WEBSITE SUCCESS
In This Edition

Page 3 Web Site and Support Groups
Page 4 Young Editorial Board
Page 5 The Claire Cooper Interview
Page 6 Society Publicity
Page 7 Animal Day at Cambridge
Page 8 The Spartan Interview
Page 9 Camouflage Advice
Pages 10,11 & 12 - Letters
Page 13 SRUSD Research For 2009
Page 14 Research - Computer Based Study
Page 15 Face Equality Campaign
Page 16 Information for Members

This is our second “Young Persons Dispatches” and the Young Editorial Board have been hard at work producing many of the features in this Edition. Those who took part were Becca Moore, Abbi Rose, Karim Mayers-Kasmiri, Natalie Ambersley, Michael Johnson and Morgan Daniella Whyte.

On the back page you will find details of the Society’s Annual General Meeting to be held on 26 November 2008 at 6.00 p.m in Central Hall Westminster. Please attend if you are able. This is your opportunity to have your say and hold the trustees to account for what has, or has not, been done this year.

Next year is the 25th Anniversary of the Vitiligo Society and we are planning several events for members. Who would have thought that 25 years would fly by so quickly? In that time the Society has done a great deal to promote the interests of its members; in particular, through the provision of better information and the sponsorship of new research. We must never forget that our aim is ultimately to seek a cure but meanwhile to care for those affected.

The Vitiligo Society, 125 Kennington Road, London SE11 6SF Freephone 0800 018 2631 Office 020 7840 0844 Fax 020 7840 0866
www.vitiligosociety.org.uk email: ken125@vitiligosociety.org.uk Registered Charity No 1069607 : Company No 3542195

Items for publication in the next issue should be addressed to The Editor, Dispatches, The Vitiligo Society, 125 Kennington Road, London, SE11 6SF, (email: Jeff_lock@vitiligosociety.org.uk) and should arrive by the end of January 2009.

Statements and opinions expressed in Dispatches, whether in editorial matter or in advertisements, are not necessarily those of the Vitiligo Society. While the Society may provide product information or allow companies to distribute samples, it does not endorse or recommend particular products.

The Editor reserves the right to shorten and/or edit items submitted for publication.
We have tried it before and we are going to try again! So many people contact the Vitiligo Society and ask if there is a Support Group they could attend, and meet others with vitiligo, that we feel the 25th Anniversary Year would be an ideal opportunity to try to offer this opportunity. As you can see from the report below on our first Support Group that was held in Taunton on the 20th September it was a great success - even though only a few people turned up for the meeting it was well worth it. Being able to talk with other people who suffer from vitiligo is a great way to hear other people’s experiences of coping with vitiligo, sharing your own, as well as making new friends. If you would be interested in organising a support group please let us know. We will help with the organisation, cover the cost of the venue and refreshments - within reason, even the BBC are cutting back on the amount of champagne they drink! We will also send letters to members in the area letting them know what is planned in addition to placing the information on our website. If you feel you would like to take part in a Support Group in your area but would rather not take part in the organisation please also let us know and we will see what we can do.

TAUNTON GROUP : HOPEFULLY THE FIRST OF MANY

Caroleann Pitfield, Senior Co-ordinator /Practitioner/Trainer Skin Camouflage Exeter, very kindly offered to organise a Support Group in Taunton for the Vitiligo Society - Taunton being a convenient and central location for the South West. She summarises the day: Unfortunately because we were not able to get an article in the local paper announcing the Support Group I was not unsure if anyone would turn up. Six people came, all members of the Vitiligo Society, except for one who came with her sister. So I really was delighted to at least have some people turn up on such a lovely sunny Saturday! Not knowing what to expect I did rather think people would pop in for a coffee, see the skin camouflage presentation, have a chat then go but they all stayed together from start to finish. All seemed to have lots to talk about to each other which was just wonderful.

WEB SITE LAUNCH SUCCESS by Robert Fluin

As members will know, in July 2008 The Vitiligo Society launched our new website, this is part of an ongoing project to raise our profile and increase awareness. To achieve maximum publicity and coverage we were helped by a small publicity company.

In short, the website is a success. Based on a comparison of figures from March 08 (old website) to August 08 (new website) the number of people visiting the website has doubled, with over 200 people a month spending in excess of 30 minutes looking through the features available, and (now that people can join almost instantly through our website) memberships are on the increase. For those of you who are yet to visit the website we would encourage you to do so. The website is easy to navigate and user friendly, you can find information on treatments, research, upcoming events and much more. You will also have access to the Members Area and exclusive content, however before doing so you will need to register. This is easy. On the home page click the big JOIN TODAY button which will then take you through to the registration form. Fill this in as instructed, creating a suitable username and password then enter in your Member Number. Once completed you can access the Members Area using your username and password. If you have any problems phone me (0800 018 2631) or email me (robert_fluin@vitiligosociety.org.uk)

One area of interest within the members area may be the Forum. Here you can enter into discussions on treatments, skin camouflage, etc… with other members. You may also find the answers to questions you may not get from just reading through literature from people posting their first hand experiences of treatment use and life experiences. The Forum is a great place to talk about vitiligo with people who suffer from vitiligo and I highly recommenced making use of this.

The new website has brought some very positive comments particularly from members of our Medical and Scientific Advisory Panel (MASAP). “the new website looks good and the medical professionals page looks good” Professor David Gawkrodger “the new website looks wonderful! It’s so positive and informative am sure it will make a big difference to a lot of people” Dr Linda Papadopoulos “the website looks great, I like the opening video!” Dr Dorothy Bennett
THE EYE SEES ALL  by Jeff Lock

On Saturday 6 September 2008, the Young Editorial Board gathered to put together another edition of Dispatches. But before work commenced there was the small matter of a flight on the London Eye. The weather was squally and inclement but the views were still substantial. London stretched away from us in every direction stimulating our brains to more frenetic activity back at Vitiligo HQ.

First there was the matter of editing the celebrity interviews conducted back in June. Then the board put its mind to writing down a coping strategy for young people who have vitiligo.
THE CLAIRE COOPER INTERVIEW  by the Young Editorial Board

Not vitiligo but one had a very large birthmark which was not hidden, on reflection it could have been vitiligo

Did you go to stage school?
Yes at 18 for an acting degree at Guildford School of Acting. 8000 students were auditioned for 20/25 places. I won a full scholarship

How many auditions did you have for your role in Hollyoaks?
I had three auditions and then the Hollyoaks producers had to get the agreement of the Channel 4 producers for me to have the role as well

Does filming Hollyoaks take up a lot of your time?
Yes, if it is a heavy workload as at the moment till October. I start at the studio around 6.30am for a 12 hour day and then spend some time learning lines after dinner till around 10.30. The cast are really good fun and I’m really proud to be part of Hollyoaks.

Do the cast do their own stunts?
Some are done by the cast such as the water stunts when Claire’s car went over the edge but otherwise they are done by stuntmen

When do you get your scripts to learn?
You get scripts about a month before you film them but I read them closer to the filming date otherwise the story lines can become confusing. We also may film a number of blocks in one day and not necessarily in story order, for example in the story about Jacqui’s baby we filmed in one day:
1. Jacqui losing the baby,
2. Before the baby was lost
3. then sometime after losing the baby.

Would you say that you have anything in common with your on stage character Jacqui McQueen?
Lip gloss but different shades. Seriously both of us are fun and playful and there is always an element of me in a role that I play

Do you take the character home with you?
I try not to but it can be difficult if it is an emotional scene like when Jacqui lost the baby. One of the things they try and teach at drama school is to let go of a character.

When were you younger did you want to be an actress?
When I was a gymnast I realised that I liked the performing element and by 13/14 I knew I wanted to be an actress and if I failed at this an Interior Designer. As a child I liked drawing and painting, I was passionate about the arts but also did well at the more academic subjects, which was useful as my acting course was also quite academic at times.

Do you like seeing yourself on TV or in movies?
No not really. I always notice my faults but this is how you learn what you need to improve upon. I believe that you can either act or you can’t, although your acting can be fine tuned you need creativity in the first place and need to continue to search for it to improve your performances.

Who are your heroes?
Gary Oldman, Johnny Depp. However other people in my life such as my friends and family are more inspirational to me than a recognised celebrity

Do you have any insecurities?
I would like to be taller, have less freckles and thicker lips. Everyone has hang ups and you only live in the world that you live in. You need to think for the wider world and weigh your problems up in this. I also believe that you need to be with people who generate positive energy as this energises you
SOCIETY PUBLICITY

SHAZIA MURZAH

Shazia Mirza, one of the UK’s leading comedienes, recently visited the Society’s offices at Kennington and kindly took part in the promotional film which is now on our website.

Shazia gained fame as a stand-up Muslim comic – a brave thing to do in all the post 9/11 xenophobia. She told us how she trained for stand-up by being a science teacher, as the best way to control her unruly pupils was humour. Shazia told us about her forthcoming TV series. One episode will feature her meeting girls in Liverpool, whose one ambition in life is to date Premier League footballers and for whom sunbeds are a weekly must, despite being aware of their great damage to skin. Like a lot of people, Shazia had seen people around with Vitiligo, but didn’t know much about it until her visit; that’s why the Society’s so useful as a source of information and support to both sufferers, their families and the medial world. Shazia recently had a show at the Edinburgh Festival; look out for her new TV series in the autumn. So a big Thank You to Shazia for taking the time to help us.

NEW TEAM MEMBER: ROBERT FLUIN

I have recently started working for The Vitiligo Society in Kennington. This is an experience I feel privileged to have. The Vitiligo Society once helped me to understand what vitiligo is and I now get to help other people who suffer from vitiligo in the same way. Long standing members may remember a series of article’s that I had written for dispatches a few years ago about my personal experiences with vitiligo and the effects it had on my life. Since then a few birthdays have been and gone and I am now engaged expecting my first baby. Here at the Society my role begins with answering and dealing with telephone calls as well as responding to e-mail enquiries. I will be helping to develop and maintain the website and assisting with fundraising. Not only that, I will also be undertaking general administrative duties in the office.

I am glad to be on board and am hoping that I will be able to make a difference here. Next time you phone us here at The Vitiligo Society it may well be me who takes your call.
On 12 July 2008 Changing Faces held an “Animal Day for Families” at Huntingdon in Cambridgeshire which was attended by vitiligo sufferer Karim Mayers-Kasmiri.

Changing Faces is a leading UK charity which was founded in 1992. It supports and represents people who have disfigurements to the face, hand or body from any cause. Currently it has a team of 25 professionals with expertise in psychology, education, employment, health and social care, media and campaigning. Their work involves, (1) providing personal support for children, young people, adults and families, (2) working with schools, employers, health and social care professionals to ensure a culture of inclusion for people with disfigurements and (3) campaigning for social change by working with the media, government and opinion leaders. Changing Faces is currently conducting a major “Face Equality” campaign in the media and through its web site at http://www.changingfaces.org.uk.

The Changing Faces Animal Day was aimed at children in school years 1-3 with games and activities aimed at promoting self esteem, confidence and social skills. By using animals as the theme they explored the children’s’ reactions to a variety of mammals, birds and reptiles. After a session which involved looking and touching, the children were encouraged to discuss the characteristics of the animals and then go on to explore the characteristics that they like in people which was helpful in thinking about meeting new people and making new friends. Afterwards, Karim aged 7 wrote the following letter to the vitiligo society:

At Changing Faces we went to Cambridge (which was 100 miles there and 100 miles back = 200 miles). We went to a building and had something to eat. Then we went to the animal part. First we saw an adult barn owl called Desimo – easier Desamo. Next, we saw a 13 day old owl which was bigger than the older one. Then we saw a tortoise. I held it and showed it around. Just as I gave it back it did a BIG wee!

After that we saw a millipede. It had 274 legs. Soon two people held a lizard. It was small and cream coloured. It was put on blond hair of someone alive. Then it was put on me. It didn’t settle down but the blond hair on its chin went black. Then we saw a yellow snake from the Sahara desert in Africa. We made a bed for it. The scary thing was that I was at the head bit and it said “hissssssshisssssssss” Then we saw a brown spider called Charlotte (named after Charlotte’s Web). It was very hairy.

These are the types of faces people had: uneven jaws, one eye, a scar and vitiligo: the others were sisters.

Karim’s drawing of his day out with some help from Spartan
Rod Bradley – “Spartan” the Gladiator went to Loughborough University, where he studied Illustration, and he has worked as an artist since leaving university. Spartan was interviewed when he visited the Vitiligo Society on the 6\textsuperscript{th} June 2008.

Where you excited when you were chosen as a gladiator?
Yes I was excited, although I am a professional artist, I was helping my cousin that day with his landscape gardening business when the ‘phone call came through. I was told that I had to keep the news “secret” but that was impossible and my cousin and I spent 20 minutes “jumping” around the garden. I was just so excited.

Did you have to work hard to get fit to be a gladiator?
I was already fit - that is why I was chosen to be a gladiator. It is my way of life, my lifestyle. I have always been interested in all kinds of sport, finally specialising in American football. To play you have to be fit especially making sure that the muscles around joints are strong to ensure that you project yourself against injury. This has given me the physique that is required to be a gladiator.

What do you most enjoy about your new job?
I really enjoyed the filming and taking part in the different “events” – it was like a giant playground.

Are accidents common?
There are risks. However, you must push yourself, you have to be fearless – there is more chance of injuring yourself if you only commit yourself 50%.

Have you always wanted to be a gladiator?
Every young lad would want to be a gladiator. I was in an hotel when I overheard Ian Wright the Producer of Gladiators talking about the new programme with his production staff. I interrupted them rudely – shouted at them “I want to be a gladiator”. Normally auditions were by invitation only. This has reinforced my belief that there is a right time and place for all things and you have to take your opportunities when you can. If I hadn’t had this opportunity I had planned to play a few seasons of professional American football. I much prefer being a gladiator.

What “challenge” do you most enjoy?
I am one of the very few gladiators who can compete in all the challenges this is because I have the versatility of being both strong and fast. I think though my favourite challenge is the pyramid – this involves me standing at the top of a 25 foot pyramid and making sure a challenger doesn’t reach the top – I have to hurl them to the floor.

Had you ever heard of vitiligo before now?
Yes I had – when I was at school a lad a couple of years older than me had vitiligo. He had vitiligo on his hands, feet and neck. I never saw it as a disfigurement and he was popular at school. I also played football with someone who had a white flash through his hair from vitiligo and patches on his legs – he would not want to change himself – he thought his vitiligo made him unique.
CAMOUFLAGE ADVICE

TIPS WHEN APPLYING CAMOUFLAGE OVER MOISTURISER, SUN PROTECTION AND TOPICAL MEDICATION by Elizabeth Allen

Traditional skin camouflage has an oil base, which is then set with loose powder. People who have dry skin and want to use moisturiser and for those who wish to apply sun protection or their topical medication prior to their skin camouflage should follow these simple steps:

1. Treat the skin by applying the moisturiser - sun protection - topical medication (as recommended by manufacturer) 2. wait about 20 minutes for your skin to absorb the product 3. blot off any excess with a disposable tissue 4. apply your skin camouflage over the "treated" skin

No camouflage product can be considered rub-proof, although they are smudge-proof and once correctly set are waterproof. Durability of the camouflage depends on where it is placed - if on an area of skin, such as the nostrils, and you repeatedly blow your nose, then the camouflage will need reapplying frequently. Stability of the camouflage depends on what products are used under and over it. It helps if the moisturiser - sun protection - topical medication is oil-free. Oil free sun protection can be applied over the set skin camouflage area, providing it is not rubbed into the skin (the spray on sun protection is very handy as you can then carefully wipe the product across without disturbing the camouflage). Also, oil free make-up can be applied over the set camouflage but again care needs to be taken during application not to disturb the camouflage.

It can be argued that people with oily, combination or normal skin (as measured in beauty terms) have little or no need for a moisturiser where their skin camouflage is applied. This is because the oil in the camouflage acts in the same way as a moisturiser.

People who have an oily skin may find that their camouflage is less stable, and will need to repowder frequently. If keeping the camouflaged skin matt is a problem, then use a powder that is rice based, such as Kryolan’s Anti Shine (available from C H Fox, a 30g pot costs £10.00 (plus P&P)) which is a microfine, colourless setting powder.

No camouflage product can be considered rub-proof, although they are smudge-proof and once correctly set are waterproof. Durability of the camouflage depends on where it is placed - if on an area of skin, such as the nostrils, and you repeatedly blow your nose, then the camouflage will need reapplying frequently. Stability of the camouflage depends on what products are used under and over it. It helps if the moisturiser - sun protection - topical medication is oil-free. Oil free sun protection can be applied over the set skin camouflage area, providing it is not rubbed into the skin (the spray on sun protection is very handy as you can then carefully wipe the product across without disturbing the camouflage). Also, oil free make-up can be applied over the set camouflage but again care needs to be taken during application not to disturb the camouflage.

BASC tested it during a training programme, on one of the hottest days of the year (some years ago!!) and after several hours all the willing victims had one half of their face matt, the other side you could fry eggs on!!!

There’s Nothing New!!!!

Oil and beeswax creams are among the oldest skin preparations known, with recipes surviving from the Ancients. Most preparations were used for cleansing the skin, some were perfumed with incense (for ceremonial use) and others were recommended to restore the complexion. Products containing more exotic ingredients were frequently used, such as “anti-wrinkle” balms; one recipe required a mixture of writing fluid, hippopotamus fat and gazelle’s dung to be applied for four days! (Think I’ll stay with the laughter lines!!).

We therefore must be very thankful to the Greek physician Galen, who, in the second century not only warned about the dangerous ingredients used but also devised the first “cold cream” to combat (albeit without success) the use of skin whiteners that contained mercury. He recommended the use of an emulsion of flower water, molten beeswax and olive oil. This basic recipe, sadly, was left to gather dust (the people preferring the exotic to the simple!) until in the 19th Century Theron T Pond resurrected it.

Cold creams and cleansing creams are essentially the same kind of product. They are usually creams which have high oil content, known as “water-in-oil” emulsions. Such an emulsion, by design, is not particularly stable, therefore, when applied, the water content quickly evaporates giving a cooling effect to the skin (hence the popular term “cold” cream). When applied to the skin, the cream leaves the oil phase to mix with, and dissolve, any grease and dirt on the skin, which is removed when the cream is wiped away.

We use a form of “cold cream-moisturiser” to remove camouflage and cleanse the skin.....which is why, if not fully wiped off it will destabilise any make-up or skin camouflage immediately applied on top.

Article written by Elizabeth Allen of the British Association of Skin Camouflage
Dear Editor

Hair Update (1)

I’ve just come on leave and have been ploughing through the post – last night I read the July Dispatches. Lesley Murray talks about vitiligo in the hair. I’ve had that for a long time, and also on the outer end of my left eyebrow. None of this looks obvious as my eyebrows thin towards the outer ends anyway, and the hair was on the temples, thus giving me an unwarranted elder statesman look. I say was, because some years ago I went blonde, and now the white hair only shows on close inspection – the blonde has a golden tinge. My body hair also goes white, but only some time after the skin. (Too much information?)

As far as sunblock is concerned, I have found that anything goes. I am using a factor 40 which I bought when I was still in South Africa, but I have used years-old stuff from the back of the cupboard which didn’t even have a factor on it (am I a cheapskate?) and I never burned. This was in Cape Town. Fat chance I have of getting burned here, but I still put it on, particularly my neck and the back of my neck, the blonde bits being short. If I do burn, I generally get a few patches of pigment back, but they don’t last and I have long since stopped getting excited about them.

I am too fair for the picture to show the vitiligo, but it does show you don’t have to be scared of the sun. It was taken in Barrow-in-Furness in June this year, and for there to be any sun to take a picture by is unusual in that town. You can see the eyebrow...

Yours sincerely
Rose King

Editor : Whilst some people with vitiligo do not tend to “burn” many are particularly vulnerable and care should be taken. – Please see Members Offers in Members Area of our new website for a free offer of a sun care product.

Dear Editor

Hair Update (2)

I read with interest Lesley Murray’s article about Vitiligo affecting the colour one’s hair and seem to remember following her last letter about Dove self tanning moisture with a letter of my own about Johnson’s Holiday Skin, which you published, and which is another excellent self tanning moisture.

I have had Vitiligo for about 30 years and one of the first things I noticed is that a patch of white hair appeared on either side of my face near my temples and, worse still, was that my left eyebrow and eyelashes turned white around the same time!! The odd thing is that my right eyebrow and eyelashes have stayed dark all these years even though Vitiligo is supposed to be symmetrical. I dye my left eyebrow and eyelashes with an eyebrow tint which normally lasts for about a month.

Best wishes,
Vanessa Wilkins

Dear Editor

BEN RUNS FOR VITILIGO

Dear Editor

Well, on Sunday 5 October I did the Great North Run (“the world’s biggest and most prestigious half-marathon.”so they say) in 1hr 55mins 54secs; and it looks like about £350 will be making its way to you via justgiving. This is a dreadful picture I look on the Tyne bridge (while doing the run)

Regards Ben Funning
Dear Editor

Will My Children Inherit Vitilgo?

I am a 35 year old woman who has had, what I guess, are relatively small patches of vitiligo (hip to hip, back of neck and under arms) since age 6. These have been fairly stable though I think the patch on my neck appeared in my teens.

However, I am now considering having children. After struggling to accept the psychological consequences of my vitiligo myself, am anxious about passing the condition on to any children I may have and saddling them with what I have found to be a very distressing condition. I am particularly anxious about the possibility of any children I have having more severe or visible symptoms which would be likely to cause them significant distress.

I understand that there is a 5-7% risk of passing vitiligo on to one’s children. Is there any research indicating subgroups of vitilgo sufferers who are more likely to pass the condition on? Is there anything I could do as a mother-to-be to reduce the likelihood of passing on the disease?

Regards
Leanne Jones

Dear Leanne

Your message was sent on to me to see if I could comment, which I am happy to do.
Yes, there are a couple of things that affect the relative chances of a child of yours getting vitiligo.

(1) It is more likely if vitiligo is already running in your family - did your parents, grandparents, brothers or sisters have it, or did they have any other autoimmune conditions, like thyroid disease, or late-onset diabetes?

(2) Similarly it is more likely if your husband/partner has vitiligo etc in his family.

If no-one else in your family or his family has vitiligo, then the chances are not much higher than normal, though it might be misleading to try and give a figure for the probability, as it does depend on many things.

I can’t think of anything you could do to change the chance of passing it on, sorry, but there are many very positive ways of dealing with vitiligo, and the Vitiligo Society (and its web site) can be very helpful in finding those out.

So I’d say that even if you find you are someone with a chance of passing it on, it’s important not to worry that you are doing something bad for the child, in having a child. So long as the child is loved and valued, s/he should be able to cope with the condition if s/he does get it.

Regards
Professor Dorothy Bennett

Dear Editor

Good News

Good news with piperine. I just wish progress was sooner. With regard to taking vitamins B12 and Folic Acid, I tried both and would report that the hairs on my forearms grew and some were black. Something definitely happens when those vitamins are taken.

I found the enclosed newspaper cutting which says that “People with blue or green eyes have less protection from UV light than those with brown eyes, and are therefore more likely to need sunglasses. The darker your eyes the more UV-blocking pigmentation you have.”

I had black hair when I was young. I have dark brown eyes and my eyebrows are still black although my eyelashes have changed to white owing to vitiligo. I never burn when I am in the sun. This includes my forearms and legs.

Viticolor

As I mentioned to you recently, I could not get a prescription from my doctor for Viticolor as it was not on their list. I took my empty tube and typed a short note to the pharmacist telling him the products had changed companies to York. The first didn’t want to know. So I tried a larger chemist who said to return in a few days when they would have it for me. I did return and the charge for the product was £24.25. Its not on prescription after all. I thought I would drop you a line just in case you want to find out more information for others trying to buy Viticolor.

Best wishes
Ruth Williamson
Dear Editor,

More On B12 and Folic Acid

I have just read the letters page of Dispatches no.48, and having read the statement regarding safe dosages of vitamin B12 and folic acid, I'm now a little confused. In her letter, Jean Vallance mentions dosages in "microgrammes", which I think means one millionth of a gramme, but the rest of her letter and the statement then use the abbreviation mg, which I think stands for milligrams, or one thousandth of a gramme.

I have been taking a combination of vitamin supplements to attempt to reverse or at least slow down the spread of my vitiligo for over two years. As a guide, I used the amount of each active ingredient in Recouleur, a supplement I've seen advertised in Dispatches. Based on this, I've been taking 100 microgrammes of B12 and 800 microgrammes of folic acid nearly every day, and although I haven't experienced any ill effects, Jean's experience with her GP and the confusion regarding the quoted figures has caused me some concern. I'd appreciate it if you could clarify the units used as I can't work it out if I'm within the safe limits mentioned or well over!

As an aside, I'd like to say that I have had results similar to previous correspondents using this method combined with controlled sun exposure. I have had vitiligo patches on my chin for the last three years, first on one side and then the other. The first side is now nearly completely repigmented, and the other side is well on its way. However, vitiligo on other parts of my body that aren't commonly exposed to the sun have remained the same. It might simply be sun exposure, but maybe the supplements have had a beneficial effect as well.

If anyone's interested, I've been able to match the active ingredients of Recouleur by buying the following:

- Holland and Barrett B100 vitamin B complex, which contains among other things 0.1 mg of B12 and 0.4 mg of folic acid. Folic acid is also widely available separately and I've been taking another 0.4 mg a day to bring me up to the 0.8 that's in Recouleur.
- Holland and Barrett Chelated Copper 2mg
- Boots Vitamin C (500mg) & Zinc (15mg) - I've read that it's important to get the one with zinc if taking Vitamin C supplements regularly as large amounts of Vitamin C can inhibit the body's uptake of zinc.

Best regards,

John Godfrey

Editor: We have asked our expert and she has replied. "In answer to this query, John Godfrey is right 1 microgram (mg) is 1000th of a milligram. Unless they are very small quantities they are usually expressed as a fraction of a milligram. His intakes of 0.1mg B12 and 0.8mg are above the RNI but within the levels generally considered safe in the FSA report. His comments about improvement reinforce the issue of how much sun is helpful and how much is harmful. Some studies show that adding vitamins with UV treatment improves the outcome, but some don't so another area urgently needing more study! We hope this answers your concerns.

VITIX UPDATE by Ashley Wait

A user assessment on ViTiX gel, a novel treatment for Vitiligo, was conducted during 2007 by Crawford Pharmaceuticals with the cooperation of Vitiligo Society members. Feedback was collected from 50 participants at the end of 2007 and sent for review. The report on the assessment has been delayed following the acquisition of Crawford Pharmaceuticals by York Pharma at the end of 2007, with a resultant focus on successfully implementing the integration of the two companies.

York Pharma apologise for the delay in providing feedback and whilst unable to provide a definite date for publication will continue to cooperate with the Vitiligo Society to make the report available to members as soon as possible.

York Pharma (UK) Ltd
SPRUSD: RESEARCH PRIORITY FOR 2009: AN OPPORTUNITY FOR MEMBERS TO BE INVOLVED by Sally Crowe

The Vitiligo Society is a key partner in a new project that has been funded by the National Institute for Health Research (NIHR), and is being co-ordinated by the Centre for Evidence Based Dermatology in Nottingham. It is an ambitious project with several streams of work, including vitiligo and eczema, and it will last 5 years.

The project is called Setting Priorities and Reducing Uncertainties for People with Skin Disease or SPRUSD for short! What will the project contribute to vitiligo research?

☐ The current systematic review of treatments for vitiligo will be updated, and made available on the Cochrane Collaboration database www.cochrane.org. This gives doctors and other health professionals’ vital access to the most up to date research on treatments that are available for the condition.

☐ The Society, and its members will identify areas of uncertainty in treating vitiligo – and these will all be entered into a national database www.duets.nhs.uk along with uncertainties from other sources.

☐ A priority setting process that includes the Society and its members, health professionals and researchers will agree a ‘top ten’ list of research questions about treatment uncertainties in vitiligo.

☐ One of the ‘top ten’ will be developed into a feasibility study by the UK Dermatology Clinical Trials Network – this is where researchers determine the ‘workability’ of the research project (e.g. whether enough patients can be recruited for the study), challenges in doing the research are identified, and solutions are suggested.

☐ Following the feasibility study a full clinical trial protocol will be developed – a protocol is a detailed description of the way the trial will be conducted, and will include a lay summary suitable for a wide audience.

☐ The protocol will then be submitted to the most appropriate research funding organisation for approval and funding, resulting in a randomised controlled trial.

The learning from the programme will also contribute to up-to-date information for people living with vitiligo, carers and families and health professionals (especially those that don’t come across the condition routinely). It is also likely that the results will raise the profile of the Society, as this sort of work is novel, and of particular interest to the funders of the project, the National Institute for Health Research, and the Medical Research Council.

The James Lind Alliance is also a partner in this project The alliance is named after the naval surgeon James Lind who in the 1700’s, was the first person to describe a clinical trial to find the best treatment for sailors that had scurvy. He discovered that the best treatment was citrus fruit, and by describing his work encouraged others to test treatments. www.lindalliance.org.

The James Lind Alliance wants to promote more and better treatment research in the UK. It has been developing methods for collecting uncertainties in treatments, and then prioritising them. So far we have supported projects looking at treatments for asthma and urinary incontinence, and now we will be working with the SPRUSD programme team to support the work in vitiligo. The James Lind Alliance knows very little about vitiligo, but we suspect that you have important perspectives and experiences about your treatments, and at some stage in 2009 we want you to share these with us, via the Society. This is an important opportunity for the Vitiligo Society to help determine where the money goes in treatment research for vitiligo – please don’t let this pass by when we ask for your help!

It is also likely that the results will raise the profile of the society, as this sort of work is novel, and of particular interest to the National Institute of Health Research and the Medical Research Council.

Sally Crowe
What was the aim of the study?

Some people who have a visible difference report difficulties such as staring and questioning by the public. These can be very distressing and in some instances may lead to feelings of anxiety, particularly in new social situations. Organisations such as Changing Faces and the NHS provide services to help those who experience these problems. Research has suggested that psychological interventions based on communication skills and addressing the assumptions made by others can be helpful. A new computer-based online psychological programme has been developed to help individuals who experience difficulties associated with having a visible difference. It consists of 8-weekly sessions focussing on social skills, and behaviour and thought change. This study evaluated this new programme in comparison to standard face-to-face support.

What did I do?

83 people (49 female, 34 male) with various types of visible differences including skin conditions, craniofacial conditions, scarring due to burns, and other injuries, alopecia, birthmarks and amputation took part in the study. Participants were aged from 18 to 83 years, with an average age of 45. Participants were placed in one of three different groups; standard face-to-face therapy, the new computer programme or no intervention. Participants were asked to complete a series of questionnaires at the start of the study, at the end of the 8-week sessions and then again 3 months and 6 months later. Data is still being collected from participants at the 3-month and 6 month follow-up points. The data represented in this report is based on the complete pre and post-intervention results and preliminary 3-month results. Full results for 3 and 6-month follow-up will be provided towards the end of 2008.

What did I find?

The results indicated a significant reduction in anxiety and depressive symptoms experienced by the participants in the face-to-face and computer intervention groups. A significant reduction was also found for appearance-related and body image concerns. The results for both the intervention groups were similar, indicating that that the new computer programme was equally effective at helping individuals with visible difference to cope more positively, as the traditional face-to-face method. There was no change in anxiety, depressive symptoms or appearance and body-image concerns for participants in the no intervention group.

What’s next?

The aim of the study was to find out whether the new computer-based intervention was an effective way of providing psychological support for people who have a visible difference. The study found that the new computer programme was as effective as face-to-face intervention at providing psychological support to those with a visible difference. More data will be collected over the next six months, which will help us to evaluate the longer-term impact of both the computer intervention and the face-to-face intervention. Further analysis will examine whether the computer programme is more helpful to some individuals than others, for example according to age, gender or type of visible difference. Further research will evaluate whether the computer programme can be used by people in their own homes.

What do you think?

I hope this summary provides you with some details about the results of the study. If you find that you have any comments about this summary or any additional questions about the research (now or in the future), please feel free to get in touch with me.

Email: alyson2.bessell@uwe.ac.uk
Telephone: 0117 3281894
Postal Address:
Faculty of Applied Sciences
University of West of England
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Contact Information

If you would like any information or support relating to living with visible difference, please contact Changing Faces.

Telephone: 0845 4500 275
Website: www.changingfaces.org.uk
Email: info@changingfaces.org.uk
Postal Address:
Changing Faces
The Squire Centre
33-37 University Street
London
WC1E 6JN
In January 2008 Changing Faces conducted independent research to investigate people’s attitudes toward disfigurement. When directly questioned the vast majority said that they did not discriminate against people based on their facial appearance. However an Implicit Attitude Test revealed that 9 out of 10 people had negative attitudes towards people who have disfigurements. Many of these attitudes are unintentional and unwitting but still result in prejudice and discrimination against people with disfigurements in the way that

- They are treated at work
- They are treated at school
- They are portrayed in the media, film and advertising
- People react to them when they are out in public.

Face equality is about being treated fairly and equally irrespective of facial appearance. It is about creating a society in which everyone is valued for the unique contribution that they can make to society.

Changing Faces is launching a campaign that champions face equality and encourages people to stand out and show their support. They want to encourage people to learn more about their own attitudes by getting themselves and their friends to take the survey. They want to educate people on how they can personally do things differently and bring about a wide scale shift in the policies and practices throughout society: specifically

- Individuals to spread the word, stand out and support face equality
- Health and social care professionals to develop services that treat patients with disfigurement as having psychological and social as well as medical needs
- The education system to ensure that all staff are adequately trained to develop a culture and practice of inclusion for people with disfigurements
- Employers to create a culture and practice of face equality for people with disfigurements as employees and customers
- The media, advertisers and the film industry to adopt

The Vitiligo Society supports the Face Equality Campaign and encourages its members to visit changingfaces.org.uk

The Positive Side of the Coin: Information Please
Have you encountered any notable good or positive reactions to disfigurement or skin disorders amongst health professionals, teachers or others responsible for public services? If so, please let us know so that we can illustrate the fact that there countless examples of good practice out in the world at large. Send your replies to Vitiligo Society, 125 Kennington Road, SE11 6SF or by email to Jeff_Lock@vitiligosociety.org.uk.
25th ANNIVERSARY
BIG NEWS : BIG YEAR

As you may or may not know, next year will be our 25th Anniversary here at the Vitiligo Society. Unbelievable but true. The Vitiligo Society has been helping people with vitiligo for 25 years. Next year we will be celebrating as well as looking ahead to the next 25 years. We have many plans including a National Vitiligo Awareness Day and are also hoping to organise a joint symposium with the Royal Society of Medicine entitled ‘VITILIGO BUSTING THE MYTH’

What would you like?

If you have any ideas please let us know; events, venues, topics, etc…
If you would like to help us organise an event then we would also like to know.
All ideas are welcome.

Annual General Meeting
26 November 2008 at 6.00 p.m.
Central Hall Westminster

Members are cordially invited to attend the Vitiligo Society’s Annual General Meeting in the Broadbent Room, Central Hall Westminster on 26 November 2008 at 6.00 pm. Refreshments will be available.

The purpose of the AGM is to present the Society’s accounts and to report on performance in 2007/8. Other formal decisions on the running of the charity. Such as changes to the Board of Trustees will also be put forward for agreement. Once formal matters have been dealt with, there will be the opportunity for informal discussion on topics raised from the floor.

Please come along if you are able. If you are unable to do so, it is very important that you complete and return your proxy forms in advance to Society HQ at 125 Kennington Road, London SE11 6SF

Next Parents’ Group Meeting

Another Parents’ Group Meeting will be held on Saturday February 7th 2009 at 2pm at Society HQ, 125 Kennington Road, London, SE11 6SF. Please can anyone who wishes to attend let us know in advance by telephone or email.

SUPPORT GROUPS IN 2009

It is planned to hold a Support Group Meeting for all members in the south east of England in London in February 2009 and one in Manchester in April 2009. Please check website for details. If you are interested in attending, please let us know.