B.A.D. GUIDELINE PUBLISHED ON VITILIGO

50th Edition Of Dispatches

THIS EDITION IS SUPPORTED BY A GRANT FROM THE GOLDSMITHS’ COMPANY
“Credit Crunch” and “Global Financial Disaster” have become the most commonly used newspaper headlines of 2009 often in tandem with stories about the hardships which charities are facing because of the reduction in income from all sources. In this 50th edition of Dispatches we are appealing to members of the Vitiligo Society to keep paying their subscriptions despite the financial storm which howls around all of us. The Society does some great work and needs to exist for the benefit of everybody with vitiligo.

On 28 March there is a special meeting of the Trustees which will discuss the Society’s strategy for the next 12 months. If there is anything you would like to see discussed please send us an email to ken125@vitiligosociety.org.uk.

We are looking forward to another Walk for Skin in May/June this year (see page 15). This is always a great day out and provides valuable funds for the Vitiligo Society and the British Skin Foundation. Please limber up those legs and support the walk.

Finally please come to the vitiligo symposium featured on Page 13. This is a special event for members.

This edition of Dispatches is supported by a donation from the Goldsmiths’ Company towards widening access to in-depth information about vitiligo.
YOUR SUBSCRIPTIONS AND DONATIONS

The Vitiligo Society is acutely aware of the impact that the current economic problems are having upon us all. In many cases incomes may have been reduced or lost and those depending on savings are facing a reduction in interest rates. However, as always, our financial reserves are limited and our position is vulnerable unless all our members continue to pay the annual £26 subscription fee. Our work on behalf of vitiligo sufferers is vitally important.

Without your contributions we would be unable to support the many research initiatives which are going forward.

Without your contributions we would be unable to run our outstandingly successful web site which continues to get almost 250 visits per day.

Without your contributions we would be unable to provide help line facilities for those who call the Society in distress.

Without your contributions we would be unable to issue Dispatches which keeps members in touch with the personal experiences of others and what is happening in research.

Without your contributions we would be unable to mount informative events such as the forthcoming vitiligo symposium at the Royal Society of Medicine.

If your subscription is due please continue to support us. We need your help even more at this time. We would also ask life members to consider a special donation.

OUR SPECIAL THANKS

As well as income from subscriptions, the Society receives many generous donations from other benefactors and we would like to acknowledge the following and express our sincere appreciation of their help.

**THE GARFIELD WESTON FOUNDATION**
A major supporter of the Vitiligo Society, specifically - the helpline, publicity, research and our new website

**THE SELLARS FAMILY TRUST**
A long term supporter of the Vitiligo Society, most recently match-funding our new website

**BRITISH ASSOCIATION OF DERMATOLOGISTS**
A significant contributor who has recently given us a one-off infrastructure award to renew our IT system
BAD GUIDELINE PUBLISHED by Jennifer Viles

Guideline for the diagnosis and management of vitiligo:

In November last year a document was published in the British Journal of Dermatology (Br J Dermatol 2008; 159: 1051-76) which will have far reaching implications for the treatment and care of all people who have vitiligo. A major contribution to the guideline was provided by two members of the Vitiligo Society’s Scientific and Advisory Panel, Professor David Gawkrodger and Jane Watts together with Maxine Whitton - (Maxine is a Patron and long standing supporter of the Vitiligo Society and is currently updating the Cochrane Review on vitiligo - a systematic review of randomised controlled trials of all available treatments for vitiligo worldwide.)

The full BAD document can be viewed via a link from our website which can be found under “Medical Professional” but what follows is a brief description of its substance.

The document states “This detailed and user-friendly guideline for the diagnosis and management of vitiligo in children and adults aims to give high quality clinical advice based on the best available evidence and expert consensus, taking into account patient choice and clinical evidence”. The guideline is intended for use primarily by dermatologists but has been written in such a way that is it “a resource for interested parties including patients”. “Recommendations and levels of evidence have been graded” and, where there was a lack of evidence, research recommendations have been made based on the consensus of the authors.

The various types of vitiligo have been described, the process of diagnosis in primary and secondary care discussed, and available treatments for vitiligo have been assessed. The treatments considered ranged from offering no treatment (other than camouflage and sun care) to the use of steroids, vitamin D analogues, topical calcineurin inhibitors and depigmentation. The use of systemic treatments was analysed as well as creams and ointments often in combination with phototherapy and surgical approaches. In addition the effectiveness of psychological interventions such as cognitive behavioural therapy was considered.

It is hoped that the Royal College of Physicians will publish a more concise version of the full guideline, which will obviously be of tremendous benefit, not only to GPs and nurses, but also to patients. At a time when patients are encouraged to be “partners in care” with NHS practitioners, as outlined in the recently published NHS Constitution, the Guideline is a useful resource for patients, providing clear, reliable and comprehensive guidance on all issues relating to vitiligo and its management to which they can refer when discussing their condition with staff within the NHS.

With the increasing numbers of “100% cures for vitiligo” claimed on the internet and elsewhere it is of paramount importance that such a comprehensive review has been completed which gives such a trustworthy and complete overview of vitiligo for patients. The guideline also brings the prospect of greater understanding of vitiligo among medical personnel.

The Guideline has been in the making for several years. The persistence of the Vitiligo Society and the commitment of Prof Gawkrodger has brought it to fruition. The development of this document was a combined effort that took many months and a great deal of effort. For the first time a comprehensive, evidence based guideline of all treatments for vitiligo is available to inform clinical decisions and stimulate future research. There is no doubt that it has done much to raise the profile of vitiligo which has for so long been the Cinderella of skin diseases.

The Guideline is the product of the combined efforts of the British Association of Dermatologists, the Royal College of Physicians in London, the Cochrane Skin Group and the Vitiligo Society. Chaired by Professor David Gawkrodger, the Guideline Committee brought together people with a wide range of expertise; Professor Alex Anstey and Anthony Ormerod, both Consultant Dermatologists Lindsay Shaw a trainee dermatologist who is also a paediatrician, Ilnma Mauri-Sole a GP with an interest in dermatology, Jane Watts, dermatology nurse practitioner, Maxine Whitton, patient and Cochrane review author, Jane Ingham and Katherine Young, both from the Royal College of Physicians.

Even though it was only published in November the Guideline is already having a major impact and is the second most quoted paper in other British Journal of Dermatology research papers.

The Guideline is a useful resource for patients, providing clear, reliable and comprehensive guidance on all issues relating to vitiligo and its management
Dispatches No 50 | March 2009

5

One of the main reasons that, slowly but surely, vitiligo is gaining a more prominent appreciation and understanding within the medical profession is due in no small measure to the commitment, dedication and time given my members of the MaSAP to help the Vitiligo Society.

At a time when we have much to thank Professor Gawkrodger, and other involved members of the MaSAP, for the “Guideline for the diagnosis and management of vitiligo” we thought it would be a good idea to recognise their contribution through a series of articles about this important voluntary body.

We start with David Gawkrodger who has been a long serving member of MaSAP having also acted as Chair.

David also contributed to the professionally acclaimed Vitiligo Society’s “Information for Medical Professionals – VITILIGO Its Aetiology, Diagnosis and Treatment” contributing the first article Definition and Differential Diagnosis and an article on Surgical treatment.

Professor Gawkrodger was born in Bristol and went to school in Bath and it is therefore perhaps not surprising that his interests outside dermatology are painting and art appreciation together with travel. David has been a consultant dermatologist in Sheffield for 20 years. He was appointed honorary professor of dermatology at the University in 2003 and awarded the degree of DSc by the University of Sheffield in 2007. Prior to his appointment in Sheffield, he trained in dermatology for 7 years at the Royal Infirmary, Edinburgh, and before that for 4 years in general internal medicine at Stoke on Trent and the Queen Elizabeth Hospital, Birmingham, after graduating from the University of Birmingham.

David’s main research interests over the last 25 years have been in clinical and experimental aspects of vitiligo and contact dermatitis. He is the author of the best-selling textbook ‘Dermatology: An Illustrated Colour Text’, just published in a 4th edition, and has written over 200 scientific papers in peer-reviewed journals. Currently he is Chair of the Dermatology Expert Advisory Group of the UK Commission on Human Medicines. He is the immediate past President of the Dermatology Section, Royal Society of Medicine where he secured the opportunity for the Vitiligo Society to collaborate with the Royal Society of Medicine in a Medicine and Me Symposium on Vitiligo which is planned for the 21st November 2009 (details on page 13).

David Gawkrodger has also served as President of the British Contact Dermatitis Society, past Chair of the Dermatology Joint Specialty Committee of the Royal College of Physicians and past Treasurer of the British Association of Dermatologists.

Thank you, David, for giving so much time to the Vitiligo Society.

MaSAP PROFILES : DAVID GAWKRODGER

Professor David J Gawkrodger
Member of the Vitiligo Society’s Medical and Scientific Advisory Panel (MaSAP)

One of the main reasons that, slowly but surely, vitiligo is gaining a more prominent appreciation and understanding within the medical profession is due in no small measure to the commitment, dedication and time given my members of the MaSAP to help the Vitiligo Society.

At a time when we have much to thank Professor Gawkrodger, and other involved members of the MaSAP, for the “Guideline for the diagnosis and management of vitiligo” we thought it would be a good idea to recognise their contribution through a series of articles about this important voluntary body.

We start with David Gawkrodger who has been a long serving member of MaSAP having also acted as Chair.
SOCIETY MANAGEMENT

THE ESSENTIAL TRUSTEE  BY JEFF LOCK

The Vitiligo Society is a registered charity run by a board of trustees. But what is a charity and what is a trustee? The information for this article is taken from “The Essential Trustee” a publication of the Charity Commission which is shown above. If any members of the Society are interested in becoming a trustee, a copy of the publication can be provided on request.

WHAT IS A CHARITY?
Charities are organisations set up for the support of the community. They enjoy tax benefits which are conferred by the government. They may, in certain circumstances, trade for profit but they must use such profit for the aims of the charity. To qualify as a charity, an organisation must meet strict conditions about its overall purposes: in particular, it must demonstrate that its purposes are for the public benefit. It must also have a constitution which sets out the manner in which it will be governed. Some charities are established for research training or education or to focus on meeting the wider needs of a particular deprived area. Others are set up to give direct help, advice, grants or support to people in various kinds of need, for example older people or those with a particular medical condition.

For the benefit of its members, the Vitiligo Society is an incorporated charity registered with both the Charity Commission and with Companies House. It is managed by a Board of Trustees. Trustees are the people who form the governing body of any charity. They may be known as trustees, directors, board members, governors or simply as committee members. Trustees are responsible for overseeing the management and the administration of a charity. They are volunteers and receive no remuneration other than out-of-pocket expenses. Trustees work together as a team and have collective responsibility for their charity.

WHAT ARE THE DUTIES OF A TRUSTEE?
Trustees must accept ultimate responsibility for directing the affairs of their charity. They must ensure it is solvent and well run and is delivering the charitable outcomes for the benefit of those it was set up to serve. They have duties of compliance, prudence and care.

DUTY OF COMPLIANCE
Trustees must ensure that their charity complies with:

- Charity law and the requirements of the Charity Commission. This means that the charity must prepare reports on its work and must submit the annual accounts required by law.
THE ESSENTIAL TRUSTEE

- Its own rules and charitable purposes as set out in its own governing documents.
- The requirements of other legislation and regulators, if any, which govern the activities of the charity. These will vary according to the type of work undertaken and the number of employees.
- The requirements for trustees to act with integrity and avoid any personal conflict of interests over the use of charity funds or assets.

DUTY OF PRUDENCE
Trustees must ensure

- That the charity is, and will remain, solvent. This means that trustees must keep themselves informed of the charity`s activities and financial position.
- That charitable funds and assets are used wisely to further the aims and purposes of the charity.
- That activities are not undertaken which place the charity`s property, funds, assets or reputation at risk.
- That special care is taken when investing charity funds or borrowing money for the charity to use.

DUTY OF CARE
Trustees must

- Keep up to date with what the charity is doing and give enough time and energy to attend meetings and contribute to decisions which are being made on its behalf.
- Exercise reasonable care and skill, using personal knowledge and experience to ensure that the charity is well run and efficient.

Background - I am the HR Director at the University of East London, having had previous similar roles in a local authority and another university. I've been a Trustee of the Society for 18 months.

Connection with vitiligo - My wife and eldest daughter have vitiligo. My wife's father had vitiligo, with both his and my wife's pigmentation turning from entirely Asian dark-skinned to completely white (called 'universal vitiligo'). My wife and I help to organise the Society's Parents Group, which seeks to help parents of children with vitiligo.

Views on Being a Trustee - The Trustees are unpaid volunteers whose role is to help the Society assist as many people who suffer with Vitiligo as possible. Trustees are from different professions, with a wide background of skills and experience (medical, scientific, financial, marketing, journalism, HR) and above all, enthusiasm and commitment. We meet on average every six weeks and work with our very capable Manager, Jennifer Viles, and her colleagues to try to move the Society forward.

Views on the Future of the Society The Society is doing vital work. Its recently revamped website has attracted a lot of praise from Society members and professionals in the medical and scientific community. Our helpline provides practical advice and support to people who often haven't encountered vitiligo before and are distressed to find that they or their loved one has the condition, whilst our magazine 'Dispatches' has in-depth articles from experts on all aspects of vitiligo. We strive to obtain grants, donations and sponsorship from members of the public, industry and private and public organisations.

We are, however, modestly resourced and the Society needs substantially more income to fund highly expensive research into curing vitiligo and to providing a more pro-active service than we can deliver now. Whilst the current recession doesn't help, the UK is a wealthy country and we need everyone's help in tackling what can be a highly distressing condition.

Mike Moore : One of Our “Essential Trustees”

Mike has been a trustee of the Vitiligo Society since April 2007. Dispatches asked him to summarise his background, his views on the society and his thoughts on being a trustee.

Background - I am the HR Director at the University of East London, having had previous similar roles in a local authority and another university. I've been a Trustee of the Society for 18 months.

Connection with vitiligo - My wife and eldest daughter have vitiligo. My wife's father had vitiligo, with both his and my wife's pigmentation turning from entirely Asian dark-skinned to completely white (called 'universal vitiligo'). My wife and I help to organise the Society's Parents Group, which seeks to help parents of children with vitiligo.

Views on Being a Trustee - The Trustees are unpaid volunteers whose role is to help the Society assist as many people who suffer with Vitiligo as possible. Trustees are from different professions, with a wide background of skills and experience (medical, scientific, financial, marketing, journalism, HR) and above all, enthusiasm and commitment. We meet on average every six weeks and work with our very capable Manager, Jennifer Viles, and her colleagues to try to move the Society forward.

Views on the Future of the Society The Society is doing vital work. Its recently revamped website has attracted a lot of praise from Society members and professionals in the medical and scientific community. Our helpline provides practical advice and support to people who often haven't encountered vitiligo before and are distressed to find that they or their loved one has the condition, whilst our magazine 'Dispatches' has in-depth articles from experts on all aspects of vitiligo. We strive to obtain grants, donations and sponsorship from members of the public, industry and private and public organisations.

We are, however, modestly resourced and the Society needs substantially more income to fund highly expensive research into curing vitiligo and to providing a more pro-active service than we can deliver now. Whilst the current recession doesn't help, the UK is a wealthy country and we need everyone's help in tackling what can be a highly distressing condition.
Dear Dad

Over the last 6 years I have been walking in your shoes.

I know that when you were in your 20’s and living in India you developed vitiligo. You coped as best you could - incidents where people regarded you as a ‘leper’ and refused to touch anything after you had touched it - hurt you. I also remember you telling me how you would try and mask the patches with crude make-up to enable you to earn a living only to have the searing heat of India reduce it to a streaky mess.

I cannot imagine what it must have been like to have doors slammed in your face and to be ostracised by some elements of society. I always admired your innate strength, cheerful good humour and kindness. I hope you were aware that you were always loved and cherished by your family and friends.

Sadly you died when my youngest daughter was only six weeks old. Following your death over a period of five years or so, the vitiligo continued to rampage all over my face and body. We never got the chance to discuss how it had affected your way of life once you had universal vitiligo or my reaching the same state.

When I became ‘universal’ at 41 I hoped that at last I would be able to wear open necked shirts and tee-shirts without a care in the world. For years I had acquired the whole range of polo necks and could spot a suitable ‘long sleeve – high neck top’ at 20 paces. I was reasonably knowledgeable about the colours that would suit my olive Indian skin complexion.

After I lost all my natural pigment I became aware that colours that had complemented my brown skin now made my starkly white skin look washed out. I realised that I would have to rethink my entire wardrobe. Amazing as it seems - but it was something that hadn’t occurred to me - I had just assumed I would be able to wear anything in my wardrobe. I told my family and friends of my predicament and they started to look for colours they thought would suit me. As yet, I haven’t considered contacting any stylists at ‘Colour Me Beautiful’ www.colourmebeautiful.co.uk, who I hear are very helpful.

Another loss which caught me unawares was the loss of my cultural identity, which affected me immensely.

Incidents which I have always taken for granted started to have deeper significance. For instance, for as long as I can remember I have always nodded, sometimes smiled, at another Indian woman who gave me eye contact in passing, as an unspoken acknowledgement that we shared a cultural bond. It was something I hadn’t pondered over and only really became aware of after losing my pigment. Nowadays, any Indian woman I have eye contact with look slightly bemused when I nod and smile. Sometimes they smile politely back. It seems that we no longer share that common connection.

However, Dad, I would like to finish by saying that there have been benefits to losing my skin pigment.

Not having to spend over an hour trying to balance my skin tone with make-up: spending hundreds of pounds over the years on it. Never having to wake up in the morning to find another white patch has appeared; Hoping it wouldn’t be a hot day, as I would have to retouch my make-up, again and again; Hurrying home, trying not to notice the curious stares and whispers of children in the street when it was impossible to cover up all the patches. Being able to answer my front door without checking in the mirror to see what state my make-up was in. Wanting to hide away at home but forcing myself to leave the house, knowing that a toddler and baby need fresh air. The ruination of numerous light coloured top collars, discoloured by make-up stains. Not having to wear polo-necks. Not being able to swim. Being able to wear tee-shirts of any shape and size and being able to leave the top button undone on all my blouses. Being afraid of blowing my nose, and cuddling my children when outdoors in case that disturbed my make-up. Not having to use my imagination on ‘101 ways to use a scarf’. And finally... Not having to think what to wear in case I am unable to hide my Vitiligo patches.

All my love
Paula
With the widespread popularity of social networking sites such as Myspace, Facebook and Bebo, the Vitiligo Society was happy to accept a proposal that the Society should have a presence on Facebook. As a society, we are always thinking forward and seeking out new ways in which we can develop and bring greater recognition to vitiligo. So with that in mind, we saw great advantages in a networking group for those with vitiligo or who may know someone with the condition. Our aim in doing so was to bring people together from across the board. With more than 150 million members worldwide Facebook seemed like the perfect opportunity to do just that.

The Vitiligo Society sees this as an optimistic move towards creating further awareness of a condition that affects 1 in 100 people. Not only does Facebook help to connect people from around the UK, but it also allows us to reach out to people globally, obtaining a vast range of information and reactions from different corners of the world.

The response to the group so far has been very positive, with over 250 members, sharing news, views and stories with others affected by the condition. The images people have posted showing their vitiligo are amazing; in some pictures vitiligo appears to look artistic and somewhat picturesque. They are truly are inspirational. Amongst this, you can also find informative video clips and discussion boards, which are significantly valuable, as it allows the opportunity for members to openly discuss areas of their choice, and ask questions to which they may be seeking answers.

Every vitiligo sufferer has a different story to tell, and the great thing about the group is that people can freely share their personal journeys and views with others, which can subsequently act as a form of support, whilst introducing a sense of “togetherness”. There are many psychological and emotional effects that come with having vitiligo, whilst some can handle those feelings better, others find it more difficult, which is why it makes the group such a great way to interact and meet with people who share something unique.

For me personally, I found reading people’s positive comments very encouraging. Like many I have battled immensely with the physical effects of vitiligo, so when I started reading about those who chose not to hide away, I found it empowering and started to ask myself “why shouldn’t I wear short sleeved tops if I wish”? It’s important to feel proud and not let your condition make you feel as though you should shy away.

The positive response to the group has led to an increase in visits to the society’s own website, which has recently been revamped, with more people registering to become full members of the society which is excellent news. For those who have joined the group, please continue to support and share your stories with the rest of us. For those who haven’t you might like to consider joining.
Dear Editor

ANTI-VITILIGO OIL

I have just come across a product being advertised on the internet called (temptingly) Anti-Vitiligo Oil.

I’ve posted a question about it on the members forum, but then thought it might also be a good idea to publish it in Dispatches. My question is does anyone know anything about this so-called effective treatment for vitiligo or any of the other products advertised on the internet which purport to “cure” the condition? There is also a homeopathic remedy called Leucotin being advertised that offers a 100% guarantee of effectiveness - which is highly suspicious in itself!

Those of us who have had vitiligo for many years and waited patiently for an effective treatment have learned to be cautious about such claims on the basis that most of them are bogus and that, if a safe and effective treatment is out there, we would already have heard of it from the medical fraternity.

However, we also know that some treatments do have limited benefit for some people and I wondered if anyone had any anecdotal evidence of any improvement (or otherwise) following use of these products.

Yours sincerely

Caroline Goleczka

Reply From Maxine Whitton

Dear Caroline

Like all these products its claims are not based on any published evidence and are exaggerated. There is no cure for vitiligo. The fact that there are so many so called cures around is in itself an indication that the answer to this disease has not yet been found. Even if some well researched treatments can bring back normal colour no-one can guarantee that it will be permanent. Leucotin appears to be a homeopathic preparation and there is no evidence that homeopathy works. The leucotin website shows its composition and one of the ingredients is psoralea (mis-spelt I think) a plant based remedy from which the word psoralen is derived. I get so angry about these sites which exploit people with vitiligo who are desperate for something to help them.

The list below comes form the website.

**Composition of Leucotin:**

<table>
<thead>
<tr>
<th>Ingredient Name</th>
<th>Dilution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Echinacea</td>
<td>D4 + 40C</td>
</tr>
<tr>
<td>Ars Suf Flav</td>
<td>D10 + 100C</td>
</tr>
<tr>
<td>Chaulmoogra</td>
<td>D10 + 100C</td>
</tr>
<tr>
<td>Hydrocotyle</td>
<td>D2 + 20C</td>
</tr>
<tr>
<td>Psoralia</td>
<td>D1 + 10C</td>
</tr>
</tbody>
</table>

Maxine Whitton

Reply From Jennifer Viles

Dear Caroline

The Vitiligo Society has also researched other advertised products, in one instance sending a Trustee, Dr Jeff Corne, a pharmacologist, to the address given in the advert to find out more about the product and its claims. He found it to be an accommodation address only and its tenants unknown to other offices in the building. Having obtained and researched the PhD thesis that had been mentioned in the literature we could find no evidence to support the claim that the product had the ability to cure vitiligo.

This is one of the reasons why the *Guideline for the diagnosis and management of vitiligo* and the shortly to be published Concise Guide are so important because of the trust we can place in their content.

Jennifer Viles

Dear Editor

BEWARE USA POSTAGE

I would like to warn anyone buying products for their Vitiligo from U.S.A. I ordered Vitiligo Cover Lotion from the USA and it took almost a month, when it finally arrived I was charged another £11.97 for V.A.T and Royal Mail handling charges. My advice is to order only from the U.K. no matter what you are told by the American companies.

Regards

Jean Vallance

I get so angry about these sites which exploit people with vitiligo who are desperate for something to help them.
Dear Editor

A TRYING TRIATHOLON

Please find the enclosed cheque for sponsorship money that I collected for a triathlon I did back in June 2008. It was a beautiful day, not too hot, not too cold and everyone there seemed to enjoy their experience. I was completely proud of myself, as I entered the event without any proper training. Very much my own fault as I had plenty of time but never got around to doing it. I did keep telling myself all I needed was a positive mental attitude and hey, it paid off. It just makes me realise that we can achieve anything we put our minds to. So everyone out there get into the moment and go for it.

I was particularly proud of my daughter Ciara aged 16. She entered the event only to have an accident early on. She was coming down a steep hill when her helmet tilted back and as she adjusted it she lost her balance and came off her bike. The handlebars went into her stomach and caused a lot of inner and outer bruising. She also had some bruising to her hands and face. We waited quite some time for the ambulance to come but she eventually got patched up and decided to carry on as she did not want me to do it on my own. She only got another few hundred yards and the pain became too much for her. She was very tearful but insisted that I go on to complete the event. What a brave girl! I don’t remember what my time was, but due to all the commotion and waiting for the ambulance I did come in last but it’s the taking part that counts. As I travelled around the course on my own I found it all very surreal. I felt as if I was one of the Famous Five on a sort of adventure.

Love Debbie Egan

---

Dear Editor

BLACK PEPPER OIL (Posted on Facebook)

I have started to see great improvements since I started using black pepper oil,
Just mix it with a base oil and then apply to the affected area. Its a lot easier and cheaper than most other treatments.

Yours sincerely
Alex

The Society referred this communication to Dr Amala Soumyanath: Here is her reply

Regarding the pepper oil issue, here is some information:

Oil of black pepper, which is produced by distillation of black pepper, does not usually have appreciable amounts of piperine. So if it does work for vitiligo (an intriguing thought), its probably not because of piperine!

The oil may cause skin irritation and should never be applied to the skin directly without dilution in another oil. As there is not enough data available to fully predict the risks of long term application of the oil to the skin, we cannot recommend its use by people with vitiligo. Anyone using the oil does so at their own risk, and should stop immediately if they observe any adverse effects. On the safety front, oil of black pepper and piperine are considered “generally recognized as safe” by the United States Food and Drug Administration (USFDA) and are used as direct food additives. However, this only applies if they are used in an “appropriate” way. This is somewhat vague, but I would take it to mean when added to food in small quantities, rather than slathered on the skin.

Oil of black pepper is used as a pesticide and also in aromatherapy, where it is rubbed into the skin. However, it is not applied neat, but diluted in another oil. It is reported to be irritant on sensitive skin, so should be used with caution. There are some constituents of black pepper oil e.g. saffrole that may be carcinogenic. However, there have not really been adequate studies to prove or disprove that oil of black pepper can cause skin cancer.

The following link may provide some reassurance on the lack of major risk of black pepper oil.

http://www.epa.gov/opp00001/biopesticides/ingredients/factsheets/factsheet_000669.htm#description

I hope this helps.

Regards
Amala
HELP NEEDED : SKIN CARE CAMPAIGN SCOTLAND

by Jennifer Viles

We are looking for a member of the Vitiligo Society to assist the Skin Care Campaign Committee for Scotland. The SCCS is probably best described as the interface between dermatology patient groups in Scotland and the dermatology bodies - Dermatology Council of Scotland and the Scottish Dermatology Society. They also have close links with the Scottish Skin Care Industry Group - those companies who produce dermatology products. They are in real need of more active members and they have asked if we have a member who would be interested. The volunteer should be willing to do a bit of work for the group (as they no longer have an employee) : ideally somebody with some basic accounting knowledge though this need be nothing more than running an account for their local boy scouts.

If somebody could assist with the accounts, then it would also help if they were in the Glasgow area as a “second signatory” as the current Chair lives in Bearsden just outside of Glasgow.

The SCCS have told me they realise that all of the above is a pipe dream but a person with vitiligo would be made most welcome whatever their expertise. Minimum involvement would be four meetings per year. Expenses would be met by SCCS.

If there is anything else you wish to know please either contact the Vitiligo Society 020 7840 0844 or 'phone the SCCS 0141 942 4068 and speak to Leigh Smith.

COVER STORY

by Jeff Lock

Through our involvement with the Facebook Vitiligo Society Support Group we have heard some interesting personal testimonies about coping with vitiligo. Floriane Chevaucherie from France has wholeheartedly embraced the fact that she has vitiligo and has sent us a number of beautiful photographs, one of which we have used on the cover of this edition.
MEMBERS RESPONSE NEEDED

SYMPOSIUM AT THE ROYAL SOCIETY OF MEDICINE by Jennifer Viles

SATURDAY 21 NOVEMBER 2009 STARTING AT 13.30 AND FINISHING AT 17.30 PRECEDED BY THE SOCIETY AGM: FREE TO MEMBERS WE NEED TO KNOW IF YOU WOULD LIKE TO ATTEND

To mark the 25th Anniversary of the Vitiligo Society it is proposed to hold a Vitiligo Symposium at the Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE. There will a panel of medical experts to answer questions but we are planning to drive the Symposium through input from members. So far, the following inputs are planned.

- The Psychological Impact of Vitiligo - Maxine Whitton
- Ethnicity and Gender - Gurdeep Romanay
- Vitiligo and Young People - Robert Fluin
- Experiences of UVB Treatment - Paul Johnson
- My Life With Vitiligo - Darryl Monte

Are there any other topics you would like covered at the symposium? This is your opportunity to be heard and we need to know as soon as possible how many members will wish to attend this event. Please register your interest by calling us on 0800 018 2631 or by email on ken125@vitiligosociety.org.uk

$3,000,000 STUDY INTO VITILIGO: YOUR HELP NEEDED

Dr Richard Spritz reports that he has now received a major grant from the U.S. National Institute of Health to carry out the largest vitiligo research study ever undertaken.

The international VitGene consortium is a genome-wide association study, aiming to identify susceptibility genes for generalized vitiligo, the most common pigmentation disorder. This study offers the best hope to discover the true biology underlying vitiligo, and thus to open up paths to investigate new treatments and cures. The project will have several phases, which altogether will take about 4 years.

Phase 1, taking place now, is the initial genome-wide screening phase, testing 610,000 genetic markers in 1500 Caucasian patients and 1500 unaffected individuals (“controls”) from the USA, Canada, and United Kingdom (UK). About 80% of the samples come from our laboratory and about 10% each from Prof. Gawkrodger’s group at Sheffield University (UK) and Profs. McCormack and Wallace’s group at the University of Florida.

Phase 2, to take place 1-2 years from now (sample collection going on now), will follow up promising results from Phase 1 in another ~2750 different Caucasian patients and ~2750 controls from the USA, UK, and continental Europe, as well as in ~400 additional Caucasian vitiligo families (patients and their relatives).

Phase 3 (sample collection going on now) will test genes proved out in Phases 1 and 2 in other, non-Caucasian groups. Currently, VitGene includes 38 investigators in 21 countries.

Thanks to the many of you who have already sent in questionnaires and saliva samples, and thanks to NIAMS for funding our work. We very much appreciate your support! However, we still need additional samples from BOTH patients and unrelated, unaffected ‘controls’ of Caucasian, Hispanic/Latino, African/African-American, Indian subcontinent, and Asian ethnic origins. Please participate if you haven’t done so already.

Please go to the Vitiligo Society website or follow the link www.vitiligosupport.org/downloads/vitquestionnaire.doc

Save this to your local computer to fill out, and return via mail or email to richard.spritz@ucdenver.edu
My name is Clare Lushey and I am a Research Associate at the Centre of Evidence Based Dermatology at the University of Nottingham. As you may have seen in the last issue of Dispatches, we are undertaking a research study in collaboration with the James Lind Alliance, looking at ‘Setting Priorities and Reducing Uncertainties for People with Skin Disease’ (SPRUSD). This independent research is being supported through a programme grant funded by the National Institute for Health Research (www.nihr.ac.uk). The vitiligo aspects of the programme of work will last for three years and include several research activities:

1. Updating an existing systematic review of interventions for vitiligo. This will provide health professionals and patients with the most up-to-date information about the known effects of treatments for vitiligo, and will help us to identify areas requiring further research.

2. Identifying what people with vitiligo and health professionals would like to find out about treatments for vitiligo. These questions will be entered onto the Database of Uncertainties about the Effects of Treatments (www.duets.nhs.uk).

3. Prioritising these uncertainties for future research. The priority setting process will involve people with vitiligo, parents or carers of children with vitiligo, health professionals and researchers, all working together to agree a ‘top ten’ list of unanswered questions about treatments for vitiligo.

4. Developing one of the ‘top ten’ uncertainties into a feasibility study. This will lead on to a funding application to the NHS for a full clinical trial on a topic that has been identified as a priority.

5. Producing web-based patient information resources and clinical decision aids, which will help people with vitiligo, parents or carers of children with vitiligo, and health professionals to make informed choices about treatments for vitiligo.

The purpose of this research is to reduce uncertainties about treatments for vitiligo and to set priorities for future research. This work is of vital importance because it aims to:

- Gather what we already know about the effectiveness of treatments for vitiligo.
- Identify what we do not know about treatments for vitiligo.
- Work with people with vitiligo (including parents or carers) and health professionals, to prioritise uncertainties for future research.
- Ensure that future research addresses questions that are important to people with vitiligo and those who care for them.

As members of the Vitiligo Society, you will have important questions about treatments for vitiligo and we hope that you will share these with us. Your questions will be collected using a survey that will be available through the Vitiligo Society’s website and in future issues of Dispatches. You can choose to be involved further in the process if this is of interest to you, or simply submit questions that you think are important.

All questions will be reviewed by a prioritisation team made up of patients, carers, health professionals and researchers. At the first stage, the team will individually select their ‘top ten’ research questions from those that have been submitted. These will then be discussed during a prioritisation workshop and the team will collectively decide on the most important research questions for the future.

This is an important opportunity for you to become involved and have your say in research into vitiligo. The work will take place between March and December 2009. Further updates about the progress of this research will be featured in later issues of Dispatches.

If you would like to find out more about this research, or would like to submit a question that you feel has not been answered by your doctor, please contact me (Clare Lushey) by telephone: 0115 84 68633 or email: clare.lushey@nottingham.ac.uk.

Useful websites:

- Centre of Evidence Based Dermatology: www.nottingham.ac.uk/dermatology
- James Lind Alliance: www.lindalliance.org
- UK Dermatology Clinical Trials Network: www.ukdctn.org
WALK FOR SKIN: ANOTHER GREAT YEAR  by Jeff Lock

It's that time of year again when we appeal to members of the Vitiligo Society to take part in the annual Walk for Skin organised by the British Skin Foundation. Every year the BSF funds over half a million pounds worth of research into skin diseases such as vitiligo. This year’s event will take place on a Sunday between 10 May and 7 June 2009 depending on which location you choose. There are eleven fabulous new walks in town & country parks and each walk is generally 3-6 miles long, with shorter options available at most venues. As last year, most of the venues (but not all) will include added attractions at the Walk for Skin Village: live music, entertainment, refreshments and of course fantastic goody bags for all participants.

Joining the Walk for Skin couldn’t be easier. Simply choose a venue and register free of charge, either (1) online at www.walkforskin.org.uk or (2) by phone on 0207 391 6341 or (3) by returning a registration form. Once registered, entrants will receive a sponsor form, a walker’s pack and information about their chosen venue.

When submitting your registration for the event please ensure that you clearly nominate the Vitiligo Society to receive 50% of the money you raise. This will help to support our vital work. Every penny of the other half will be put towards research funded by the British Skin Foundation into all skin diseases.
NEWS AND EVENTS

PARTICIPATIVE EVENTS FOR VITILIGO SOCIETY MEMBERS

North West Support Group – Manchester Saturday 18th April 2009

The Support Group for the North West will be on Saturday April 18th 2009 at the Gardens Hotel, 55 Piccadilly, Manchester M1 2AP in the Gorton Suite from about 10.0am until 4pm. The hotel is in the centre of Manchester, near Piccadilly bus station, not far from the train station and a short walk from Victoria train station so access by public transport is easy. There are also several car parks in Manchester city centre. It will be just an informal day when members and their families can call in and find out what's new in vitiligo and how our Society is doing. You will be able to chat to other members, and me, who have had to deal with their vitiligo over the years. There will be tea, coffee and biscuits and also some of my world famous homemade cakes (well, they're famous among my friends anyway).

Della from Clarins will also be on hand to chat and give help on skincare and advice on make up to anyone who would be interested. For anyone who knows me and has come to one of my support group meetings before, I will be glad to see you again and for anyone who hasn't, please come as I will be pleased to meet you too - I'll look forward to meeting you all. If you are interested, or hope to come, please let the office know (contact details on Page 2 of this edition) - so we can make sure there are enough cakes to go around!

Lynne Ashley

Scottish Support Group – Glasgow Tuesday 7th July 2009

This year the British Association of Dermatologists’ Annual Meeting is being held in Glasgow and we are planning to hold a Support Group on Tuesday evening 7th July 2009 from 17.30 – 19.30 at the Scottish Exhibition and Conference Centre. If any member from Scotland is interested in coming to this support group please let me know - 020 7840 0844. Nearer the time we will be writing to all members in Scotland to let them know further details.

British Association of Skin Camouflage: Request for Help from Vitiligo Society Members

Attention any members who live within travelling distance of Chester. The British Association of Skin Camouflage periodically holds training initiatives in Chester. If anyone would be interested in attending on a Sunday afternoon in May or September as a model for trainees’ formal assessments and allow professional trainees to practice on your arms or legs. Anyone volunteering will receive luncheon plus £50 towards travel and inconvenience. The events are held in a Best Western Hotel, close to Chester Railway Station. Please email Elizabeth Allen at base9@hotmail.com for more information visit www.skin-camouflage.net

Events Sponsored By Changing Faces

Island of Adventure
Saturday 25 April 2009, 10.30 to 15.30 in York
This is an event for young people from all over the country who will be starting secondary school this September. For more information please email info@changingfaces.org.uk or call 0845 4500 275

Meeting The Challenges When A Pupil Has A Condition That Affects The Way He/She Looks
Two one day seminars
- 2 April 2009 for education professionals
- 21 May 2009 for anyone involved in early learning or play groups.

For more information contact Jane Frances at Changing Faces on 0845 4500 275: or email janel@changingfaces.org.uk