressful situations. In broad terms, coping strategies can be divided in to three categories; 1) Strategies that help us deal with the actual stressful event or situation e.g. confronting someone who's staring

2) Strategies that help us deal with the feelings that we are left with as a result of a stressful event e.g. distraction or positive self-talk
3) Strategies that enable us to block out, withdraw or avoid stressful situations and our feelings about it e.g. covering up skin, avoiding sport, the beach, intimacy and so forth.

I would like to emphasize at this point that there is not a “right” or “wrong” way to cope with vitiligo. However, over using one single strategy seems to result in lower life satisfaction whilst using a combination of strategies seems to increase a sense of empowerment and result in higher self-esteem and quality of life.

For example, constantly confronting people who are staring may be perceived as being aggressive and is likely to be emotionally taxing for oneself. On the other hand, avoiding showing skin or avoiding social situations or intimacy is likely to leave you feeling alone and isolated. Likewise, whilst distracting oneself with humour or downplaying the emotional impact of other people's behaviour, like staring, may immediately be effective in diffusing the situation, it may result in a long term negative impact on self-esteem.

It is unreasonable to expect to always deal well stressful situations. Our ability to cope well depends on many factors including how tired we are, if we are having a bad day or good day where in the menstrual cycle women are and so forth. Yet it appears that we feel most satisfied when we feel that we have options that are available to us.

Sense of empowerment has also been closely linked to psychological wellbeing and coping. In other words, if you feel that you have no other option but to cover up or diffuse a situation, you may eventually end up feeling hopeless and powerless. If you feel that you have options available to you (like talking about your skin, explaining the effect of someone's comment etc.), the unpleasant emotions following such and an encounter is likely to be less damaging.

You may still choose to walk away or avoid a confrontation because you feel tired and choose to use positive self-talk instead to buffer yourself against unpleasant feelings. The difference is in your choice and sense of empowerment.

In finishing this article, I like to offer you my thoughts on how to do a little self-inventory to identify your coping strategies and how to go about expanding them if needed.

- Honestly assess how self-aware you are of your skin condition. Perhaps rate it from 1-10 and note which situations are better and which ones are worse.
- Note how you commonly deal with situations that make you self-conscious. Do you avoid them? Enrol the support of others? Make fun of situation? Confront? Talk to yourself (either positive or negative)?
- Ask a trusted friend or family member how they perceive your coping style(s). This helps with objectivity.
- Think about how you could broaden your repertoire to be more diverse in your coping style. If you were successful in this, how would your life be different?
- Which situations would you like to deal with differently? Is it fear, anxiety or some other feeling that hold you back

from making these changes? If so, seek the help of someone you trust or get a counsellor to help you.

- Make a list of how you would like to be perceived and treated by others and start treating yourself in this way. This includes your internal self-talk.

Unfortunately, we cannot trust that we will always be well received by others and the fear of being ill received can be paralyzing. Luckily, we can learn to trust our own ability to successfully deal with our own emotions following such unfortunate encounters. Teaching this to children and adolescents is particularly important as dealing with their own feelings is hard even at the best of times.

I understand that this process is heartbreaking for parents of children with vitiligo. I suggest that parents do their own self inventory and assess which coping strategies they are role-modeling with regards to coping with vitiligo. As parents, it is sometimes difficult to keep faith in children's resilience and ability to deal with hurt and sadness as it is a natural instinct to care for and protect our children against harm. It is therefore helpful at times to get support and/or counseling to deal with your own anxieties and sadness regarding your child's struggle and journey of learning to successfully cope with vitiligo.

Thank you to those who contributed to this newsletter, especially Dr Michelle Rodrigues and Yalda Manafi. Special thanks to Nikki Howe who has designed the logo and the website for the Vitiligo Association of Australia.

www.vitiligo.org.au

Next meeting:

The next general meeting of the Vitiligo Association of Australia will be held during the Australasian Dermatology College Annual Scientific Meeting on Saturday 14th May at 4.30 PM in the River View Room 4 at the Perth Convention Centre.

All members, members to be, and any persons who wish to know more about vitiligo or the support group are welcome to attend.



For more information, please contact Benjamin Daniel
benjamindaniel1@gmail.com