

Dispatches

VITILIGO
SOCIETY



THE MAGAZINE OF THE VITILIGO SOCIETY NUMBER 51 July 2009

*Promoting a
positive approach
to living with
vitiligo*



In This Edition



The big news this month has been the sad death of Michael Jackson, the pop singer, possibly the most famous sufferer from vitiligo. It is still not clear when he

contacted the condition or how it progressed across his body but it seems clear from what has been stated in the media that it was responsible for the change in the colour of his skin. Of course, we will never know for certain what psychological impact it had on this reclusive and vulnerable superstar.

On pages 3, 12 & 13 of this edition are the details of a special event for Society members on 21st November at the Royal Society, which will feature leading figures from our Medical and Scientific Advisory Panel and promises to be both entertaining and informative. We would like as many members as possible to attend (Please fill in and return the form which is enclosed.) It should be a very good day out.

Finally, Jennifer Viles the Society Manager has recently been away on sick leave for a few weeks. Please accept our apologies if this has made it difficult to get in touch. Jennifer is back now and normal service should be resumed.

Page 3 RSM Event for Members



Pages 4 & 5 Vitiligo Myths



Page 6 Gurdeep Romanay



Page 7 Walk for Skin



Pages 8 & 9 Protopic



Page 10 Letters



Page 11 Effectiveness of Oral Ginkgo Biloba

Page 12 & 13 RSM Event for Members



Page 14 MaSAP Profile



Page 15 People



Page 16 Participative Events for Members

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

Trustees of the Society

Tony Bewley, Daniel Britten, Jeff Corne, Hilary Fassnidge, Elana Kelly, Bernard Lamb, Debra Leeves, Mike Moore, Gurdeep Romanay, Rob Symonds, Dennis Wilson-Cole, and Chris Williams

Staff

Kalpana Pabari, Jennifer Viles

Editor for this issue

Jeff Lock

© The Vitiligo Society 2009
ISSN 1367-5877

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 September 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.

VITILIGO EVENT FOR MEMBERS AT THE ROYAL SOCIETY OF MEDICINE ON SATURDAY 21 NOVEMBER 2009



To mark the 25th Anniversary of the Vitiligo Society we are holding a Vitiligo Symposium at the Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE. One of the speakers will be Lord Bates of Langbaugh (above). Presentations will be given and there will be a panel of medical experts who will answer questions.

Lord Bates is a member of the Conservative front bench in the House of Lords. He is shadow minister for the Cabinet Office, and also a Whip. As Michael Bates, he was MP for Langbaugh between 1992 and 1997. Lord Bates is also a former Paymaster General.

Throughout his time in politics he has been a tireless advocate for the Conservative Party in the North East of England and for the North East at Westminster. Working recently with William Hague on Campaign North and the Northern Board as Deputy Chairman of the Conservative Party (North). He also has a close association with vitiligo.

“I feel honoured to have been asked to speak at the Royal Society of Medicine and the Vitiligo Society’s Symposium - Medicine & Me on Saturday, 21st November 2009 which will also celebrate the start of the 25th Anniversary of the Vitiligo Society.

As some members of my family are affected with this condition, I feel encouraged by the offer of support and understanding which the Vitiligo Society endeavour to carry out. It is imperative that we take steps to promote and fund research so that the causes of vitiligo are established and effective treatment secured.”

**This is a prestige event for members.
Many eminent doctors and dermatologists will be giving their
time and effort to support the occasion.
It will also be filmed for future use.**

**Please support the Vitiligo Society and enjoy the occasion
by attending on Saturday 21 November 2009.**

**SEE
PAGES 12 & 13
FOR MORE DETAILS
AND HOW YOU
CAN ATTEND**

VITILIGO MYTHS by Rob Symonds

Vitiligo is a subject which generates a plethora of myths, half truths and uncertainties. You only have to type “vitiligo” into an Internet search engine to find a host of herbal remedies, unusual treatments and miraculous cures most of which, unfortunately, seek to exploit the anxieties of sufferers. Even in the medical world, neither diagnosis nor prognosis is always consistent. Consequently an aura of myths and false assumptions has grown up around vitiligo.

So, I asked Jemima Mellerio, Consultant Dermatologist at St Thomas’ and Great Ormond Street hospitals, about some of the most common misconceptions.



People with vitiligo are more prone to skin cancer

There is no evidence for this. However it is always sensible to wear a high factor sunscreen (SPF 15 or greater) to protect depigmented and normal skin from potentially harmful UV light.

Vitamins can help with repigmentation

There is no evidence from clinical trials that taking vitamin supplements can repigment areas of vitiligo or prevent new areas from appearing. (Note : But some research has shown that the outcome of some treatments may be improved with the addition of certain vitamins).

Vitiligo is a symptom of other internal problems

Statistically speaking, people with vitiligo are at a slightly increased risk of developing other so-called autoimmune diseases, such as thyroid disease, alopecia areata or pernicious anaemia. However the absolute risk of someone with vitiligo having another autoimmune disease is actually quite small.

Pigmented skin can turn white when it is damaged

This is true. Vitiligo can sometimes occur in scars or areas of skin that have been traumatised. This is known as the Köbner phenomenon.

Eating ‘white foods’ (such as onions) can make vitiligo worse

There is absolutely no evidence for this. A healthy balanced diet is as important for someone with vitiligo as anyone else.

Exposure to sunlight can make vitiligo worse

Exposure to the sun can cause sunburn to vitiligo patches but this does not usually trigger a worsening of the condition.

There is no treatment available on the NHS to treat vitiligo

This is not true. There are many well established treatments including topical steroids, light therapy and cosmetic camouflage that are fully available on the NHS. Although these treatments have variable success rates, they should be offered and made available to people with vitiligo. Your GP will be able to provide some of these, but if necessary, you can ask for referral to a dermatologist.

Stress makes vitiligo worse

There is no evidence in the medical literature to back this up. Anecdotally, some people with vitiligo feel that stress definitely worsens their condition.

VITILIGO MYTHS continued

Members of my family are also likely to have vitiligo

If you have vitiligo there is a 6% chance your siblings will have it too, rising to almost 25% if you have an identical twin. The risk seems to be greater with earlier onset vitiligo. Most people with vitiligo, however, do not have anyone within their immediate family with the condition

Some people have been known to spontaneously re-pigment

Yes. It is not uncommon for patches of vitiligo to spontaneously repigment, however total spontaneous re-pigmentation is rare.

Vitiligo is harder to treat the longer you have had it

In general terms this may be true. However, it is always worthwhile treating any patch of vitiligo regardless of duration, since sometimes even very long standing patches may improve.

There is more than one type of vitiligo

Typically vitiligo affects particular areas of skin such as the hands and feet, around the eyes, mouth and ears or in a more generalised pattern (usually fairly symmetrically). Occasionally, particularly in children, asymmetrical blocks of vitiligo can occur. This is known as segmental vitiligo. The treatments you are offered may vary depending on the site and extent of your vitiligo, but are essentially the same whether it is the generalised or segmental type.

Some people can be 'cured' of vitiligo

Established treatments can have a very good effect in re-pigmenting the skin, sometimes completely. However, at present there are no treatments that influence the future course of the disease and that can prevent new areas from de-pigmenting. Sometimes people make claims about 'cures', but in reality these cannot be supported by evidence from clinical trials.

Carrots and orange foods can help vitiligo

Carotenoids are chemicals found in brightly coloured fruits and vegetables (such as carrots), some of which are precursors of vitamin A. If consumed in large quantities they can temporarily give the skin an orange hue, but it is unlikely this would improve the appearance of vitiligo to any significant extent as it will also affect normal skin, therefore doing little to mask any difference in skin colour.

Eating fish and drinking milk together can trigger vitiligo

There is no evidence to support this

People with darker skin are more likely to have vitiligo

Vitiligo may be more noticeable in people with darker skin types, but broadly speaking, it occurs in people across the world in all different ethnic groups.

Vitiligo can affect anyone at any stage of their life

Yes, this is true, although around half of cases first show signs of vitiligo in childhood.

Vitiligo is contagious

No, absolutely not

GURDEEP ROMANAY : NEW SOCIETY TRUSTEE

You may recognise me from previous articles which I have written in Dispatches. I have been a member of the Vitiligo Society for nearly 10 years although I have had the condition for 23 years.

My vitiligo started when I was 10 years old with a small patch on my ankle. This did not change shape or size until I reached my early 20's when it started to spread. Over the years my vitiligo has got progressively worse. I believe that stress plays a huge role in the spread of vitiligo. It is very easy to become conscious of the white patches forming on your body but it's important to stay positive.

I have tried many treatments over the years ranging from steroid creams to homeopathic treatment. Some have helped but others have made it worse. I know from my personal experience that vitiligo can affect you in so many different ways. Some people try to hide it by covering it up with make up, others do not talk about it with anyone. What I have learnt over the years is that you

have to accept the condition before anyone else will. It is very easy to hide away but suffering alone is not the answer. My friends and family have been a huge support and have been there through my tough times. I have had the added obstacle of being Indian and having to deal with the ignorant stereotypical comments which some people within the community make.

The vitiligo society has been amazing and has helped me through my difficult times. I can recall the many occasions I used to phone the society and speak to Jennifer. She didn't need to say anything as she was listening to what I had to say and that was what I needed – someone I could talk to and understood my concerns.

The reason I have become a Trustee of the society is so I can help raise awareness of the condition and give support to people like myself. Although I have my friends and family, no one truly understands what you are going through unless they also have vitiligo. The society is here to offer support and remind people that you can live a happy life with vitiligo. It can be difficult but it's up to us to make a difference and educate people on what vitiligo is. The more people who understand this, the less of a taboo it will be. I know how difficult it is to be going about my normal daily routine and have people staring at my skin. It's not their fault though as some people just don't know what the white patches on our skin are. The vitiligo society needs everybody's

support – not just of trustees. I hope that you can help to shape the future of the society and what it stands for.

I have written many articles in Dispatches and also in Red magazine, Top Sante and the Times newspaper. The reason I do this is to help others by telling my story. I will also be presenting at the Royal Society of Medicine – Medicine and Me Symposium. I would encourage you to come and along with your friends and family to show your support at a very important event. The more we all raise awareness of vitiligo, the stronger we will all become and will be able to explain to educate those around us.

I look forward to providing as much support as I can to the society and those living with vitiligo.

“I will also be presenting at the Royal Society of Medicine – Medicine and Me Symposium. I would encourage you to come along with your friends and family to show your support at a very important event.”

“The society is here to offer support and remind people that you can live a happy life with vitiligo.”



WALK FOR SKIN : ANOTHER GREAT YEAR by Jeff Lock

This year the “Walk for Skin” took place at 11 different venues across the country. These included Manchester, Coventry, Cardiff, Newcastle, cheddar Gorge, Glasgow, Southampton, Edinburgh, Dundee and Leeds. These pictures show the grand start in London Kensington Gardens on Sunday May 11th with TV personality Denise van Outen cutting the tape. It was a warm sunny day and there were more than 300 participants. The “Walk for Skin” helps the British Skin Foundation to fund half a million pounds of research into skin diseases such as vitiligo every year. The Vitiligo Society also benefits from directly from those walkers who have specified the Society in their nomination. As well as those shown in the pictures the society was also represented at Kensington Gardens by Morgan-Daniella White and family



Vitiligo Supporters

Left :Natalie Ambersley, Lucy McLeod and Darcel de Vlugt

Centre: Mary Hill

Above Right : Gurdeep Romanay and friends

Right : Mike Moore and family

FOCUS ON PROTOPIC (TACROLIMUS) by JEFF LOCK



Protopic (Tacrolimus) is made from a rare soil bacterium discovered in 1984 on the island of Honshu which is the largest island of Japan. The island, which is larger than Great Britain, is mountainous and volcanic, It has frequent earthquakes and its highest peak is the active volcano, Mount Fuji.

Tacrolimus is an immunosuppressive drug whose main use is after organ transplant, to reduce the activity of the patient's immune system and so lower the risk of organ rejection. But it is also used in a topical preparation to treat certain skin diseases such as eczema and vitiligo. The drug is owned by Astellas Pharma Inc and is sold for dermatological use under the trade name Protopic.

Most experts believe that vitiligo is the result of the immune system mistakenly generating anti-bodies to the sufferer's pigment cells, which attack and kill or weaken such cells. Protopic works to down-regulate (suppress) the immune response in a local area of skin, where the vitiligo is located; it has a similar effect to steroid treatment, but without the side-effects. The ointment is showing very good success in many (but not all) people who are using it.

The most common advice for patients by doctors is to apply the ointment twice a day with many doctors also recommending that their vitiligo patients expose themselves to natural sunlight a few times a week for 15 – 30 minutes.

What is most reassuring to many users is that Protopic does not seem to be readily absorbed into the bloodstream or body, therefore keeping the treatment fairly

localised. The product itself is available in two strengths .03% strength (usually for children) and also 1%.

One thing that should be remembered is that whilst Protopic is showing good results for many it can still take time for others to see any improvement. A period of three to six months is not unusual to see initial results but 100% repigmentation is still difficult, especially on certain parts of the body, such as the hands. Best results have been observed on the face. Even so, once an

area has re-pigmented it may be subject to a future relapse; some patients have reported long-lasting results whereas others have experienced a relapse.

There are some investigations into testing Narrow Band UVB Light Treatment in combination with Protopic and this combination has shown enhanced repigmentation in some studies. Further studies are required to determine the safe parameters for this combination.

Hi, I'm Andres Miguel Rubio. I'm 27 years old and I live in Spain.



The first time I got vitiligo was a year ago. I saw white patches on my face and I went to the doctor. The patches extend over my face, mostly on my left cheek.

I heard of Protopic because I went to a dermatologist and he advised me to use this product. At the beginning I saw a little improvement in my patches but

nowadays I still see them growing. I am also taking some pills with vitamin H called Hachemina. I don't drink because of the protopic, and I use it every day, but, unfortunately I don't see any real improvement in the patches.

Well, I'm a quiet person and a try to be calm always. I think I'm quite good with my vitiligo, but obviously I don't want it extend all over my face. I am looking for a treatment that will stop my vitiligo but I don't think I've found it yet. I hear that stress is bad for the illness. So I try to get on with my life and not think too much about my vitiligo. However in summer is quite hard be normal with this patches. more if you are dark skin like me

Editor's Note : Andres and Tiffany (see next page) are members of the Vitiligo Society Group on Facebook and responded to a request for information on experience of using Protopic

FOCUS ON PROTOPIC (TACROLIMUS) continued

Hello, my name is Tiffany Green. I'm 23 years old and I live in the US (Jacksonville, FL). I noticed the loss of skin pigment about a week before I went to the doctor. I remember it like it was yesterday, I went to see my dermatologist on Thursday, April 9, and after a quick look she informed me that I had Vitiligo, and that I was actually the third person to come in that morning with it.



The extent of my Vitiligo is confined to the area around my mouth, and, because it appears to be restricted to that small area, Protopic was the medicine prescribed. It has only been 6 weeks since I've been using Protopic, so I do not see any significant results, as the Dr. said I wouldn't this early. However, I was told that after 3 months of using Protopic I can opt to have Laser.

Coping with Vitiligo has been the hardest thing in life thus far, I believe. I've cried many days and nights, including on the drive home from the Dr's office. I feel like after growing up and finally accepting myself, flaws and all, I'm forced to start all over again and try to embrace something that breaks me down every time I look in the mirror. My family has been very supportive. They tell me I'm *beautiful* every chance they get, but I know it's primarily because of my skin condition so it doesn't really help much. I'm pretty sure that if there were a definite cure for Vitiligo a lot of people would readily jump in line to be cured, but, I believe that God made us all the way that he intended for us to be, and at the end of the day Vitiligo is something we can learn to appreciate because it separates you from the rest of the world, and deems you unique. Although I'm not 100% comfortable with it, I think the best way to cope with it, is to simply accept it.

“Further Studies Are Required.”

The British Association of Dermatologists Guideline reports the following studies on Tacrolimus and concludes that further studies are required.

“Twenty children treated over 8 weeks with either topical clobetasol (a steroid) or tacrolimus were shown to have repigmentation that amounted to 41% with clobetasol and 49% with tacrolimus. Lesions on the face and thorax responded better than those on the abdomen or legs: lesions on the hands did not respond. Skin atrophy was noted in 5 of those treated with the steroid while two of the 20 who received tacrolimus noted burning.

Comparisons have been made of topical tacrolimus alone with

tacrolimus and Excimer UV radiation. In one study of 14 patients aged over 12 years, 23 lesions received a combination of tacrolimus ointment twice daily and Excimer UV twice daily for 12 weeks and were compared with 20 lesions that received Excimer UV alone for 12 weeks. For the combination of topical tacrolimus and excimer UV, 16 of the 23 had 75% or more repigmentation compared with four of the 20 lesions treated using the Excimer alone. In UV exposed areas i.e. Face, neck, trunk or limbs 75% repigmentation or more was seen in 10 of 13 using the combined treatments compared to none of the 13 lesions that received the Excimer alone.

Side effects included stinging in the tacrolimus group, moderate erythema

(redness of the skin) at least once in all patients, and bullous lesions (blisters) in four of 43 lesions. Another study that included only 20 lesions in eight adults comparing Excimer plus topical tacrolimus versus Excimer plus placebo found repigmentation to be more in the the tacrolimus/Excimer group.

Further studies on the efficacy of topical calcineurin inhibitors are required. The long term side effects of the calcineurin inhibitor drugs are unknown and this should be borne in mind if prolonged treatment (i.e. longer than 12 months) is proposed.”

LETTERS

Dear Editor

POOR TURN OUT AT NORTH WEST SUPPORT GROUP

I went along to the North West Support Group which was held in the Gardens Hotel, Manchester on 18th April last. Lynn Ashley had kindly arranged to have coffee in the Gorton Suite and baked some very fine cakes for all who would attend. I could not believe the abysmal attendance from members. In total there was only three of us, or five counting Lynne and the lady from Clarins. Nevertheless we had a very nice talk and discussed any difficulties we had and what camouflage we individually found the best for ourselves. It is always nice to meet other members with the same skin problem that I have, and we appreciate each others company and chat. Della from Clarins was most helpful. I have always found difficulty covering my hands and I am now using Clarins Concentre Teinte for my hands and am very happy with it.

Lynne did mention during discussions that a number of support groups had folded due to lack of support and how Vitiligo Society members had fallen in numbers. From memory, I think she said it was a thousand. I was sad to hear that. I certainly do not want our precious Dispatches magazine to stop coming through the letter box. After 25 years it would be very sad to see our society disappear like others have. It is up to the members to ensure this does not happen. Let us all support the Society as much as we can. Perhaps, the next north west region meeting could, for instance, be held in a member's house if they have plenty of space or in a church hall instead of hotel rooms which would save the Society money it can ill afford. We must keep going

Best Wishes **Ruth Williamson**



Dear Editor

WALK FOR SKIN : EDINBURGH 31 MAY 2009

I thought I would send you a photo of my daughter Charlotte, who is a member, and Samantha and myself after finishing the walk around Holyrood Park, The weather was hot and the walk took in some beautiful scenery.

We had a great day out and raised £168.52 from family and friends which has been sent and received by the British Skin Foundation, so you should be receiving 50% in due course.

Yours sincerely

Shirley Jackson

Dear Editor

SUN MOUSSE

For the first time since I received it last year, I've had an opportunity to try my sample of The Sun Mousse. A bit surprising on first squirt - the foam just keeps on expanding - but it works, and has a moisturising effect. I have trouble getting it all rubbed in - looked over my shoulder earlier and there was an escaped nodule of foam. For a moment I thought I was growing wings, but there, I'm not good enough for that!

Yours sincerely

Rose King

EFFECTIVENESS OF ORAL GINKGO BILOBA IN TREATING VITILIGO



On 23 June under the headline “Ginkgo Can Help Jackson Skin Disease” the Daily Mail reported that:

“Ginkgo Biloba, a traditional Chinese remedy, could help patients with vitiligo, a condition characterised by pale white patches on the skin and from which Michael Jackson was said to suffer. Previous research has found that Ginkgo stops the condition from getting worse and can even make the white patches disappear.”

This is being tested in a clinical trial at the University of Toronto where patients will take a pill based on the extract twice a day for two weeks.

Around 100,000 Britons have vitiligo which can appear on the face and neck. These areas have little or no melanin, a substance which gives skin its colour. Although the exact cause is unknown it is thought that “oxidative stress” - damage to the cells caused by oxygen - plays a role. Ginkgo Biloba has been known to have antioxidant effects.”

Unfortunately, at the time of going to press the Society has no information on the Toronto trials. However, the “previous research” referred to above is available and occurred in India in 2003.

The introduction to the 2003 report states “Vitiligo is an acquired depigmentation disorder of great cosmetic importance affecting 1-4% of the world’s population. The basic pathogenesis of vitiligo or of any of the putative subsets of vitiligo, remains unknown. Recently, epidermal oxidative stress has been documented in vitiligo patients. In patients with active vitiligo, both an imbalance of the intracellular redox status and a significant depletion of enzymatic and nonenzymatic antioxidants have been shown representing an abnormal oxidative stress leading to epidermal cell injury. In patients with active vitiligo it is important that the initial therapy should be directed at arresting the progression of the disease.”

The summary of the outcome of the trial reads as follows.

“For effective treatment of vitiligo it is as important to arrest the progression of the disease as it is to induce repigmentation. Recently oxidative stress has been shown to play an important role in the pathogenesis of vitiligo. Ginkgo Biloba extract has been shown to have an antioxidant and immunomodulatory properties. In a double-blind placebo-controlled trial we evaluated the efficacy of Biloba extract in controlling the activity of the disease process in patients with limited and slow spreading vitiligo and in inducing repigmentation of the vitiliginous areas.

Fifty two patients were assigned to two treatment groups (A and B) in a double-blind fashion, but only 47 patients could be evaluated, because one patient in Group A and four patients in Group B withdrew for reasons unrelated to the study.

Patients in Group A were given Biloba extract 40mg three times daily whereas patients in Group B received a placebo in similar doses.

A statistically significant cessation of active progression of depigmentation was noted in patients treated with Biloba. Marked to complete repigmentation was seen in 10 patients in Group A, whereas only two patients in Group B showed similar repigmentation.

The Biloba extract was well tolerated. Biloba seems to be a simple, safe and fairly effective therapy for arresting the progression of the disease.”

Report authors : D Parsad, R Pandhi and a Juneja, Postgraduate Institute Chandigarh and Himilayan Institute of Medical Sciences

The Society will try to discover more information on the current trials in Canada.

VITILIGO EVENT FOR MEMBERS AT THE ROYAL SOCIETY OF MEDICINE : SATURDAY 21 NOVEMBER 2009 STARTING AT 11.30

11.30 Doors open

11.45 The Vitiligo Society AGM

12.30 Delegate Registration and coffee

13.20 Welcome Address Dr David Misselbrook Dean RSM

13.25 Introduction – Lord Bates

Primary care, secondary care

13.35-13.50 First presentation – “The initial diagnosis”

13.50-14.10 Response – Dr Stephen Kownacki Chair Primary Care Dermatology Service

14.15-14.30 Second presentation – “Having got to see a dermatologist – what can I expect?”

14.30-14.50 Response – Prof David Gawkrödger Consultant Dermatologist and lead author BAD Guideline on Vitiligo

14.50 Tea

Psychological Implications and future research

15.10-15.25 First presentation – “Psychological Implications” – gender/youth/ethnicity

15.25-15.45 Response – Dr Linda Papadopoulos Counselling Psychologist

15.45-16.00 Second presentation – “Research - When can we expect a cure?”

16.00-16.20 Response – Prof Steven Ersser Chair in Nursing Development and Skin Care Research

16.30-17.15 “Ask the Experts” – Chair Dr Tony Bewley

Panel: Professor Dorothy Bennett, Prof Steven Ersser, Prof David Gawkrödger, Dr Stephen Kownacki, Andrew Langford, Dr Linda Papadopoulos, Maxine Whitton

17.20 Final Remarks/Close of Meeting

VITILIGO EVENT FOR MEMBERS AT THE ROYAL SOCIETY OF MEDICINE : SATURDAY 21 NOVEMBER 2009 STARTING AT 11.30

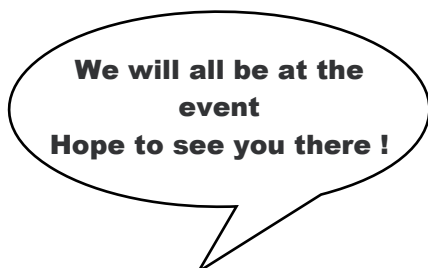
WE NEED TO KNOW IF YOU WILL BE ATTENDING

To mark the 25th Anniversary of the Vitiligo Society we are holding a Vitiligo Symposium at the Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE. This is free of charge to members of the Society. Presentations are planned as shown on this page and a panel of medical experts will answer questions

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.

WHAT SHOULD I DO NEXT ?

Please register your interest by completing and returning the registration form enclosed with this edition.



MaSAP PROFILES CONTINUED : LINDA PAPADOPOULOS



As reported in the last edition of *Dispatches*, 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 by members of the Medical and Scientific Advisory Panel to help the Vitiligo Society.

Dr. Linda Papadopoulos is one the most well-known and respected Counselling and Media psychologists in the UK today. She is also renowned in the field of Psychodermatology where her books and research articles on the link between the skin and the psyche are considered seminal in the field. In fact it was her research into the effects of psychological stress on the skin that was originally profiled on British TV 10 years ago which has since led to Dr. Linda's opinions and

analysis becoming some of the most commonly called-upon by broadcasters both here and in the United State. Her books on Body image have been translated into several languages and her latest edited text in Psychodermatology, published by Cambridge University Press, has been commended by dermatologists and therapists alike. Dr. Linda's comments regarding the psychology behind news and current events are often syndicated by the press and discussed by both TV and radio networks as well as in newspapers and magazines. She is a Contributing Editor with a very successful regular monthly column, in *Cosmopolitan* magazine where she also writes celebrity-psychology feature interviewing celebrities. Apart from her regular television & radio appearances Dr. Linda is also regarded as an accomplished academic psychologist. She has a very prolific publication

record and has published widely in peer reviewed academic journals, in the field of Psychodermatology and Counselling and is often invited to give specialist lectures at numerous Universities and Medical Schools both in England and throughout the World. She lives in London with her little girl Jessica and Husband Theo.

Linda will be an expert presenter at the special symposium for members at the Royal Society of Medicine on Saturday 21 November starting at 11.30 a.m. So if you would like to hear her opinions or ask her a question, you should register to attend the event. The details are on page 13 of this edition.

COVER STORY : ALL THE FUN OF THE FAIR by Jeff Lock

The photo shows Vitiligo Society member Abi Rose at her "vitiligo stall" at the Harpenden Carnival which is organised every year by the local Round Table and attracts up to 7000 visitors. Abi and her helpers found that most people did not know what vitiligo was and were interested to find out about it. They also gave details of the society to three people who knew someone with it.

One lady told Abi that she had been admiring her lovely pale skin and not realised that it was pale because of the loss of pigment. Abi was helped on the stall by her cousin Tom and two friends Izzy and Emily.

Abi is currently 13 and in year 8 at St George's secondary school. During the past year she has played for the school lacrosse teams - either in goal or defence. Outside of school she goes to Scouts. She loves the camping and outdoor activities that she gets up to. She was in the Harpenden Scout Gang Show in Jan 2009 and will be in it again in Jan 2010.

Abi's interests include Karate (she is now a brown belt), attending Stagecoach (drama, dance and singing), reading, msn and shopping. Her vitiligo covers more than 50% of her body but it's visibility depends on how much the pigmented areas have tanned.



Abi wanted to raise the funds as a "Thank you" to the society for the support she received in coming to terms with her vitiligo and as her Scout leader said the other week - "she definitely does not hide it ! Abi raised a total of £200 for the Society.

Fred Fredriksen : Vitiligo Society Chairman 1987 to 1990



It's great when people who have been associated with the Vitiligo Society for many years, still turn up at 125 Kennington Road to lend a hand with current problems. "Fred" Fredriksen, a former Chairman of the Vitiligo Society has been around recently helping us to amend the Access database which holds all the details of Society members.

Fred first became involved with the Society in about around 1985. At that time, he and his wife were acting as foster parents for a young girl of African descent. At the age of 9 the girl developed the first symptoms of vitiligo and Fred and his wife were naturally concerned to discover as much information as possible. After visiting their GP they became members of the London Vitiligo Group as it was then known.

The first meeting they attended was at the Royal Festival Hall. Fred remembers that, although the group was already a registered charity, it was far from being the businesslike organisation that it is today. It had no premises and very little funding. The first employee was a lady called Margaret Down who worked for 20 hours a weeks from her own home. Post was delivered to a box number in

Dulwich. Much of the funding came from the ROC Cosmetic Company. An early success for the Society came in February 1986 when the BBC TV "Help" programme showed a ten minute documentary about vitiligo. This resulted in a meeting in the lecture hall at St Thomas's Hospital which was attended by more than 200 people. Following this, leaflets on vitiligo were distributed to GPs and hospitals.

Fred remembers that the first Society newsletters were simply a matter of cut and paste. They were produced at home on a rota basis by whoever had drawn the short straw. The finished newsletter was photocopied and then stuffed into envelopes by hand.

Thanks for all the work you have done for the Society, Fred.

PARTICIPATIVE EVENTS FOR VITILIGO SOCIETY MEMBERS

HAVE YOUR SAY IN DEFINING THE FUTURE OF VITILIGO RESEARCH

As you may have seen in the last issue of *Dispatches*, the Centre of Evidence Based Dermatology at the University of Nottingham 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).

The vitiligo aspect of this research study involves identifying and deciding the most important research questions for the treatment of vitiligo. To do this we are asking people with vitiligo, the parents or guardians of children with vitiligo and health professionals (e.g. doctors and nurses) to tell us their questions about treatments for vitiligo that they would like to see answered by research. We have developed a survey to collect research questions, which you may have already received through the Vitiligo Society. We would like to take this opportunity to thank the many people that have completed the survey. If you have not had the opportunity to tell us your research questions through the survey, we now have an online survey available. To complete the survey go to: www.vitiligostudy.org.uk where an information sheet and survey is available.

If you would like to know more about this research study or would like to receive a copy of the survey in the post please contact a member of the research team by telephone: 0115 8268633, email: vitiligostudy@nottingham.ac.uk or by post: Vitiligo Study, Centre of Evidence Based Dermatology, University of Nottingham, King's Meadow Campus, Lenton Lane, Nottingham NG7 2NR.

This exercise will result in a list of the Top 10 most important research questions in the field of vitiligo. We then hope to develop at least one of these suggestions into a full scale clinical trial.

DATES FOR YOUR DIARY

Saturday 3 October 2009

LIVING WITH VITILIGO Parents' Support Group

125 Kennington Road SE11 6SF
starting at 14.00

Please let us know if you are going to attend by calling 020 7840 0844