

# Dispatches

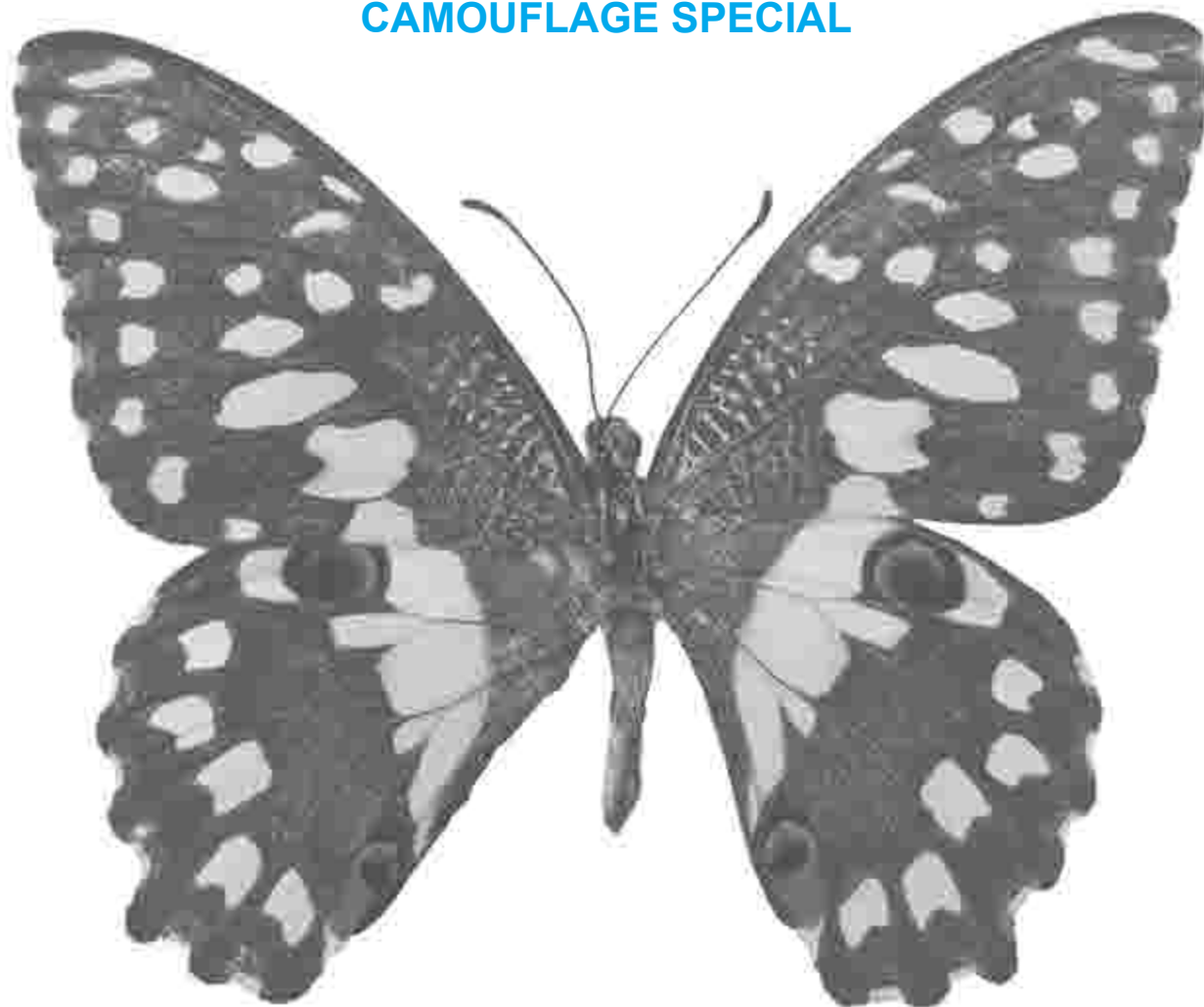
VITILIGO  
SOCIETY



THE MAGAZINE OF THE VITILIGO SOCIETY NUMBER 56 March 2011

*Promoting a  
positive approach  
to living with  
vitiligo*

## CAMOUFLAGE SPECIAL



## ALSO INSIDE

**TOP TEN  
UNCERTAINTIES  
FOR THE TREATMENT  
OF VITILIGO**

**DERMATOLOGY  
SERVICES IN THE  
RESTRUCTURED  
HEALTH SERVICE**

# In This Edition



## A Suggestion For Raising Money For the Society

I'm proud to say that since I last wrote an editorial I have not only become one year

older but have also raised £200 for the Society through the simple device of asking my friends to donate a small amount of money rather than giving me birthday presents. Now that I have become really old, I find that I have everything I need and friends really struggle to find good presents. Consequently they are delighted when I say - instead of giving a present, please donate £5 per head to my favourite charity. Why not try it with your friends the next time you have a birthday?

## Please Renew Your subscriptions

This editions coincides with our annual request for the renewal of your subscriptions. This year it is especially important that the Society remains in good financial health because we are facing a major reorganisation of the health service and we strongly suspect that dermatology services will come under severe pressure. Please ensure that the Society is there to fight the dermatology corner in your name. There is a special feature on page 3.

## Top Ten Uncertainties

At long last we are able to print the the top ten uncertainties for the treatment of vitiligo which have been defined by a research project managed by the Centre for Evidence Based Dermatology at Nottingham. These have been around since March 2010 but we were unable to publish until they had appeared in the *British Journal of Dermatology*. The important thing now is that we must support the efforts of Nottingham University to go forward with a fully funded study on one or more of these factors.

## Vitiligo - Denzil's Story

Finally, with Spring in the air, I recommend that you read the excellent feature by Denzil Murphy which describes his day-by-day efforts to carry on a healthy life in the open air despite the limitations of vitiligo.

## Jeff Lock



## CONTENTS

Page 3 -	Dermatology in the Restructured Health Service
Pages 4&5	Ten Treatment Uncertainties
Pages 6	Camouflage Article
Page 7 -9	Denzil's Story
Page 10	Camouflage in Hot Places
Page 11	Camouflage Coping Strategy
Page 12	Letters
Page 13	Your Views on Dispatches
Page 14	Photographic Project
Page 15	Coping Strategies
Page 16	Walk For Skin and Online Survey

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The Editor reserves the right to shorten and/or edit items submitted for publication.

## **DERMATOLOGY IN THE RESTRUCTURED NATIONAL HEALTH SERVICE: PLEASE RENEW YOUR SUBSCRIPTIONS SO THAT WE CAN CONTINUE TO FIGHT FOR YOUR SERVICES**

What will dermatology services look like in the National Health Service after the completion of the government's restructuring plans which will see patient budgets delegate to GP consortiums? The answer is that, no one really knows. But the health service is under pressure to make economies and it is more likely that "soft" areas such as dermatology will be targeted. Dermatology services are already understaffed and unless we fight to make our voices heard the situation can only get worse. The Vitiligo Society has been playing an active role in the Dermatology Council for England (there are separate councils for Wales and Scotland) and supports the following manifesto issued by the council which has been submitted to the government as part of the white paper consultation process.

### **Key Manifesto Requirements in Skin Care**

The Dermatology Council of England believes that the following minimum standards should apply to the provision of skin care services in the UK. The Council therefore calls upon the Government to commit to providing these standards.

1. Equitable access to the full range of dermatology services throughout the UK through the development of agreed gold standards for all dermatology services, no matter where a person lives. When health-care targets exist, they should not disadvantage any group of patients.
2. All dermatology services should provide holistic support, treatment and care. In order to achieve gold standard status, all services must offer access to psycho-social support, including specialist nurses, camouflage services and where appropriate, counselling and psychotherapy.
3. Minimum requirements for dermatology patients should include:
  - § ready access to a healthcare practitioner who is adequately trained and experienced enough to diagnose and manage their condition, and has demonstrated that their training is up to date. This should apply to the assessment of both skin cancer and inflammatory skin disease.
  - § prompt and easy access to specialist care, when required
  - § continued follow up care, if required, by the same team
  - § free prescriptions if their skin condition is chronic
  - § access to a comprehensive skin surgery service and a full range of medication as prescribed
4. Provision of high quality dermatological surgery for the surgical management of skin cancer, including high quality Mohs micrographic surgery when required.
5. As with cancer services, 'supportive care' must become integral to dermatology.
6. Medical undergraduate training and GP training should be sufficient at least to ensure that all doctors have a basic knowledge in dermatology for common and important diagnoses.
7. Basic nurse and pharmacist training should also include dermatology and those specialising in dermatology should have easy access to post-qualification training if they desire it.
8. Patients should be properly consulted in the design of their local dermatology services, particularly if there are to be major changes to the way that skin care services are to be delivered. It should not be possible for a service provider to withdraw from their role without consultation with patient representatives.

## TOP TEN UNCERTAINTIES FOR THE TREATMENT OF VITILIGO

By Dr Viktoria Eleftheriadou and Maxine Whitton

As you may remember from previous issues of *Dispatches*, the vitiligo project is part of an independent research programme commissioned by the National Institute for Health Research (NIHR) looking at setting priorities and reducing uncertainties for the prevention and treatment of skin disease. This project is being coordinated at the centre of Evidence Based Dermatology, University of Nottingham.

The aim of the vitiligo project was to identify the Top 10 treatment uncertainties from the various potential and currently available treatments for

vitiligo and to submit a grant application for a large-scale randomised controlled trial of one of the treatments. There were several stages: initially, a survey was conducted to collect uncertainties about the treatment of vitiligo from patients and healthcare professionals. This identified 93 unique treatment uncertainties.

Next, a ranking exercise was conducted, which allowed people to vote for their favourite topics. This process identified the Top 23 treatment uncertainties important to both patients and healthcare professionals. Finally, the Final

Prioritisation Workshop resulted in a list of Top 10 research priorities for the treatment of vitiligo. This workshop was a full day event at the British Associations of Dermatologists House in London, on the 25<sup>th</sup> of March 2010.

The Final Prioritisation Workshop was a great success. Forty people attended: almost half of them were patients and half healthcare professionals, including dermatologists, specialist nurses, general practitioners, researchers and camouflage professionals.

We are delighted to reveal the Top 10 vitiligo treatment uncertainties:

1. How effective are **systemic immunosuppressants** in treating vitiligo?
2. How much do **psychological interventions** help people with vitiligo?
3. Which treatment is more effective for vitiligo: **light therapy or calcineurin inhibitors** (e.g. tacrolimus, pimecrolimus)?
4. How effective is **UVB light therapy when combined with creams or ointments** in treating vitiligo?
5. What role might **gene therapy** play in the treatment of vitiligo?
6. How effective are **hormones or hormone related substances that stimulate pigment cells** (MSH analogues, afamelanotide) in treating vitiligo?
7. Which treatment is more effective for vitiligo: **calcineurin inhibitors** or **steroid creams/ointments**?
8. Which treatment is more effective for vitiligo: **steroid creams/ointments** or **light therapy**?
9. How effective is the **addition of psychological interventions** to patients using **cosmetic camouflage** for improving their quality of life?
10. How effective is **pseudocatalase cream** (combined with brief exposure to UVB light) in treating vitiligo?

In addition, two treatment uncertainties were suggested as “*ones to watch*”, as these interventions were still in an early investigative stage.

11. How effective is piperine (black pepper) cream in treating vitiligo?
12. What role might stem cell therapy play in treating vitiligo?

## TOP TEN UNCERTAINTIES continued



Final Prioritisation Workshop, BAD House,

The results of the vitiligo project are being widely disseminated to both the clinical and research community. Dr Viktoria Eleftheriadou has given presentations on the Top 10 treatment uncertainties in September at the 16<sup>th</sup>

Meeting of the European Society of Pigment Cell Research, Cambridge, UK and at the First Vitiligo World Congress, Milan, Italy. Maxine Whitton also spoke about the project at the Patient Day meeting at the Vitiligo World Congress.

Five research vignettes based on the Top 10 uncertainties have been submitted to the HTA NIHR (Health Technology Assessment), an independent funding body, and are currently being considered for funding of a trial on treatment for vitiligo.

If you are interested in finding out more details about the vitiligo project, the

article is published in the British Journal of Dermatology (*Eleftheriadou, V. et al. "Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership". British Journal of Dermatology 2011, no. doi: 10.1111/j.1365-2133.2010.10160.x*), which is widely available online to all internet users (free of charge).

Our next step is to work towards the development of a trial protocol based on the identified Top 10 uncertainties. In making our decision we had to take into account several factors including feasibility, willingness of clinicians to recruit patients and convenience for patients. Also, we had to take into consideration, previous trials and their results on the chosen topics.

We are really pleased to inform you that our team is working on the following research ideas.

- Effectiveness and safety of hand held NB-UVB devices at home for the treatment of limited or early vitiligo
- The effectiveness of topical corticosteroids compared to topical calcineurin inhibitors

Of course, it will take time for us to complete all the preliminary work needed to complete a trial protocol and we are not currently recruiting patients. However if you are interested in taking part please keep an eye on our website [www.vitiligostudy.org.uk](http://www.vitiligostudy.org.uk) as well as the *Dispatches*. We will keep you updated!

Finally, we would like to say a big thank you to all the people who contributed to the vitiligo project. We have received great support from the Vitiligo Society throughout the entire project and the contribution of patients has been crucial to its success.

We really appreciate your time and willingness to be part of this unique and important opportunity to have your say in research into vitiligo.

Please don't hesitate to contact us (Dr Viktoria Eleftheriadou) if you have any enquires or suggestions on the: [vitiligostudy@nottinham.ac.uk](mailto:vitiligostudy@nottinham.ac.uk)

**The views expressed in this article are those of the authors and not necessarily those of the NHS, NIHR or the Department of Health.**



Dr Viktoria  
Eleftheriadou

## IS CAMOUFLAGE THE BEST WAY TO COME TO TERMS WITH VITILIGO? By Maxine Whitton



people with vitiligo want to hide the problem.

There is no cure for vitiligo and the treatments available have limited success with no guarantee that the condition will not recur, so many people resort to covering up the affected areas, particularly hands, neck and face, either with clothing or cosmetic camouflage. In addition, many GPs routinely prescribe cosmetic camouflage which is the only preparation licensed for vitiligo under the ACBS scheme. The wide range of camouflage products available coupled with skilful instruction in how to apply them can make a huge difference. Remarkable results can be achieved when a good match is made with the normal skin tone to the delight of the person with vitiligo.

It seems to be true that most people with vitiligo can cope better when the face is not affected. The face, quite apart from being an important element in our identity, also plays a vital role in the way we communicate with the rest of the world. Our ideas of beauty are mainly centred on the face. A disfigurement or blemish, even a small spot on the face can be seen as a disaster. It can leave the person with a visible difference exposed to teasing, bullying, staring and rude comments, often from complete strangers. Fear of contagion can also lead to recoil from touch. It is therefore not surprising that

However, the use of these products is not without problems. Concealing the white patches is not the best way to come to terms with vitiligo. It is all too easy to hide behind the make-up and pretend that nothing is wrong. This can lead to increased anxiety born of the fear of it rubbing off and people seeing the affected area as it really is.

Another factor to take into account is that vitiligo is unpredictable and generally spreads. While it is possible to cover the affected, exposed areas, these may get bigger or more of them could appear. Sufferers therefore have to

spend more and more time disguising the white patches, leading to further anxiety. It is also worth bearing in mind that with active disease there are likely to be other affected areas which cannot be covered. On the positive side the products are usually water-proof and may allow swimming if patches are not too extensive. The creams can also be used in conjunction with some other prescribed creams and ointments, usually corticosteroids or calcineurin inhibitors which can improve the condition in some cases.

Cosmetic camouflage is most useful when it is part of an informed choice and after acceptance of the disease. If the person with vitiligo is covering up their patches at all times, in some cases (reported anecdotally) even before going to bed, then they are too dependent on it. If on the other hand they choose when to use it and feel comfortable without it in familiar surroundings and with friends and family, the likelihood is that they are coping better with their disease. There is no doubt that many people with vitiligo have found that cosmetic camouflage makes a big difference to their self-confidence and it remains an important part of dealing with this enigmatic disease.

*(Maxine Whitton, BA Hons, Hon MSc, Patron of the Vitiligo Society)*

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### WHAT DO YOU THINK ?

**We would love to hear your views on the use of camouflage.**

**Please write to us or email the editor at :**

**[Jeff\\_Lock@vitiligosociety.org.uk](mailto:Jeff_Lock@vitiligosociety.org.uk)**



## VITILIGO: MY STORY by Denzil Murphy (Including Denzil's Use of Camouflage)



Out of bed and curtains back. Oh dear, what a pity, the sun's out. Not the sort of reaction I would have had 10 years ago prior to a hot and sunny holiday to Goa.

My story started there and a journey of disbelief, realisation, helplessness, anger, and self pity, ensued. So what sort of a person was I and what sort of person am I now? Well, I'm 55, of Anglo Indian parentage, I hold down a professional position involving a considerable amount of customer facetime, and I consider myself very fortunate to have inherited a dusky coloured skin tone.

In my first 45 years I enjoyed, for the most part, all the good things in life although my parents were not wealthy. I achieved a good education, travelled around the world with my profession, possessed reasonable good looks and an outgoing gregarious and friendly personality. My wife even remarked once that I could throw a party in an empty room. Amongst all this was my love of the sunshine. In less than an hour my skin colour would darken, in a healthy way, and I never burned.

That all changed in 2000. Prior to departing these shores for hot and sunny climes I would go for one single sunbed session just to prepare my system for the difference between the cold of the UK and the heat of the destination. The wisdom of this ritual has since been seriously questioned. After the session I went home to complete packing for the next day's departure.

I must point out at this juncture that my physical condition was at a low ebb. I was under a lot of stress as a manager for my company and thoroughly exhausted. This holiday couldn't come soon enough. I also had a tooth infection that, despite root canal work, would not recover and I was taking the hard-hitting Metronidazole, and the not so strong Amoxicillin, in an effort to cure it. Finally, and it sounds trivial, I cut my lip shaving on the day of our departure. Trivial it may have been but it didn't stop bleeding until we reached India and this too added to my run down, depressed condition.

Whether or not all, or some, of the above conditions caused the onset of my vitiligo will always remain a mystery but I have read that some cases not attributable to heredity, including my own, have been due to receiving a severe shock. I remember reading about a lady who fell during rock climbing whose Vitiligo began the next day and others who have succumbed due to stress. Mine was still to present itself.

The strength of the sun in any part of the world had never had an adverse affect on me. With that in mind I donned a pair of beach shorts and slumped gratefully under the hot Goan sun. My girlfriend and I had literally been sunbathing for a little over ten minutes when she exclaimed that something had happened to my face. I shrugged it off but she insisted something was amiss. The mirror in the chalet reflected back to me, what I now know to be vitiligo. Both cheeks had a blotchy, mottled

effect as did a large part of my forehead. Horrified by this vision I, initially, went back out into the sun. I irrationally figured that, for reasons unknown, I had lost areas of colour from my face and that the best course of action would be to let the sun fill the patches back in. Maybe it would all go away. The condition worsened that day, and the next, and the affected areas, far from re-pigmenting, went pink and sore.

I have read and self studied practically everything to do with vitiligo but my unanswered question that I must throw in here is this. When I was physically, and to a degree mentally, at my lowest point surely my immune system would have been too and if it was equally as diminished as the rest of me, and is the villain of the piece, how exactly did it achieve the power to rob me of my pigmentation. I'm sure someone will know the answer.

On my return to the UK, and at great expense, I made appointments to see two separate skin disorder specialists. They both turned out to be of absolutely no help whatsoever and neither of them diagnosed vitiligo. In fact after a bit of prodding and scrutinising they wondered at the lack of hair follicles in the affected areas, took Polaroid photographs, gave me the bill and sent me on my way. One of them did venture, however, to say that he thought it may have been caused by 'photo toxic shock'. This was the point at which I realised I was pretty much on my own and thus began my journey of discovery and self help.

At first the patches on my face were the only areas affected and I learned through plaintive phone calls that the Red Cross offer a camouflage service to those with skin tone or birthmark problems. I tried all their products (Dermablend etc.) with the creams, spray fixers and powders but the process was long and messy. The

## VITILIGO: MY STORY by Denzil Murphy (continued)

finished result looked earthy and the match wasn't particularly close but for the time being I persevered as that was all I had. I would like to take this opportunity to thank those Red Cross staff that tried to help me in the early days.

Over the last ten years I have tried almost every cosmetic product on the market to disguise the white areas and their relentless advance. After about a year little white dots of pigment loss started to appear on my hands (right more so than the left) initially at, and around, the areas of old scars. Over the next few years these areas expanded and then started to merge together. As of today most of my fingers have lost their pigmentation along with a gradual creep along the backs of my hands. (See photo.)

Other areas too started to show signs of the problem: not all of them are visible to others. It is said that vitiligo affects all the extremities. Take it from me, it's true. After roughly three years my feet began showing signs of loss with two small, symmetrically positioned, patches appearing at each ankle. Elbows were next and additionally to date there are patches and many dots on the undersides of my wrists and forearms. My toes are now going the same way as my fingers. In the meantime the facial, neck and hand areas have continued steadily to worsen.

I once put the roof down on the car and tried an experiment to see if exposing my mainly depigmented hands to the sun during a days driving would somehow initiate regeneration. It didn't. In fact it seemed to accelerate the problem. I think I know what you're going to say now. Why have a soft top if I have vitiligo? I still love to drive with the top down and you can't abandon all pleasures. But it was back on with the driving gloves and the baseball cap.

That about covers the areas affected and I can report that all patches have increased in surface area steadily and relentlessly.

Five years ago I tried a six-month course of UVB treatment. In fairness there was a small degree of re-pigmentation to the sides of the face, under the eyes and on the ridge of the nose, but it was really too little to be of consequence. The overall effect was to slowly cook me to the point where for a good day afterwards I was red and sore. I have tried many, and all, suggested cures such as topical creams, excesses of folic acid, some strange cream from Cuba etc, etc. I am now convinced that, since no cure currently exists, all I can do is to disguise the visible areas as best I can.

Today, after a massive amount of experimentation, I use moisturisers on my face followed by Smashbox Photo Finish Bronzing as a primer with additional Laura Mercier Pure Honey Mineral powder under my eyes. Then I blend it all in. On my hands I moisturise followed by St Tropez Step 3 Tinted Self-Tanning Lotion and / or Clinique skin supplies for men Non-Streak Bronzer.

Don't get me started on just how difficult and embarrassing it is, as a man, to source and test these products. Sitting at a cosmetics booth with an audience is a seriously withering experience. Anyway I blend and vary the quantity of any of the above cosmetics depending upon the season and the end results do differ, in depth of colour, considerably between summer and winter. In the summer sun all the

exposed naturally brown bits still turn every shade of dark whilst leaving the white bits very white. This is the worst time of the year for me and I'm sure many others.

I long for the ambiently warm / hot overcast days when I don't have to wear a hat or any sort of sun protection. Although it is now my least favourite type of holiday we still tend to book getaways to the sun. My wife loves to sunbathe and I am now forced to enjoy the ambient air temperature only since I now have to spend all my time in the shade.

In the winter months the darker areas of my skin fade to a much less noticeable shade and the amount of 'colour' I need to apply is far less or none at all. It is during these months that I am at my most adventurous. I do go to the shops, answer the door, talk to neighbours and sometimes forget that I haven't applied any cosmetics. The converse is true of the summer. Once that contrast between the light and dark patches become more obvious I deliberately avoid doing any of those, and other, things.

In the course of everyday living I have discovered that what to wear, where to put personal items about ones person, and how easy it is to retrieve these





## VITILIGO: MY STORY by Denzil Murphy (continued)

items, needs careful prior planning. The reason for this? If you wear light coloured clothing and you have personal items in various pockets it is necessary to dig deep to retrieve said items. End result is cosmetic darkening around pocket openings, shirt pockets and the like. I find that asking my long suffering wife to put all these things in her handbag solves the problem. Except for the credit cards of course.

Equally I am careful about the shirts that I wear, particularly in warm climates. An open necked shirt is usually out, unless it is collarless or of a dark material, because the cosmetics I will have applied around my affected neck area deposit themselves, very noticeably, around the collar. If an event calls for smart casual and open collar I will invariably wear a tie in order to prevent this transference of colour to my collar. It looks a bit overdressed but I don't think anyone's twigged yet.

Swimming and scuba diving are two areas that have affected my behaviour greatly. I love to scuba when the opportunity presents itself but I find myself experiencing a massive attack of anxiety and hand wringing prior to the event. Why? Because when I first disappear below the waves I do so, for all intents and purposes, as a 'normal' person. However, being submerged removes any cosmetics I would have had applied and the cold of the water accentuates the colour differences of my skin patches. As soon as I bob to the surface and remove the equipment I appear as quite a different person to the one that went out earlier. The colder the water the more noticeable the contrast. I have witnessed looks of absolute shock and horror on the faces of those around me. For me that is emotionally upsetting and crippling, and it never seems to get any easier to accept. Because the love of Scuba outweighs the distressing stares received I convince myself that I will probably never bump

into the dozen or so people I have just spent the day with on the boat.

Swimming is a different matter altogether. At the pool you are something of a captive audience and if it's a resort pool you will probably frequently see the same people for a week or two. Swimming has the same affect on my appearance as it did for Scuba but in addition I have found that the chlorine adversely affects the colour of some cosmetic applications. For example, the areas upon which I principally use St Tropez, my hands, turn a bright orange and it doesn't just wash off. That tinge stays for days. For that reason I never swim but will only wade chest deep to cool off.

The area of waterproof 'colour' has proved something of a disappointment. I have tried a few products to be applied when swimming / diving but there are two main problems. The colours do not seem to remain constant and they really don't appear to be as waterproof as they claim. The search continues.

In the scheme of things I know, deep down, that my condition is not really so bad but still I remain extremely self conscious. I am more than happy to remain indoors and unseen. Throughout, my wife has been a pillar of strength and reassurance to me but despite all this help I'm still having difficulty coming to terms with vitiligo. That said, I do appear to be getting a little bolder but it is taking an inordinate length of time.

How do I feel now? Well, I'm still cripplingly conscious of my appearance and my self confidence remains somewhere in the weeds. As an act of preservation, I manage to shield myself, to a degree, behind a facade. Apparently, to others, I still appear as gregarious and outwardly confident as I ever did but make



Denzil With his wife Linda

no mistake, it's all an act. Funnily enough I am more worried about friends seeing me without my cosmetic 'colour' applied than I am about family and strangers.

After reading through this I sound to myself as if I am full of vanity, as well as self pity, and that I should hoist myself up by my bootstraps and just get on with it. Well that's probably right but, almost imperceptively, I do believe I'm getting there. I'll write and let you know in another 50 years or so.

I have the utmost respect and admiration for those vitiligo sufferers who have the condition so much more noticeably than me. How brave and resolute they are to persevere and continue as normal. Those people who have already managed to take it in their stride, and made all the necessary mental adjustments, are my heroes. I hope that one day I can get my head around my lack of acceptance and then maybe I will be as 'in control' as they are.

Until then, the suns still out. Oh well, on with the hat, suncream and gloves.....Let's go.

Denzil

## CAMOUFLAGE IN HOT PLACES by Mary Hill



I found I had vitiligo when I was in my late 30s. I was island hopping in Greece, spending most of my time in the sun acquiring a tan. (I was always a very pale person and gaining a tan in the summer became very important to my self confidence.)

One day a woman approached me on the ship and pointed out that I had white patches on my upper back and shoulders and said I should see a doctor when I got home.

I arranged an appointment with a dermatologist. He advised me that I had developed vitiligo and that it was not dangerous but that it might spread, and that I should protect my skin. No treatment was offered, nor have I attempted to get any since despite knowing a lot about what is available through the Vitiligo Society: they seem very time consuming.

My vitiligo developed over the years. Initially I had the classic symptoms of white patches which remained white when the rest of me tanned. I found the back of my hands the worst place to get burnt and had some very serious burns before I got more aware that I had to take precautions and keep them covered or smother them in thick sun protective cream, which was a nuisance because everything I touched became greasy.

I am now in my 60s and have very little skin that is not affected by vitiligo. Over the years I have realized that holidays in the sun, spending most of the time trying to get a tan, and laying on the beach were a no-no. So I looked for holidays that were more cultural, more interesting and kept me out of the sun. I prevented myself

from burning by covering myself up rather than using loads of creams.

Over the past few years I have visited the USA, South India, Jordan, South Africa, Cuba and last year Viet Nam and Cambodia. Explaining to my fellow holiday makers that I cannot strip off or lay in the sun is sometimes difficult. I do not want to stand out as being different, but at the same time, I want people to realize I have a real medical problem. I usually joke about having something in common with Michael Jackson and will explain more about vitiligo if anyone is interested. I always sit in shady places. A quick dip in the sea is OK as long as I cover up immediately afterwards.

What creams and lotions do I use? Well, I have tried various “fake tans” with varying results. I do need to give myself some colour as I am a real pasty-white without anything. I find the products that are more of skin cream and that gradually give me a pale tan the most satisfying and easiest to use. (Johnsons, Dove, Garnier, Boots) They need to be used continually and sometimes clothing gets stained by it, but it washes out and it’s a small price to pay. Throughout the year I use a day skin cream with an SPF 15 on my face, and also Boots No.7 Dual Protection tinted moisturiser over it which also has SPF 15. This is the only make up I use on my face skin and it is excellent.

Last Summer I discovered “Boots Soltan Once 50+ SPF protection for up to 6 hours” which I use on my body, and Boots Soltan Once Face + gradual tan with SPF 15 protection for up to 6 hours, on my face - this is one of the few products that offer skin protection and gradual tan. I do not believe expensive brands offer anything better than more basic makes such as Boots, Dove, Garner

and Johnson. It is always better to apply sun protection creams when you are dressing, rather than wait until you arrive in the sun and try and apply it then, you will find you will miss areas such as back of neck and shoulders. You can always reapply some more on the beach as time goes on.

Different types of environments affect skin burning. For instance in the UK, it can be quite bright and sunny but with a cold wind, but this can be the worst conditions in which to get burnt. But I also find that very humid conditions when I am “dripping” hot often means I do not burn so much. Hot sunny dry places are amongst the worst. When I was in Cuba two years ago our tour included a coastal stay on beach you could die for (white, white sand, shallow clear hot water). It was years since I had been on the beach and made the most of it, however, I did inflict some burning on my legs, but it was at the end of my trip and quite frankly, the pleasure outshone the pain!

One further point - there has been coverage in the media over the past few years about the importance of Vitamin D and that people who cover themselves up (for whatever reason) may have a tendency to have a reduced Vitamin D level. People with vitiligo who do not spend much time in the sun, wear skin protection creams and cover themselves with clothing are at risk. I had my Vitamin D level checked by my doctor and it turns out that I am only just on the recommended level. So my doctor supplied information about diet. You should eat plenty of oily fish (such as sardines, pilchards, herring, trout, tuna, salmon and mackerel), liver, egg yolk, mushrooms, cheese, milk and butter (small amounts), and fortified foods. I hope this summer to try and get a little more sun early in the morning without skin protection to improve my Vitamin D levels.

## A COPING STRATEGY FOR USING CAMOUFLAGE

The Vitiligo Society has recently launched a series of Coping Strategies : one of which relates to camouflage. (For a full list see Page 14.) The strategies comprise the first in a series of self-help articles which will eventually cover all aspects of living with vitiligo. Please let us know whether you think they are useful.

### **Come in, do take a seat. What do you know about skin camouflage?**

The response to this usual greeting is “not very much” or “Ah, yes, isn’t it a remedial, thick cosmetic?” Unfortunately, and all too frequently, the reply can be “I don’t want to wear it but my family thinks I should” or “my doctor said it’s a special make-up for women” - which is all rather worrying! Skin camouflage should be made available to men, women and children, irrespective of age, religion, nationality and skin classification group. It is something that should be discussed as part of your dermatology care plan. Then, armed with the correct information, you can make up your own mind as to whether or not to explore wearing skin camouflage. Skin camouflage does not suit everyone; and it does not matter if you only use it for special occasions or as a coping strategy during your initial adjustment to having developed vitiligo. Neither does it matter if it becomes a long-term lifeline – the frequency of wearing skin camouflage is your personal choice. Initially you may prefer to use a very light application and then gradually build up to full density, or to enjoy the immediate effect full skin camouflage can bring. Even when the camouflage is not an accurate skin colour match, it can stop people staring or making comments and asking questions.

Using the term ‘skin camouflage’ creates no psychological barriers – it is non-exclusive – whereas “cosmetics” and “make-up” can create all kinds of anxiety to males, children and females who would not normally wear make-up. Skin camouflage cannot alter the texture of the skin, nor can it be considered a remedy (remedial camouflage suggests it’s a cure), all it can do is to make your vitiligo less noticeable.

### **So how do skin camouflage products differ from other cosmetics?**

Skin camouflage crèmes are best described as being hyperpigmented ointments, which are set with loose powder. Although concealers and make-up foundations can be very effective in masking the hypopigmentation associated with vitiligo, they do not have the necessary properties of skin camouflage. When correctly applied skin camouflage is waterproof, which means you can go swimming, take a shower or have a bath and be out in the rain without the fear of it washing off.

The products have sun-screening properties but no skin camouflage should be considered a full sunblock and certainly not as such for the whole day. Non-greasy sun protection can be applied underneath and reapplied over your camouflage throughout the day and for those who like to wear make-up, that too can be worn over the set skin camouflage!

(more .....)

To read the complete version of this coping strategy and see the other strategies please visit our website at [www.vitiligosociety.org.uk](http://www.vitiligosociety.org.uk). If you do not have access to the Internet, please send a large stamped addressed envelope to the Vitiligo Society at 125 Kennington road, London SE11 6SF

## LETTERS

Dear Jeff,

I have just caught up with the November issue of *Dispatches*, and I found the "what triggered my Vitiligo" letters to be fascinating.

My vitiligo has progressed in stages. I first got it around my groin as a baby- I have been told it was left over after nappy rash. It remained quite stable until I was a teenager when I got some new patches: in particular where clothes & underwear rub (waist band, tummy, sides of back). They would appear quickly, but then remain pretty unchanged.



My vitiligo was pretty stable again for a few years, until my early 20's when I got some new, more visible, patches on my neck, and shoulders. My sister had died, and I've never been sure if it is related or not. I was obviously very stressed and upset. But whatever the trigger, most of my 'new' patches (i.e. since being a baby) seem to turn up where clothes rub. I'd be interested if others have experienced this too. For example, my neck patch popped up after a holiday where I'd worn a halter neck swimsuit. And the shoulder patches are where my bra straps sit. Anyway, not sure if that is of interest. But it's good to share. Keep up the good work!

Kate Land

Dear Editor

Following up on your 'What caused your Vitiligo' letters. I started with patches on my elbows, knees and hands when I was about 10 or so. The assumption on my part reading previous reports was that it was triggered by puberty

As a child I was very shy and nervous and I wonder if that may have been a contributing factor. Forty more years on and I am completely white apart from patches on my face mainly the cheeks. For several years now I have been hoping that they would disappear but my skin just seems to have stabilised which I find most frustrating.

Interestingly when at school I never had 'micky' taking or any questions and it is only in recent years now I am virtually completely white that I get the questions and 'mick' taking.

Regards

Martin Nicholls

Dear Jennifer

We met briefly at the Vitiligo World Congress in Milan in September and I promised to get in touch on our return to the UK.

Like many others, I have always struggled with my vitiligo and found I had to dig deep to find the confidence and strength to face the workplace, a busy hospital where I am in close contact with members of the public as well as hospital staff/work colleagues. However due to the nature of my work, supporting often terminally ill children and their families, this has really helped me get my life in perspective and together with huge support from my husband and sons I find that as I get older (I'm 49 now and had vitiligo since expecting my first son 27 years ago) I am beginning to accept the vitiligo; I do feel more comfortable once my skin colour loss is even; I think I will find it much easier to accept being pale all over than struggle with the contrasting tan/white patches! And there is always St Tropez spray tan which is amazing! My husband Tim and I very much enjoyed the congress and it was especially lovely to meet Lee Thomas...what a special person...we have a smashing photo! We also met a lovely couple who had also attended the conference and who were staying at the same hotel; this is the first time that I had met and spoken to anyone else with vitiligo; we are now very good friends and I no longer feel anywhere near as isolated which for me has been one of the worst aspects of having vitiligo over the years. Anyway, apologies Jennifer, I hadn't intended to write an essay! In Milan you did mention something about the possibility of a vitiligo event in Bristol in the future; I would be happy to add my support to this in any way which would be helpful.

Yours sincerely Cheryl Hawes

# Dispatches Your views

Recent editions of *Dispatches* have been supported by a generous donation from VCTC - the specialist awarding organisation for vocational qualifications

Thank you to everybody who returned the questionnaire indicating your views on *Dispatches*. Here are the results of the survey.

Dispatches provides me with adequate information		Strongly Agree	Agree	Disagree	Strongly Disagree
1)	recent developments in vitiligo research.	52%	45%	4%	
2)	activities undertaken by the Vitiligo Society	52%	48%		
3)	participative events which are open to society members.	50%	50%		
4)	the personal experiences of others who suffer from vitiligo.	59%	37%	4%	
5)	medication and treatments available to vitiligo sufferers.	41%	47%	12%	
I consider that <i>Dispatches</i> fulfils its purpose in providing news and information for members of the Vitiligo Society		48%	52%		
I think that the frequency of publication (three times a year) is appropriate		42%	54%	4%	

Preferences for more features (Figures show the % of respondents who voted for each topic.)

Research	Personal Accounts	Fundraising	Medication & Treatments	Society Events	Participative Events
47%	32%	17%	76%	20%	17%

We will do our very best to take account of your views expressed in this survey.



## PLEASE HELP JESSICA WITH HER PHOTOGRAPHIC PROJECT



you, and you will be provided with an information sheet and model release form. The project will be transparent and overseen by both the UAL Ethics Committee and the Vitiligo Society.

I hope that anyone who participates in this project would be proud to be involved, and pleased with results. I am looking to work with people of any sex, age or race. As long as you can have a positive approach to this concept, and are willing to be photographed, I would welcome your contribution.

If you are at all interested in taking part, please do not hesitate to send me an email and I will send you a further information document that goes into the project in more detail. My email address is included below. If you would prefer, you can contact the Vitiligo society directly, who can pass your details to me.

Thank you so much for taking the time to read this, and I look forward to hearing from you,

Jessica Levy

[jessicafranceslevy@live.com](mailto:jessicafranceslevy@live.com)



Dear Vitiligo Society members,

I am placing this open letter in *Dispatches* to appeal for your help in a photographic project which I am currently undertaking.

I am in my final year of a photo-journalism degree at the University of the Arts London and am taking this opportunity to produce a body of work on vitiligo that, along with being submitted as part of my portfolio, will form part of a public exhibition in the summer.

Vitiligo is a subject close to my heart, having been diagnosed with the condition several years ago. I want to produce a range of photographic work encompassing the physical appearance of vitiligo, as well as possible treatments and how it affects the lives of those who live from it. When I was diagnosed with vitiligo I was given a number of documents on the condition by my GP. The word 'ugly' was used repeatedly and, although upsetting at the time, looking back I am shocked and angry that that point of view is still widely accepted.

I have decided to make vitiligo the focus of my major project as I hope I

can, in some small way, contribute to that view being changed. I hope that people who see these photographs can see vitiligo in a new, positive light- can be happy to stare at my photographs for as long as they need and not feel they must look away immediately, embarrassed, as if they had been caught gawping.

As well as being accessible, I want to my photographs to be aesthetically pleasing. Yes, vitiligo looks unusual, but it is interesting. As I am sure you know, the marks or patches are often symmetrical on the body; they are in strange shapes and are unique to each person. Features like these are what make us individual and distinctive, and I want to use this photographic project to celebrate this.

And so I am looking for people to work with me over the next few months. Your contribution can range from a single portrait session to meeting up several times and photographing your day-to-day life. There is absolutely no level of compulsion in this project; we can discuss your involvement before we begin and you can opt out at any point. I will ask for your approval before using any photograph taken of

## THE VITILIGO SOCIETY PUBLISHES COPING STRATEGIES

The Society has published the following coping strategies for vitiligo sufferers. To read the complete version of this coping strategy and see the other strategies please visit our website at [www.vitiligosociety.org.uk](http://www.vitiligosociety.org.uk). If you do not have access to the Internet, please send a large stamped addressed envelope to The Vitiligo Society at 125 Kennington Road, London SE11 6SF.

Diagnosis Psychological Treatments Young People

- Suggested Reading Sequence**
- A Guide At First Diagnosis**
- Managing Other People's Reactions**

Diagnosis Psychological Treatments Young People

- Your Emotional Journey**
- Stress - A Personal Journey**
- How To Live With Vitiligo**

Diagnosis Psychological Treatments Young People

- Making Treatment Decisions**
- Skin Camouflage**

Diagnosis Psychological Treatments Young People

- For 7 - 11 Year Olds**
- For 12 - 15 Year Olds**
- For Parents and Carers**
- Young Persons' Video**

## WALK FOR SKIN 2011

The British Skin Foundation have announced details of the 2011 Walk for Skin. As well as the guided city and parkland walks, to which you've become accustomed, they are offering a series of walks aimed at the more adventurous..

### London Walk for Skin – 22 May 2011

This year's event kicks off in London on the 22nd May with a guided walk taking in the historic sites along the city's famous river Thames.

### Leeds Walk for Skin – 26 June 2011

Leeds will once again be hosting a walk which will take place on the 26th June in Roundhay Park, just a couple of miles from the city centre.

And for those who feel up for a challenge:

### Cheddar to Glastonbury Walk for Skin – 30 July 2011

On the 30th July there will be a day long walk from Cheddar to Glastonbury where you can experience the spectacular Somerset countryside as well as the historic and picturesque towns of Wells and Glastonbury.

### North Pennines Walk for Skin – 17 September 2011

The 17th September sees the Walk for Skin heading to the North Pennines for a truly spectacular 10 mile/16 Km walk starting at the village of Dufton in the Eden Valley and taking in some of the most stunning scenery in the UK.

### South Downs Way Walk for Skin – 24 September 2011

On the 24th of September the village of Ambereley in West Sussex takes centre stage as the start of a spectacular and challenging 9 mile walk along the South Downs. Along with the amazing scenery, this fully guided walk offers a taste of the area's varied history.



### Registration

To take part in these events please visit the BSF website at [britishskinfoundation.org.uk](http://britishskinfoundation.org.uk) and download a registration form or you can simply pick up the phone and call 020 7391 6341 and one of the BSF events team will be happy to take your details. Please remember to nominate the Vitiligo society as your chosen charity when you return the form. The BSF can also help you to organise an event of your own and can even help you to stage your own Walk for Skin at a location of your choice. Just drop them an email at [events@britishskinfoundation.org.uk](mailto:events@britishskinfoundation.org.uk) or call on 020 7391 6341



## ONLINE SURVEY

### **Please take part in our online Medication and Treatment Survey.**

The Society is gathering information on what treatments vitiligo sufferers have undertaken and the perceived success of each. This information will be published to our members and used to inform future research.

So far more than 200 people have undertaken the online questionnaire but we need many more to ensure that the widest possible coverage of vitiligo sufferers and their experiences.

The medications and treatments about which we ask questions are:

- steroid creams,
- vitamin D analogues (Calcipotriol/Dovonex)
- Tacrolimus (Protopic)
- Pimecrolimus (Elidel)
- Narrowband UVB - without Pseudocatalase
- Pseudocatalase with Narrowband UVB
- skin graft
- herbal or homeopathic medicines
- skin depigmentation
- psychological and counselling



Please undertake this survey by visiting our website and clicking on the link on the right hand side of the home page. The survey is anonymous: there is

no requirement to enter your personal details

### DATES FOR YOUR DIARY

**Saturday 24 September 2011**

**Parents' Support Group**  
125 Kennington Road SE11 6SF  
starting at 14.00 hours

Please let us know if you plan to attend