



in this issue..

Page 2

Skin Care Campaign update:

- Building for the future
- What on earth have I taken on?

Page 4

The All Party Parliamentary Group on Skin:

- Quarterly activity update

Page 5

Patient group focus:

- Introducing Alopecia UK

Page 6

- The psychological and social aspects of disfigurement: Changing Faces' introductory courses and in-house study days

Page 8

News round up:

- Acne Support Group unveils new self help tool
- Shingles Support Group outlines long term impact of the condition
- HITS (UK) annual family day
- Skin project exhibition, House of Commons, July 2007
- Sunburn doubles the risk of skin cancer
- DeBRA's Mad Hatter's Week is coming – don't keep it under your hat!

Page 11

Forthcoming Events

15 years on...

As we all know, emollients are one of the essential parts of caring for our skin and it was the government's proposal to introduce a 'restricted list' for prescribing these preparations which inspired Tina Funnell to set up the Skin Care Campaign (SCC), 15 years ago.

We were extremely grateful to the APPGS Chairman, the Rt Hon Bruce George, for inviting us to a reception in the House of Commons on 26 March to celebrate the 15th Anniversary of the SCC where we were welcomed by Baroness Masham, (APPGS Vice Chairman).

As well as congratulating the SCC on its 15th Anniversary, Baroness Masham also paid tribute to Peter Lapsley on his retirement as Chief Executive for all his work with the SCC and the APPGS Steering Group. Baroness Masham also welcomed Andrew Langford as the incoming SCC Chief Executive.

It was delightful to see so many of our friends from the various patient, professional and corporate groups and to have the opportunity to celebrate 15 years of shared activity.

Over the years the SCC has grown and now has a membership of over 30 patient support groups for people with skin disease. Following devolution, SCC Scotland and, most recently, Skin Care Cymru have been established.

We have also strengthened our collaborative links with all those involved in providing care and services in dermatology - British Association of Dermatologists (BAD), British Dermatological Nursing Group (BDNG), Primary Care Dermatology Society (PCDS), Royal Pharmaceutical Society (RPS) and the pharmaceutical industry. This ensures that the patient perspective is represented in all arenas including the Department of Health through participation in, for example, the 'Action on Dermatology' programme, the Dermatology Workforce Group and the Patient Carer Network. Additionally, the SCC has a close relationship with the All Party Parliamentary Group on Skin (APPGS) and has been a significant contributor to all of the APPGS enquiries.

Some of the issues, among the many, that the SCC has addressed during the past 15 years are:

- The stigma of skin disease;
- The absence of any mention of skin disease in the GP contract;
- Self-management in chronic skin disease;
- Training of health care professionals in dermatology;
- The impact of skin disease on quality of life;
- The adequacy and equity of dermatology services in the UK.

Keeping informed and being aware of the continuing changes in the NHS and health services is a major challenge for the SCC. Currently the implications of the implementation of practice based commissioning (PBC), payment by results (PbR) and changes in primary care trusts (PCTs) are causing concern about care and services for people with chronic long term conditions. In collaboration with patient and professional groups, the SCC will continue to pursue any issues that impact on the lives of people with skin disease.

Finally, I am also pleased to inform SCC patient group members that the SCC Board has agreed a special membership arrangement with the APPGS so that membership of the APPGS will be an inclusive benefit for all patient support group members of SCC.

Lynette Stone CBE
Skin Care Campaign Chairman

Skin Care Campaign update

Andrew Langford, Chief Executive, Skin Care Campaign



Building for the future

To start with I'd like to say a HUGE thank you to everyone who has welcomed me so warmly to the Skin Care Campaign over the last few weeks and, in particular, to Peter who has given me a fantastic handover and

as comprehensive a briefing on the challenges we currently face as I could possibly have asked for.

I am delighted and honoured to be the new Chief Executive of the SCC and look forward to building on the work already undertaken by you all to improve patient care and to raise awareness of the physical and emotional impact of skin conditions on patients and their families.

As many of you know my background is in nursing, however my interest in improving the lives of those with a skin condition is both personal as well as professional as I have two young nephews with eczema.

I have seen first hand the anxiety, hurt and exhaustion experienced by my sister and brother in law as they watch their child in pain and discomfort. As a father myself I am in awe of those parents who, in addition to the general challenges of parenting, must battle to secure the best possible care for their child while, at the same time, coping with the demands of their daily treatment regime.

It would be foolhardy of me at this early stage to outline my objectives for the SCC. What I'd like to do first is to get out and meet with the different patient support groups to hear their concerns, what they expect from the SCC and to gain a much better understanding of the individual effects of each skin condition and the consequences of these in terms of patient care.

This knowledge, combined with an understanding of the political environment we are working in and the needs expressed to me by the professionals involved in this particular healthcare arena, will enable me to develop my long term objectives for the SCC in an informed and considered manner.

As you will see in my 'official' CEO article, there are huge challenges to contend with at present as the government continues to 'rationalise' (read 'cut' or 'dilute') dermatology services and I will endeavour to keep everyone informed of changes, new challenges and our successes in the coming months.

One area I have identified for immediate improvement is the SCC's profile in the media. While the SCC and our PR

consultancy, Ash Communications, strive to respond to any media requests, I believe it would be prudent to take a more proactive approach. To do this successfully we need examples of the experiences of those with skin conditions – both positive and negative – that highlight the trials and tribulations faced by people every day and how high quality patient care makes such a vital difference. If you are able to contribute to our bank of patient stories please contact either myself or Ash as we'd be delighted to hear from you.

To further strengthen our partnership with the media, I would also urge you to contact me if ever you see an article on skin care that you feel the SCC should be responding to. In our fast moving world it is crucial that we respond to such articles immediately before they become yesterday's news so do either drop me a line or give me a call.

Another of my immediate aims is to strengthen our relationships with Skin Care Scotland and Skin Care Cymru as I am a firm believer in 'together we stand, divided we fall'. By working together and understanding the issues we all face I know we can become a formidable force across the UK. NB: If my trips to meet with either were to also coincide with a decent match at the Millennium Stadium or Murrayfield I'd be a very happy man!

You have been very lucky in the past to have had the wit and eloquence of Peter's articles. I cannot begin to compete with either of these qualities but, as I hope this introduction shows, I will be as upfront and informative as possible.

I very much look forward to working with you all.

Andrew

What on earth have I taken on?

On joining the team at the start of March I rapidly realised the enormity of the task I've taken on. I have quickly learnt that there is so much going on and so much that needs dealing with NOW.

Having had the luxury of three in-trays in my previous role – 'act now', 'deal with in time' and 'maybe get around to' – I have quickly learnt that I'll only need the 'act now' tray as Chief Executive of the SCC!

There is an endless list of fronts on which we are battling to improve patient care - frequently in the face of cutbacks, red tape and limited awareness and understanding of skin disease and its treatment - but to follow is a summary of the areas on which we have been focusing our efforts in recent months.

Primary and hospital based skin care services

Possibly the most pressing issue for us all is the continuing pressure from the government to move nearly all skin care services into primary care and the cutting, or radically reducing, of hospital based dermatology services.

Before retiring, Peter wrote to Patricia Hewitt expressing the SCC's concerns. To follow is a summary of that letter:

"I am writing to apprise you of the serious risks to patient safety, care and choice, and to specialist dermatology services, posed by the indiscriminate way in which much dermatology is being removed from secondary to primary care.

.....We have great respect for GPs' generalist skills and for the way in which they already diagnose and treat the great majority of skin disease. Given the inadequacy of their dermatology training, however, it is entirely wrong to expect them to diagnose and treat skin diseases which they believe should be referred to a consultant dermatologist.

Increasingly, PCTs are attempting to address the lack of dermatology training for GPs by appointing GPs with a Special Interest in dermatology (GPwSIs).

Many GPwSIs provide valuable services within their communities – notably those who have fulfilled the British Association of Dermatologists/Department of Health Guidance on training and Continuing Professional Development (CPD), who often work part-time as clinical assistants and whose services are fully integrated with secondary care. Such GPwSIs place great value on their relationships with their consultant colleagues and would always expect them to be involved in the planning of any service redesign.

Our concern, however, centres on the growing number of GPwSIs who do not meet the requirements of the guidance and lack such experience and expertise. Many of them have been appointed by PCTs in the evident belief that they can be used to replace consultant dermatologists. They can not.

The Primary Care Dermatology Society, the Royal College of General Practitioners and the British Association of Dermatologists have recently developed an accreditation process for GPwSIs in Dermatology. It is to be launched in the spring along with the Department of Health's generic guidance on the appointment of Practitioners with Special Interests. It is essential that it should be made mandatory.

As well as its implications for patient safety, care and choice, the current determination indiscriminately to remove much secondary care dermatology into primary care is seriously undermining the viability of many secondary care dermatology departments. If it continues, such departments may close with the resultant loss of

essential clinical teams, denying many patients access to specialist services. Importantly, also, it will denude the NHS of the very resources it needs for the training, supervision and CPD for those providing intermediate dermatology services.

The Department of Health's Dermatology Workforce Group (DWG) has just published on-line its Models of Integrated Service Delivery in Dermatology, which may be found on the home page of the Skin Care Campaign website at www.skincarecampaign.org. Building on the work of the NHS Modernisation Agency's 'Action on Dermatology' programme, the DWG model focuses on separating diagnosis from treatment, on prompt and accurate diagnosis at whatever level may be necessary, and on the facilitation of the self-management of much inflammatory skin disease through nurse-led clinics in primary care. It is safe, provides good patient care and offers patients choice. It greatly reduces the dermatology workload in primary care. But it also emphasizes the need for properly resourced secondary care dermatology services for the diagnosis and management of complex or difficult cases, for the training of medical students and doctors, to contribute to the training of nurses and pharmacists, and to continue the world-leading research for which British dermatology is renowned. We commend it to you as a very much better way of delivering dermatology services than the wholly unacceptable and unsustainable unilateral approach being taken at present, and we ask you to give it your most careful consideration."

It is essential that we encourage anyone seeing a GP or primary care based 'specialist' to ascertain that they are adequately qualified and experienced to deal with that particular skin condition. I hope that in the future we can have a list/register of qualified GPwSI's/PwSI's for patients to refer to prior to their consultation. In the meantime, I would like to hear from anyone who has had a bad experience as a result of this system so that we can build up a bank of evidence to add further weight to our argument.

18 week pathway for skin lesions

A multi-disciplinary team, including the SCC and Changing Faces, has agreed a pathway with the DoH that will ensure that anyone with a skin lesion receives a full and appropriate assessment and treatment, at whatever level they require, within 18 weeks of their initial consultation with their GP. Should a lesion be suspected to be cancerous then the person will immediately be moved on to a two week pathway for immediate care and support.

Both the SCC and Changing Faces ensured that integral components of a complete care package such as support, education and information for all those affected – including proper psychological support when required – were built in to the pathway model.

Skills for health – phase 1

“Skills for Health is the Sector Skills Council for the UK health sector. Our aim is to help the whole sector develop solutions that deliver a skilled and flexible UK workforce in order to improve health and healthcare.”

Guidelines produced by Skills for Health will clearly outline the competences required by practitioners to diagnose and treat skin conditions.

I wish I could report that all of the steering group’s hard work had resulted in the successful signing off of phase 1 by all stakeholders but, unfortunately, not all parties will agree to this in its current form.

More work needs to be done to ensure consensus is reached and it is still felt that attaining the competences (with skills, knowledge and experience) could lead to diagnosis and treatment being given by someone other than a qualified Doctor.

Energy saving light bulbs

Ecologically speaking, few would disagree that any move towards increased energy efficiency is fantastic. However, current energy saving light bulbs are candescent and people with light sensitivity arising from a

range of health conditions can only tolerate incandescent lighting.

Such people face being unable to use electric lighting in their homes, or to go anywhere that electric lighting is in use. This will result in even greater social exclusion and increased ill health.

It is possible to produce incandescent energy saving light bulbs and the government must encourage further research into the production of these to avoid the additional health and social costs of being environmentally friendly to some patients.

If you haven’t already, please could you sign the petition on the 10 Downing Street website supporting Right to Light and SPECTRUM with their campaign -

<http://petitions.pm.gov.uk/righttolight>

And so ends my first report as Chief Executive of the SCC. Please keep an eye on our website as I will endeavour to update this on a monthly basis from now on so that you are kept abreast of the action being undertaken.

Once again, thank you for my warm welcome and I look forward to working with you all in the future.

Andrew

The All Party Parliamentary Group on Skin (APPGS)

Quarterly activity update

A number of the APPGS’ activities so far this year have focused on the increasingly problematic issue of reductions in the number of GP referrals to secondary care dermatology services. This issue has united the SCC, BAD and APPGS to take collaborative action against the increased use of schemes designed to reduce referrals. The three groups have launched a cohesive campaign to highlight concerns about the effects of such schemes on patient safety, care and choice, as well as the implications for the future of training and research in dermatology – much of which takes place within the secondary care setting. The APPGS is extremely concerned that referral reduction schemes will compromise the future of dermatology services, many of which are already under threat as a result of healthcare deficits.

The APPGS has taken action to raise these concerns with members of the group, and with health interested politicians. A briefing note prepared by the SCC earlier this

year, which highlighted the impact of referral reduction schemes on dermatology patients, was circulated to MPs and Peers. The briefing was accompanied by a range of parliamentary questions which members were asked to table on behalf of the APPGS, in order to put pressure on the Department of Health to respond to its concerns.

The Chairman of the All Party Group, the Rt Hon Bruce George MP, has also sent a separate letter to the Minister with responsibility for dermatology services, the Rt Hon Rosie Winterton MP. Accompanying this letter was a copy of the Dermatology Workforce Group’s report, *‘Models of Integrated Service Delivery in Dermatology’* (copies of which have also been circulated to parliamentary members of the APPGS). The letter sought to highlight concerns about the referral reduction issue, and endorse the findings of the Dermatology Workforce Group’s report as a workable model for future dermatology services. It also reminded the Minister that she has yet to formally respond to the issues raised with her at the meeting at the end of last year, and to encourage her response to all of these issues as soon as possible.

The APPGS is now launching a wider targeting exercise of MPs, based on the issues highlighted above and using information supplied by the BAD. In particular, this will target the MPs in areas where it is known that referral reduction schemes are in place, and where there is evidence that these schemes are detrimental to the service provided to patients with skin disease.

The APPGS will also continue to endorse the Dermatology Workforce Group's integrated service models document as the level of service that healthcare providers should aspire to provide for dermatology.

The other key issue the APPGS has looked at over the past few months is the forthcoming publication of the Department of Health's (DH) accreditation guidance for Practitioners with a Special Interest (PwSI's), and the more specific accreditation guidance on the appointment of General Practitioners with a Special Interest in Dermatology (GPwSI's).

The latter guidance has been developed by the GPwSI Working Group, led by Dr Tim Cunliffe. Dr Cunliffe and Dr Julia Schofield - who was involved in the development of the DH's PwSI guidance - were kind enough to present to members of the APPGS at the start of the year on the background and themes of this hugely important guidance. The APPGS was particularly grateful for this insight, which preceded the official publication of the guidance.

The issue of GPwSI's was addressed in the APPGS' ninth report on *'The Adequacy and Equity of Dermatology Services in the United Kingdom'*. The report recognised the

potential value of GPwSIs who were properly trained in dermatology, and who worked closely with their secondary care colleagues to add substantial value to service provision. However, there are a number of GPwSIs who are not properly accredited, and it is these individuals that the guidance seeks to target.

The APPGS stands ready to fully endorse the guidance as soon as it has been published, and will be tabling a motion in parliament to this effect. It is also concerned by recent suggestions that the guidance will not be a mandatory national standard, contrary to earlier indications by the DH. To this end, a question has been tabled in the Commons to ask whether the guidance will be mandatory, and the APPGS will be applying additional pressure on the DH to ensure that it receives the recognition it deserves.

Finally, the APPGS was delighted to host a reception in the House of Commons recently to celebrate 15 years of the Skin Care Campaign and to bid a fond farewell to Peter Lapsley as he prepared to stand down as its Chief Executive. We are all extremely grateful for Peter's hard-work and enthusiasm over the past decade, and for the remarkable achievements he has made on behalf of patients with skin disease. The APPGS is happy to welcome Peter's successor, Andrew Langford, to the role and looks forward to working with him in the future.

For further information about the All Party Group, or to obtain copies of the Group's reports, please contact the Secretariat on 020 7368 3103.

Patient group focus

Introducing Alopecia UK



About Alopecia

The word alopecia simply means 'hair loss'. The majority of people who contact Alopecia UK have alopecia areata and androgenetic alopecia. Alopecia areata is a form of patchy hair loss that can develop into alopecia totalis, complete loss of hair on the head, and alopecia universalis, complete hair loss from the head and body.

Although there is no known cure for alopecia, there are a number of treatments. These tend to have limited efficacy,

especially with alopecia areata, and can have unpleasant side effects.

A general rule for the chance of re-growth is, the more extensive the hair loss and the longer since the hair fell out, the less likely there is to be re-growth.

Androgenetic alopecia is more commonly known as male/female pattern baldness. In men this tends to be a well formed pattern of hairloss beginning above both temples, in women it is a general thinning of the hair all over the scalp.

About Alopecia UK

Alopecia UK started in 2003 as the website Alopecia Online. The organisation quickly grew and in 2005 became a registered charity. The website continues to grow almost month-on-month and currently receives around 70,000 visits every month.

We are currently run completely by volunteers and have a management committee, an advisory panel and a board of trustees. We also have two patrons, Gail Porter and Margaret Baker.

The three main aims of the charity are:

- to support people with experience of alopecia
- to raise awareness of alopecia
- to raise funds to support research in the field of alopecia.

What we do

As there are very limited treatment options many of the difficulties associated with alopecia are linked to coping with the effects of the condition. Our philosophy is that people should be given the information to help them make the right decisions for them, such as whether to cover up the hair loss or not, and we then provide the support and advice to back up that decision.

The majority of people who contact us come through the website. We respond to hundreds of emails a month with all sorts of questions and queries.

We have a very active and supportive online discussion forum with over 2,000 members and this has recently celebrated its first wedding! The forum has sections for people to discuss all aspects of alopecia, including a place for new members. We have found this provides a great way for people to get in touch with others in the same situation, share their experiences, vent their frustration and both give and receive advice.

Following on from the success of the discussion forum we have started to develop a network of support groups throughout the UK. We currently have eight support groups and a further 24 people who we put in touch with people in their area but who have not yet started a formal support group.

When we first started we received a lot of questions regarding provision of wigs and places to have semi-permanent make-up applied. In response to this we set up a suppliers' directory, which can be searched on our website and is sent out when people become members.

We have a very popular 'in pictures' part of the website where people send in pictures of themselves, either showing their alopecia or showing them in wigs.

In response to concern over people receiving misleading advice and guidance we launched 'Ask an Expert' allowing people to get answers to questions directly from specialists in their field. People send in questions to dermatologists, wig experts, semi permanent make up experts and, for self esteem advice, our patron Margaret Baker. The answers are then published in the newsletter and on the website.

We have also recently launched a brand new website for young people with alopecia called HeadzUp www.headzup.org.uk. The new site includes a safe forum for young people to share experiences as well as providing information and advice specifically for children, young people, their parents and guardians.

What next?

We are currently producing a series of leaflets to go primarily into dermatology units and are working towards being able to employ staff to help the charity increase its current activities and continue to grow.

Contact us!

For further information on the work of Alopecia UK contact us at:

W: www alopeciaonline.org.uk

E: info@alopeciaonline.org.uk

T: 0208 333 1661

The psychological and social aspects of disfigurement: Changing Faces' introductory courses and in-house study days

By Suzanne Millstone, Health Professional Adviser for Changing Faces



According to a government survey, there are at least 400,000 people severely affected by disfigurement in the United Kingdom. Causes include a wide range of dermatological conditions, such as acne, eczema and vitiligo, and diseases such as

skin cancer. Many people with disfigurements find it quite challenging to feel good about themselves in a society that appears to be increasingly appearance-conscious, and often find staring, comments and questions difficult to manage.

However, research has consistently found that one key factor clearly identified as predictive of a good outcome for patients with a disfigurement is the number and variety

of positive, non-avoidant coping skills and strategies they are able to employ in awkward social situations. Indeed, *Changing Faces* suggests that all patients are introduced to the idea of how they might deal with issues about their physical appearance *before* their discharge home, in order that they are able to manage challenges such as staring, comments and intrusive questions with increased confidence.

Findings further suggest that health and social care professionals can very easily fulfil this role given simple training and access to appropriate resources, thus playing an extremely vital part in how a patient learns to deal with their altered appearance.

Changing Faces offers two such training courses: **An Introductory Course: The Psychological and Social Aspects of Disfigurement**, and an **In-House Study Day: The Psychological and Social Aspects of Disfigurement**. These are specifically designed for any health or social care professional who works with children, young people or adults who have disfigurements, and so are suitable for doctors, nurses, occupational therapists, physiotherapists, speech and language therapists and social workers from many specialities.

One of the main concerns often expressed by health and social care professionals is how they can play a more active and involved role in helping to meet the psycho-social needs of patients with a disfigurement. The *Changing Faces* courses offer participants the facility to explore the different strategies they can use in order to help meet those needs. The aim is to enable health and social care professionals of all disciplines to offer their patients the same type of psycho-social support *Changing Faces* offers its clients, and to do so with confidence.

The Introductory Course takes place both at our headquarters in London, and regionally throughout the UK. A one-day interactive workshop, it offers participants the opportunity to:

- Explore the psychological and social difficulties posed by disfigurement
- Discuss how assumptions, beliefs, attitudes and language around disfigurement can influence communication
- Understand how the *Changing Faces*' psycho-social model supports children, young people and adults who have disfigurements, and their families
- Examine how this psycho-social model can be adapted to individual work settings
- Learn how to equip patients and their families with a range of communication skills and coping strategies for dealing with difficult social situations

The In-House Study Day is designed to take place within individual work settings and, while it covers all the topics mentioned above, it is also specifically tailored to meet the particular needs of staff in their own speciality/clinic/unit.

As well as examining the range of feelings and behaviours experienced by adults and children with disfigurement, and their families, the programme for both courses also includes exploring some of the key points that make it easier for someone to accept and come to terms with disfigurement, and looks at the main factors that can predict a good outcome.

Participants on both courses receive course materials, including a comprehensive package of resources and handouts.

Positive feedback from previous courses reflects the welcome opportunity felt by health and social care professionals to meet and share ideas and perspectives from a wide variety of disciplines, many of which they feel they can then incorporate into care plans and procedures for their own patients.

Dates for Introductory Courses in 2007:

Thursday 21st June: The Squire Centre, London

Thursday 27th September: Bristol

Thursday 25th October: Scotland – venue to be confirmed

Thursday 22nd November: London

Changing Faces is the leading national charity that supports children, young people and adults with disfigurement. In terms of direct support for patients and clients, our team of specialists including counsellors, teachers and psychologists, offer a wide range of services – from professional counselling by telephone, email or face-to-face in our London office, to group workshops and regional events.

For details of the Introductory Course and the In-House Study Day, please contact Suzanne Millstone, on 0845 450 0275, or Email: suzannem@changingfaces.org.uk

Changing faces
the way you face
disfigurement

News round up

Acne Support Group unveils new self help tool

The Acne Support Group has unveiled a new patient resource for those with rosacea in the form of a 'skin diary'.

Rosacea affects around six million people in the UK with 70% of patients suffering from low self-confidence and self-esteem. Symptoms include:

- Redness of the skin resembling flushing or blushing which, in time, becomes permanent
- Visible blood vessels
- Red acne-like spots
- Facial swelling
- Extreme skin sensitivity
- Facial burning, stinging or itching
- Eye irritation

What causes rosacea to develop remains a mystery and although there is currently no cure for the condition, treatments are available to reduce the symptoms. Common treatments include oral and topical antibiotics, Isotretinoin and laser therapy.

It is widely acknowledged that lifestyle factors have a major role to play in the treatment of rosacea, and that patients can help take control of their condition by identifying and avoiding key triggers. Triggers often include:

- Emotional stress
- Hot drinks
- Alcohol
- Spicy food
- Exposure to the sun or cold
- Exercise
- Medication
- Skin products

Identifying triggers is a highly individual process as what works for one person may not work for another and it is this that has led the Acne Support Group to launch its rosacea skin diary.

The diary is designed to help patients identify their personal triggers by keeping a daily record of symptoms, food and drink consumed, medication taken, skin products used, the weather and activities undertaken over a number of weeks so that any patterns can be identified.

Said Alison Bowser of the Acne Support Group: "Rosacea is a frequently overlooked condition yet its symptoms cause extreme distress and discomfort.

"The diary's ultimate aim is put people back in control of their own skin by helping them to understand the link between their lifestyle and their condition. Once a patient can identify a connection between their daily routine and either an improvement or relapse in their symptoms they can take action and thereby improve their quality of life."

Copies of the new diary will be distributed to GPs across the UK over the next few months and are designed to give health care professionals as well as patients a greater insight into the condition.

Adds Bowser: "By reviewing a patient's diary with them a GP can not only help to identify key lifestyle triggers, but also review their approach to treatment in view of the new evidence."

The diary is supported by Valeant pharmaceuticals whose non-antibiotic topical treatment, Finacea, is now available on prescription. Studies have shown Finacea to be both effective and well tolerated and the Acne Support Group welcomes this latest development in the treatment of rosacea.

For further information on rosacea and the new skin diary contact the Acne Support Group helpline on 0870 870 2263.

Shingles Support Society outlines long term impact of the condition

Winter 2006 saw the Shingles Support Society – a sub-group of the Herpes Viruses Association – seize new opportunities to publicise both shingles and the associated post-herpetic neuralgia and the huge impact this can have on people's lives.

In order to raise awareness amongst politicians we held a very useful seminar at the House of Commons in December which was attended by a number of MPs to explain the nature of this terrible disease, how difficult it is to treat and to highlight how, to date, there is no form of prevention available in the UK.

Following on from the seminar, an Early Day Motion will soon be tabled to attract the support of MPs from all the major parties.

Shingles and its associated complication of post herpetic neuralgia (PHN) can make life unbearable for those who

contract it. One woman who wrote to us said: "It is worse than the pain of childbirth and with nothing to show at the end of it."

Shingles is a recurrence of the virus that causes chickenpox which most of us catch in childhood. It is estimated that over 300,000 people develop shingles each year in England and Wales. However, recent surveys have found that if you have repeated exposure, say by nursing your children through chickenpox, then your antibodies against shingles are boosted.

Shingles mainly affects the elderly and the older a person is the more likely they are to develop debilitating PHN which can last for months and, sometimes, years. One survey (2004) showed that approximately half of a group of patients described their worst pain as 'horrible' or 'excruciating'.

The total cost to the NHS in England and Wales of treating shingles-associated diseases is estimated to be £47 million per year and a patient survey conducted by pain specialist Professor Richard Langford at Bart's has found that around 75 percent of patients are dissatisfied or very dissatisfied with the effects of current treatments.

However, antiviral therapy given in the first 72 hours can reduce the severity of an outbreak and make associated PHN easier to treat. Several different drugs can also help - tricyclic antidepressants and anticonvulsants can both be used to 'set up pain blocks'.

Thanks to an educational grant, the Shingles Support Society has been able to print information packs for patients and their GPs detailing these and self-help suggestions. A new 'patch' product may also be useful: Versatis plasters with lidocaine anaesthetic can be used by patients who may have problems adding another drug to their daily regimen.

Treatment is better than nothing but prevention would be better still. Now that really would be something to raise awareness of!

Marian Nicholson
Director

Shingles Support Society
www.herpes.org.uk/shingles

Skin project exhibition, House of Commons, July 2007

Following on from her article in the last edition of Exchange, it is fantastic to note that Rhonda Fenwick's art project about skin conditions will be exhibited in the Lobby of the House of Commons this summer. This will undoubtedly be a great opportunity not only to catch the eye of many MPs but also the thousands of visitors that visit the House.

Many thanks to Laura Moffatt, MP who has been instrumental in making this happen.

Sunburn doubles the risk of skin cancer



Britons love to soak up the sun. They seek hot climates for holidays. And they want to come home with a golden glowing tan. There is no getting away from these facts - as research continues to show.

Cancer Research UK's recent survey of 2000 people found that 50 per cent of holiday-makers aim to get a tan when on holiday. But, worryingly, half that number thinks that getting sunburnt is all part of the tanning process.

And for youngsters, burning is the norm for the majority. Among 16-24 year-olds, 30 per cent said they would definitely get burnt on holiday this summer while a further 31 per cent said they might get burnt.

Overall 19 per cent of those asked anticipated getting burnt while a further 21 percent said they might suffer sunburn.

This year the charity's SunSmart campaign is gearing its advice specifically to holiday-makers. And the key message is: DON'T BURN.

Research has shown that sunburn doubles the risk of malignant melanoma - the potentially fatal form of skin cancer. And surveys carried out on behalf of Cancer Research UK show that the most likely time for Britons to get sunburnt is when they are on holiday.

Dr Lesley Rhodes, Cancer Research UK dermatologist, said: "Getting sunburnt increases the risk of skin cancer in general. But the kind of sunbathing binges that happen when people go to much hotter climates and bake on the beach are particularly dangerous.

"This kind of intermittent intense exposure to the sun, leading to burning, particularly increases the risk of malignant melanoma. And each year in Britain almost 2000 people die from this form of skin cancer."

HITS (UK) annual family day

The HITS (UK) Family Support Network (supporting families with Hypomelanosis of Ito syndrome) will be holding its annual family day on July 7th from 12-5pm in Peterborough. The event is an opportunity for families across the country to meet up with each other in an informal setting and share their experiences. For further information please contact Terri Grant on 07940 114 943 or by email tgrant@uk.ey.com / tgrant@hitsuk.freeserve.co.uk



Dr Rhodes added that it was particularly worrying that more than a quarter of people surveyed believed burning was all part of getting a tan. “Rates of melanoma are set to treble in the next thirty years unless there is a radical change of behaviour among sunbathing bingers.”

SunSmart campaign manager, Rebecca Russell, said: “We want to raise awareness of the danger of burning - especially when people take off for holidays in warmer countries where the temptation to spend too long on the beach can be very great.

“But it is not just a problem for those who go abroad. People, especially those with fair skin, lots of moles or freckles or a family history of skin cancer, can be at risk of burning on hot summer days in the UK.”

Skin Cancer Facts

Nine out of ten skin cancers are easily treatable and unlikely to spread. They are called non-melanoma skin cancer and there are more than 75,000 new cases registered each year in the UK.

Malignant melanoma, which accounts for less than one in ten skin cancers, is the most serious type of the disease and may be fatal. It is more common in women than men.

Around 8,000 people a year in the UK are diagnosed with malignant melanoma. It usually develops in cells in the outer layer of the skin but can spread to other parts of the body. There are almost 1,800 deaths each year from malignant melanoma.

Melanoma is the second most common cancer among people aged 20-39 and early detection is crucial for successful treatment.

Who is at Risk?

Some people are born with a greater risk of skin cancer.

These people tend to:

- burn easily
- have fair skin and/or freckles
- have red or fair hair and/or pale eyes
- have had skin cancer before
- have a large number of moles (50+)
- have skin cancer in the family (especially melanoma)
- have had bad sunburn in the past.

If one or more of the descriptions on this list apply to you, you should take extra care to protect yourself from the sun. Know your skin type and use the UV Index to find out when you need to protect yourself

Babies and children need extra protection from the sun because their skin is delicate and easily damaged.

SunSmart Messages:

Spend time in the shade between 11 and 3. The summer sun is most damaging to your skin in the middle of the day.

Make sure you never burn; sunburn can double your risk of skin cancer.

Aim to cover up with a t-shirt, hat and sunglasses. When the sun is at its peak sunscreen is not enough.

Remember to take extra care with children. Young skin is delicate. Keep babies out of the sun especially around midday.

Then use factor 15+ sunscreen

Find out more at : www.sunsmart.org.uk

DebRA's Mad Hatter's Week is coming – don't keep it under your hat!

DebRA, the UK charity for people affected by the genetic skin blistering condition EB (Epidermolysis Bullosa), is inviting people to take part in its national fundraising campaign – Mad Hatter's Week.

Individuals, organisations, businesses and schools are being urged to wear their silliest or favourite hats for one day and collect sponsorship during the week-long awareness and fundraising event (June 18th – 24th).

There are many ways to take part, from holding a pirate's hat ball or a 1920s gangster party to hosting a Mad Hatter's Tea Party. Mad Hatter's Week offers an easy and fun way of supporting those who live with EB.

“Royal Ascot is not the only reason to put on a hat! This fun initiative is an easy way to do something for families whose lives have been turned upside down by this devastating condition,” said Laurence Helgesen, Head of Campaigns for DebRA.



Reproduced by kind permission of Vince Maher

Nell McAndrew models Ewan McGregor's hat at the launch of the 2006 online auction

EB is a genetic condition in which the skin and internal membranes blister at the slightest friction or even spontaneously. It affects around 5,000 children and adults in the UK and approximately 500,000 worldwide. DebRA funds a nursing service and it commissions world-leading research into the condition.

Without the public's support, DebRA would not be able to fund the vital services it provides directly to families.

This is DebRA's second Mad Hatter event. Last year DebRA Vice President Nell McAndrew launched a Mad Hatter online auction which saw hats owned by celebrities including Ewan McGregor, Ringo Starr, Liz Hurley and Alan Rickman go under the virtual hammer. Hundreds of groups and organisations across the UK also wore their hats for the day – each helping to raise more than £20,000 for DebRA.

This year DebRA is encouraging even more people to participate within their own communities, raising awareness of EB and raising funds for DebRA.

Taking part is easy:

- Register online at www.debra.org.uk/madhatter. There are plenty of ideas and tips in the Mad Hatter toolkit and a poster and sponsor forms are also available to download.
- Alternatively you can call the Mad Hatter team on 01344 771961 and register your interest.
- Then during Mad Hatter's Week (June 18-24) hold your Mad Hatter event, raise money and have fun.

Forthcoming Events and Meetings - 2007

Primary Care Dermatology Society	South & West Meeting/AGM, Bristol (1)	9-10 June
Vitiligo Society	Parents' Support Group, London (2)	16 June
National Eczema Society	Nurse training evening, Sheffield (3)	19 June
HITS (UK)	Annual family day, Peterborough (4)	7 July
XP Support Group	Owl Patrol for Teenagers, St Katharine's, Parmoor (5)	20-22 July
BASC	Chester (6)	31 August-3 September
Vulval Pain Society	Belfast workshop (7)	1 September
XP Support Group	Auction of Promises, St Katherine's, Parmoor (5)	15 September
Primary Care Dermatology Society	South & East Meeting, London (1)	28 September
Vulval Pain Society	Nottingham workshop (7)	27 October
Raynaud's & Scleroderma Association	Scleroderma Awareness Week (8)	5-11 November
Primary Care Dermatology Society	Scottish Meeting (1)	10-11 November

(1-8) For further details please see back page

- (1) For further details please contact Carol Singleton at the Primary Care Dermatology Society (PCDS) T: 01923 711678 or E: carol@pcds.org.uk
- (2) For further details please contact Jennifer Viles at the Vitiligo Society T: 0800 018 2631
- (3) For further details please contact The National Eczema Society (NW) T: 01925 766 877
- (4) For further details please contact Terri Grant on 07940 114943 or by emailing tgrant@uk.ey.com or tgrant@hitsuk.freeserve.co.uk
- (5) For further details please contact Sandra Webb at the XP Support Group T: 01494 890981
- (6) For further details please contact the Mary Thorp at the BASC T: 01625 871 129
- (7) For further details visit www.vulvalpainsociety.org
- (8) For further details contact the Raynaud's & Scleroderma Association Tel: 01270 872776

Skin Care Campaign Board Members

Lyn Stone CBE.....	Chairman
Nigel Scott/Marian Nicholson.....	Herpes Viruses Association (Nigel - Vice-Chairman)
Maureen Benbow.....	Tissue Viability Society
Alison Bowser/Keith Dibble.....	Acne Support Group
Gladys Edwards/Ray Jobling.....	Psoriasis Association
Caroline Walker/Kim Fligelstone.....	Scleroderma Society
Jane Watts/Margaret Cox.....	National Eczema Society

The Skin Care Campaign gratefully acknowledges the generous support of the following companies:

- Astellas Pharma Ltd
- Beiersdorf UK Ltd
- Dermal Laboratories Ltd
- Galderma (UK) Ltd
- LEO Pharma
- Reckitt Benckiser (UK) Ltd
- Schering-Plough Ltd
- Serono UK Ltd
- Shire Pharmaceuticals Group plc
- Stiefel Laboratories (UK) Ltd
- TyPharm Ltd
- Wyeth UK
- 3M Health Care Ltd

Copy call

The deadline for submissions to the August issue is **Monday 2 July 2007**.

Please send news stories/articles/details of forthcoming events to Claire Moulds, Editor of Campaign News at claire.moulds@ntlworld.com

If you're unsure if a story's suitable, need help pulling a news item together or have an idea for a larger article, please send the relevant details through to Claire for consideration.