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Another All Party Parliamentary Group on Skin (APPGS) Collaborative Milestone

As Chairman of the Advisory Committee, it gave me great pleasure to welcome publication on 14 March of the ninth APPGS Report – *On the Enquiry into the Adequacy and Equity of Dermatology Services in the United Kingdom*.

The Report examines the state of dermatology services in England and discusses the main areas where services are perceived to fall significantly short of what is acceptable – among those identified are:

- Areas of the country with no consultant dermatologist;
- Lack of psychological support, particularly formal support e.g. clinical psychologists, psychiatrists;
- Difficulty for Healthcare Professionals (HCP) in accessing dermatology training.

It makes a number of recommendations as to how services might further be improved.

All isn't doom and gloom, however. If we look back on the work of the past few years we can see positive changes.

Since the APPGS published its first report, there have been a number of improvements in dermatology services, many of them in response, in part at least, to the deficiencies identified by the APPGS in previous reports. Crucially, the Government has:

- placed growing emphasis on supporting people with long-term conditions;
- acknowledged that skin disease has not been taken seriously enough in the past; and
- said that, henceforth, skin diseases should be included in the policies being developed by the Department of Health (DH) for improving chronic disease management.

The combined efforts of SCC, BAD and APPGS have been central to this and we would also like to thank MPs for their focus and support.

It is worth noting that the Report has been nearly a year in the making. The Advisory Committee members represented Patients, Dermatologists, GPs, Nurses and Pharmacists. It has been a privilege to work with such a committed group of colleagues and I would like to thank my fellow expert advisory committee members for their input.

Our sincere thanks are also extended to Peter Lapsley for his sterling job in preparing the drafts and collating all our comments for this report.

During the preparation of the Report the expert group examined nearly 100 pieces of written evidence and heard oral evidence in two sessions from ten of the most senior and knowledgeable figures in the dermatology world.

In reaching its conclusions and making its recommendations to the APPGS's officers, the Advisory Committee kept in mind the need to make recommendations that were financially realistic. Most of the suggested recommendations therefore emphasize the need for better planning, training and general disease awareness, rather than for extensive extra resources.

The key recommendations addressed issues including training of healthcare professionals, the General Medical Services (GMS) contract, nurse led clinics, nurse and pharmacist prescribing, the Dermatology Workforce Group (DWG) draft service model and patient self-management of their condition. (See also APPGS column on page 4.)

It is now hoped that an active programme can be run by

the APPGS over the next few months to highlight the Report to the APPGS's parliamentary members and to push for its recommendations to be taken forward by the DoH.

It was also felt that the officers might wish to send the report to the Secretary of State for Health and ask her to come to a meeting to discuss the findings once she has had a chance to digest them.

I recommend the report as essential reading to all those who are involved in providing care and services for people with skin disease in the UK.

Copies of the report are available from the APPGS secretariat.

Lynette Stone CBE

Skin Care Campaign Chairman

SKIN CARE CAMPAIGN UP-DATE

Skin Care Campaign Wales

It is good to be able to announce, hopefully not prematurely, that work has begun on the development of a Skin Care Campaign for Wales.

For a long time, there have been serious and difficult problems with dermatology service provision in the Principality – not least a severe shortage of consultant dermatologists and an apparent lack of commitment to dermatology in primary care.

A couple of years ago and partly in response to these issues, the consultant dermatologists in Wales established the Dermatology Council for Wales (the Council) under the very able chairmanship of Dr Barry Statham. Essentially, it is a satellite of the British Association of Dermatologists. Quick to take account of patients' interests, the Council recruited Hilary Davies as its lay representative. When she had to stand down for health reasons, her place was taken by Paul Thomas QC, a barrister from Swansea.

Early this year it became evident that if there was to be a coherent drive to improve Welsh dermatology services it needed to be patient-driven. Accordingly, a meeting was held in Cardiff on 24 February to explore the possibility of establishing a Welsh counterpart to the SCC. Attended by Paul Thomas, Barry Statham, Peter Lapsley for the SCC, Rick Greville representing the ABPI in Wales, Liz Taylor for Leo Pharma and Milon Das Gupta for Serono, the meeting explored the background and activities of the SCC and agreed unanimously that efforts should be made to establish an equivalent in Wales.

The Council has already done excellent work in identifying at least some of the dermatological issues that need to be

addressed, which should give SCC Wales a useful framework for developing the clear objectives and priorities that will be so essential to its success.

Paul Thomas generously undertook to act as 'chair in waiting' for the new organisation, and it was agreed that half a dozen or so patients with a range of skills and experience should be recruited through dermatology departments to join the gestatory organisation's Board.

The Dermatology Council for Wales has offered its wholehearted support to the project and undertaken to draft a leaflet explaining and promoting it.

Recognising that there are lessons to be learnt from the way in which SCC Scotland was established and has become highly effective, we have put Paul Thomas in contact with Helen Irons, their administrator. Naturally, we shall do anything else we can to help get SCC Wales up and running as quickly and effectively as possible.

The ABPI have generously offered SCC Wales access to GJW Cymru/Wales, the leading public affairs consultancy in Wales which, if our experience of working with Portcullis Public Affairs is anything to go by, will prove an invaluable asset.

Those involved will also be contacting the Wales Council for Voluntary Action, to see what help and support they may be able to provide for the new organisation.

A further meeting has been scheduled for 9 June. We hope very much that at least some of the members of the new Board will be able to join us at it and to begin to give SCC Wales some real shape and purpose. We wish them the very best of good fortune.

Our Health, Our Care, Our Say

Following extensive public consultations, the Government White Paper, *Our Health, Our Care, Our Say*, was published on 30 January this year. Where dermatology is concerned, it is quite encouraging.

The White Paper identifies dermatology as one of six specialties in which the Department of Health will be looking at models for providing care closer to home. Throughout this year, the Department will work with these specialties in demonstration sites to define appropriate models of care. The model the Skin Care Campaign is promoting is the one developed by the Dermatology Workforce Group (DWG) which is based heavily on the excellent work done by the Action on Dermatology programme.

A health consultant, Nicola Easy, has already been commissioned by the Royal College of Physicians and the NHS Alliance to develop a project to run dermatology pilot studies of exactly this sort, and has submitted her proposals to the Department. Because of the similarity between Ms Easy's proposed project and the Department's views on dermatology expressed in the White Paper, it seems likely that the necessary funding will be made available. SCC chief executive, Peter Lapsley, has been invited to join the working party that will manage the project if and when funding is approved.

Commenting on dermatology more generally, the White Paper says that, wherever possible, patients with long-term skin conditions such as psoriasis and eczema should be managed by appropriately trained specialists in convenient community settings and should be able to re-access specialist services as and when needed. This, of course, sits very comfortably with the new patient journey developed by the DWG which places particular emphasis on prompt and accurate diagnosis; the self-management of much inflammatory skin disease properly supported by specialist clinics in primary care; and rapid re-referral to appropriate services at whatever level may be necessary.

The White Paper points out that many specialist dermatology units already provide up to thirty percent of their services in community settings, usually in community hospitals, and says that this type of service should be encouraged wherever possible. It also points to the important roles Practitioners with Special Interest in dermatology can play in providing care close to home for patients with skin disease, and encourages healthcare providers to develop such services where they are not already in place.

Such a focus on dermatology is most welcome, especially as the specialty was consistently and completely ignored by the Department until quite recently.

GPwSIs in Dermatology

In the last issue of *Campaign News*, we welcomed the creation of the General Practitioner with Special Interest in Dermatology Working Group (GDWG). Established by the Primary Care Dermatology Society (PCDS), the Group brings together representatives of the British Association of Dermatologists (BAD), the Royal College of General Practitioners (RCGP), the PCDS and the Skin Care Campaign (SCC), and will report to the Department of Health's National GPwSI Group which is examining the issues affecting GPwSIs in all specialties.

High on the GDWG's agenda is revision of the Guidance on the Appointment of GPwSIs in Dermatology, published by the Department of Health in 2003. It has become clear that this was poorly publicised and has been widely ignored by Primary Care Trusts (PCTs). A recent survey showed that only thirty percent of all GPwSIs in Dermatology have been appointed in accordance with the guidance. Rigorously developed and widely promoted guidance is essential if PCTs, concerned chiefly with cost containment and waiting time reduction, are to be discouraged from appointing inadequately trained doctors as GPwSIs and failing to encourage and enable the development of close working relationships between GPwSIs and their colleagues in secondary care.

There is, of course, a slight anomaly in the development of guidance for the appointment of GPwSIs, in that in the wider arena the Department is clearly moving towards the concept of 'Practitioners with Special Interests' (PwSIs) rather than just 'General Practitioners...'. Certainly, within dermatology, there is much to be said for involving Dermatology Nurse Specialists, Staff and Associate Specialist doctors and, perhaps, in due course, the completely new breed of 'Physician's Assistants', in the provision of intermediate care. The Group's view, however, is that it should be perfectly practicable for the revised guidance on GPwSIs to act as a model for the appointing of other practitioners as PwSIs.

As important as its review of the guidance on appointment is the Group's examination of the training needs of GPwSIs in Dermatology and the development of an accreditation process for them. At present, the GPwSI role is probably the only one within the British healthcare system for which there is no formal accreditation process. As a starting point, the Group is comparing the curricula from all the existing British diploma courses in dermatology, and will develop a core curriculum based on the one for Trainees and Specialist Registrars recently developed by Dr Susan Burge.

It may be that a separate accreditation for skin surgery will be added to the core curriculum in dermatology, not least to cater for those practitioners who perhaps only do minor

surgery or have plastic surgery experience but no dermatology experience.

All this is good news for patients who have an absolute right to be seen by properly qualified health professionals who are well supported by their colleagues in secondary care. We hope that the Group will sustain the enthusiasm and energy that has been so encouragingly evident so far.

17 Million Reasons

The Skin Care Campaign (SCC) is a member of the 17 Million Reasons partnership. Founded in the late summer of 2004, the partnership is a diverse group of some 20 organisations including patient organisations and umbrella groups, health service managers and health professionals which campaigns for a better deal for the 17 million people in the UK living with long-term conditions.

The partnership's three objectives are:

- to ensure that people with long-term conditions have rapid access to expert diagnosis and needs assessment;
- to put patients in the driving seat, with proper access to information and advice to help them make the right choices to maximise their quality of life; and
- to personalise services around each individual, with personal Care Plans to ensure people have the care they need, when they need it.

Since publication of its manifesto early the following year, the Partnership has commissioned research to discover examples of good practice in implementing its objectives. The partnership's members and networks, including the SCC, were used to provide evidence for this study. It has also developed a constructive relationship with the Minister for Health, Lord Warner, and with Department of Health (DH) officials – a relationship made easier by the reasonableness and evident attainability of its objectives and by the Government's active interest in improving chronic disease management.

Having to some extent 'made its point', the partnership is now entering a 'quieter' period. Over the next eighteen months, it plans to continue its six-monthly meetings with Lord Warner; monitor progress with the implementation of its three objectives; continue a dialogue and meetings with senior DH civil servants; ask the Department to identify the best channels of communication between itself and the partnership or its members; and discover how the DH intends to involve the voluntary sector in moving the Partnership's objectives forward.

The Partnership will reconvene in the summer of 2007 to assess what work should be done in the run up to the next general election, and to consider the merits of expanding its membership or adopting new objectives.

The All Party Parliamentary Group on Skin (APPGS)

New Report

The APPGS has been busy in the past few months preparing its latest report that was published at a Group meeting in March. It is entitled ***"Report on the Enquiry into the Adequacy and Equity of Dermatology Service Provision in the United Kingdom"***.

This, the Group's ninth Report, examines the state of dermatology services in England. It makes various recommendations designed to be relatively inexpensive to implement and which therefore emphasize the need for good planning, rather than for extensive extra resources.

- Dermatology should be incorporated into the Quality and Outcomes Framework (QOF) of General Medical Services (GMS) contract.

- The Dermatology Workforce Group's revised patient journey model should become the core for dermatology service planning across England.
- Dermatology should be given priority status in post-graduate GP training.
- Training in the diagnosis and treatment of benign skin lesions should be provided for GPs to reduce the number of inappropriate referrals to secondary care.
- Nurse-led clinics should be established in primary care to enable patients to self-manage inflammatory skin diseases effectively.
- Urgent steps should be taken to reverse the downward trend in the number of specialist dermatology nurses.

- Greater emphasis should be placed on the education of patients about their skin diseases and the treatment and management of them.
- The development of specialist expertise by at least one partner in each group general practice should be actively and financially encouraged.
- GPs should be made more aware of the information and support that patient groups can provide, and should be encouraged to make more use of them.
- The DH should ensure that NICE guidance is properly observed by the NHS.

The Group held two oral evidence sessions and received nearly 100 pieces of written evidence to inform its enquiry. We now hope to run an active programme to highlight the Report in Parliament and to push for its recommendations to be taken forward by DoH. We also plan to hold a reception later in the year at which the Report will be show-cased.

Copies of the Report are available from the APG secretariat on 020 7368 3103.

Berkeley Greenwood

2006 Clinical Dermatology Up-Date Meeting Leeds

The second *Clinical Dermatology Update Meeting* for Non-Consultant Career Grade doctors (NCCGs) was held in the Queens Hotel, Leeds on 9th and 10th March 2006. Following the success of last year's meeting, Sue Jackson, Sue Welsh and I knew that we had a hard act to follow but I am delighted to report that this meeting has been evaluated as a resounding success in terms of its clinical and educational content. The meeting achieved CPD approval from the Royal College of Physicians, with full attendance accredited as 11 CPD points.

For the second year running, LEO Pharma supported the event with an educational grant and kindly agreed to expand the numbers of attendees this year in view of the overwhelming response to last year's meeting. Over 170 delegates convened for the meeting, including Associate Specialists, Staff Grades, Clinical Assistants, Hospital Practitioners and GPs.

Leading experts covered a range of disease areas including hair and scalp disease, the diagnosis and therapy of nail disorders, photodermatoses, malignant melanoma, life threatening dermatoses and case scenarios.

Presentations were supported by numerous clinical slides and excellent investigational and practical advice, providing a well-researched overview of current thoughts on ideal management in these difficult cases. In the non-clinical based session, Dr Greg Dillaway of the BMA Negotiating SAS Committee provided an up-to-the-minute report of the ongoing stages of the new NCCG terms and conditions Contract.

The second day started with a most prestigious and presidential theme. We were honoured to have President of the BAD, Dr Robin Graham-Brown speaking about the

challenges facing UK dermatology, some of these coming directly from current NHS reform agendas. His talk also included discussions about erosion of core dermatological services, the need to maintain a strong academic base in dermatology and the requirement to provide the correct training for those responsible for dermatology care in the future.

Sue Jackson was also honoured to introduce Professor Dame Carol Black, President of the RCP, who spoke briefly about the role of the RCP in NCCGs and their future. The work of the RCP NCCG Standing Committee was presented, along with a discussion about the role of the RCP in reviewing collated evidence submitted by NCCGs applying for inclusion on the Specialist Register under Article 14 of the PMETB. This was followed by a wonderful overview by Professor Dame Black on the diagnosis and management of connective tissue diseases.

A number of other clinical presentations followed which focused on mycosis fungoides, the unmet need associated with lymphoedema and mixed lympho-venous disease, acne management, the place of Dovobet® in the longer term treatment of plaque psoriasis and oral suspicious lesions.

All sessions were party to lively debate and audience questioning and it was clear that the delegates had enjoyed the educational programme immensely and was summarised by one delegate as 'Another Triumph'.

The organising committee would like to thank the speakers contributing to the programme and LEO Pharma for their support again this year.

By Dr Glenda Hill, Co-organiser, and Associate Specialist at North East Wales NHS Trust, Wrexham, North Wales.

DERMATOLOGY COURSE UP-DATES

MSc Dermatology Skills and Treatment – University of Hertfordshire

An MSc Dermatology Skills and Treatment has been developed by the Bedfordshire and Hertfordshire Postgraduate Medical School in recognition of the need to expand knowledge and skills in response to national initiatives to shift a substantial proportion of dermatology from secondary to primary care.

This programme has been designed to meet the needs of health care professionals who wish to develop their dermatology knowledge, skills and practice. It will provide inter-professional education for a range of medical and non-medical practitioners from varied settings across primary and secondary care.

Programme Structure

The programme has been designed to provide three components encompassing:

- specialist compulsory modules (60 credits)
- modules of common interest (60 credits)
- compulsory modules (60 credits)
 - Evidence Based Practice (15 credits)
 - Discipline Related Project (45 credits).

All modules can be studied on a stand alone basis. Two specialist modules currently exist: Skin Surgery Skills and Recognition and Diagnosis of Skin Lesions. Others focusing on chronic skin conditions and other aspects of dermatology will follow.

This part time programme is offered over a two to five year period, leading to the award of an MSc in Dermatology Skills and Treatment with exit awards of Postgraduate Certificate and Postgraduate Diploma.

Skin Surgery Skills (30 credits 3/M Level)

This module is a compulsory specialist course for the MSc in Dermatology Skills & Treatment. It enables health professionals to develop and consolidate skills in minor skin surgery and is suitable for medical and non medical practitioners from a range of specialties including dermatology, primary care and accident and emergency. Initial training is performed on simulated tissue models and practical skills workshops are run by experienced tutors to provide learner-centred teaching. Proficiency is

developed during a period of supervised clinical practice and competency assessed using Direct Observational Procedure (DOPS) and 360 degree appraisals as recommended by the British Association of Dermatologists.

Course dates: April 26th, 27th, 28th, July 14th, Nov 8th 2006. Fees £750.

Recognition and Diagnosis of Skin Lesions (30 credits Level M)

This module is a compulsory specialist course for the MSc in Dermatology Skills and Treatment. It enables health professionals to develop and consolidate skills in recognition and management of a variety of skin lesions and associated conditions and is suitable for medical and non-medical practitioners from a range of specialties. Practical skills workshops are run by experienced tutors to provide learner-centred teaching. Proficiency is developed during a period of supervised clinical practice and competency assessed using an observed simulated clinical examination (OSCE).

Course dates to be confirmed – commencing October 2006. Fees £750.

For further details contact:

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Developing Skin Camouflage Practice

A Joint Initiative between the University of Hertfordshire and the Skin Camouflage Network

The Skin Camouflage Network and University of Hertfordshire have recently developed a course designed to provide a recognised national standard for preparation of practitioners working in skin camouflage services. This course, believed to be the first of its kind in the country, provides a unique opportunity for networking between healthcare professionals, skin camouflage practitioners, complementary and beauty therapists.

The Skin Camouflage Network teaches practitioners and those affected by such conditions how to apply skin camouflage so that they feel confident to face the world.

Course Structure

Entitled Development of Skin Camouflage Practice and offered at Levels 1 & 2 with a rating of 30 credits, this course focuses primarily on practical skin camouflage techniques with taught sessions covering relevant issues such as the structure and function of the skin, scar management, common dermatological conditions such as vitiligo and rosacea and associated psychological issues such as altered body image and low self-esteem. These are very important issues that often impact on individuals with disfigurements or imperfections and students learn about the principles of elementary counselling and listening skills. The course is delivered over 8 days in two 3 day blocks and one 2 day block. Students are required to select suitable skin camouflage products from a wide range of manufacturers and demonstrate their technical ability in application and colour matching.

Level 1 students are required to develop a portfolio for a minimum of two clients describing assessment of their clients' needs and how they applied skin camouflage. Level 2 students are required to write a case study about one client, describing the client's particular condition, psychological issues encountered and how skin camouflage was applied. In addition, all students are required to pass a practical assessment demonstrating their technical skill in applying skin camouflage with volunteers recruited from university staff.

Several companies supported the first course by providing books and cosmetic products including Smith and Nephew™, Dermacolour, Veil and Grimace™, Vizage and the Disfigurement Guidance Centre. Students greatly valued the interaction with industry, higher education and

professional bodies, which has allowed them to become familiar with a wide range of skin camouflage cosmetics and associated products.

One student who attended the course this year reflected on the experience: -

"I found the lectures an excellent learning experience as they clearly explored and evaluated client care. This is a subject that you can never learn enough about. Listening skills, skin diseases and disorders and psychological issues were just a few of the areas covered. These sessions offered a platform for sharing professional experiences and assimilating new knowledge in a relaxed but stimulating way. So far, it has been a positive and exhilarating experience".

Madeleine Flanagan, course leader from The University of Hertfordshire says, ***"We feel that this course is not just about teaching people how to apply camouflage make-up. It is also raising important psychological issues within a very delicate subject area and one which is often difficult for those affected to discuss openly. This work is providing insight into the specific needs of this client group and the skin camouflage practitioners who provide such an invaluable service".***

The university was really impressed with the standard of the assignments produced by the first group of candidates. Madeleine Flanagan also stated some were even suitable for publication in nursing magazines. The candidates passed gaining 30 credits.

The next course is over 3 blocks:-

First block: 23 – 25 May

Second block: 10 – 12 July

Final block: 13 & 14 September

For more information and details of the course 2006 please visit our website www.skincamouflagenetwork.org.uk

For further information and application forms or an informal discussion into whether this course is suitable for you, please contact Annemarie Brown, visiting lecturer on 07949 155266, e-mail A.K.1.Brown@herts.ac.uk or Madeleine Flanagan (Course Leader) on 07736 660584, e-mail m.flanagan@herts.ac.uk

Top Tips for Optimising your Organisation's Website

Following on from the successful patient introduction to media relations and working closely with Alison Bowser of the Acne Support Group, Ash Communications has pulled together top tips for optimising your organisation's website. The SCC hopes to run further practical training sessions for patient organisations at meetings in 2006.

New websites appear every day, which can crowd search engines making your organisation's website less noticeable. Keeping your website up to date will help it stand out from the crowd and attract more visitors.

Visitors looking for information on your website will measure the quality of that information by how up-to-date it is, the breadth of information and the links to other useful sources of information and advice.

There are many ways to refresh and enliven the content of your website which will encourage visitors to return regularly, including:

- Incorporating an updated news section on the main home page will help to draw in new visitors to your site.
- Regularly adding accurate and informative news increases the chance that other sites will link to your site.
- Including the date of your last update on the pages so users know how up-to-date the information is.

- Remembering that older information may still be of interest to visitors. Try keeping this stored in the archive section of your website.
- Providing current and past annual reports and summaries can give your members and potential members a better understanding of how your organisation operates.
- Using colour, graphics and pictures will make sure that your website doesn't appear too "text heavy", putting readers off.
- Listing your organisation's associations, accreditations and memberships on the website will increase its credibility.
- Responding to email queries as soon as possible will help present your organisation as a dynamic and active organisation. Make sure that an email contact address is displayed prominently on your site so it is easy for visitors to get in touch.
- Visiting your own website is a good way to check that all links on the site are accessible to visitors.

Following these simple hints and tips should help keep the visitors flowing to your website.

PATIENT GROUP FOCUS

Introducing Alopecia UK

Who are we?

Alopecia UK is a registered charity providing information, advice and support to people with alopecia areata (patchy hair loss), alopecia totalis (complete hair loss on the scalp) and alopecia universalis (complete hair loss on the body and

head). We are currently a volunteer run charity with a management committee of 12, as well as a number of other volunteers. At the moment there are four support groups around the UK (Aberdeen, Birmingham, London and Northumberland) and work is well under way for several more.

Why did we start Alopecia UK?

In 2003, Vicky Spencer developed alopecia universalis whilst studying for her finals at university. When she told her friends and family that she had developed alopecia both she and they turned to the internet for more information and advice. There was very little UK based information about the condition and so we decided to take action and start up our own website

(<http://www alopeciaonline.org.uk>).

The number of visitors to the site steadily grew as the content was developed and improved.

Whilst the information provided on the web site was sufficient to meet the requirements of some people, we started to receive communications from people looking for more support and more detailed information. To expand sufficiently to enable us to best meet these expectations we decided to become a registered charity. Alopecia UK became a charity in April 2005 and since then work has been ongoing to ensure the stability and long-term viability of all the activities the charity undertakes.

What do we do?

As the foundation of the charity, our website provides the focal point of the work we do. It includes general information, frequently asked questions, treatment information, advice on wigs, coping and appearance tips. The site receives over 25,000 visits a month with half a million pages viewed.

One of the most successful sections of the site is the forum. It allows people to share experiences, ask questions and communicate with others who have similar experiences. Perhaps one of the major features of the forum is that it

allows people with alopecia to remain anonymous whilst talking about the condition and its effects on them. Sometimes it is the first time they have felt able to open up.

Another surprise success on the site has been the "Photographs" section. Originally this page was intended to have pictures to show the different forms of alopecia. People then started to send in pictures of themselves for inclusion on this page, and we now have over 120 pictures.

Since becoming a charity we have been working to expand the services we provide beyond the website, for example:

- We are working alongside government bodies to help improve the provision of wigs on the NHS,
- We are working to establish a network of support groups around the country,
- We are working to raise awareness of alopecia amongst the general public, with a very successful media campaign.
- We are supporting research into the psychological aspects of alopecia as well as into treatments.

We have been amazed and gratified by how supportive people are of the work of Alopecia UK, and how keen people have been to get involved in the charity's work.

Although a lot has already been achieved it is just the start. There is still much to do to make Alopecia UK a charity that matches the needs of the alopecia community. To help us achieve this we are currently looking for new Trustees with relevant experience to help meet the challenges and opportunities that lay ahead for us, as well as stepping up our efforts to increase the number of volunteers helping us in the work we do.

NEWS ROUND-UP

Alopecia Awareness Website Launch

Our new website was launched on 1st March 2006. It started really well with over 1000 hits in the first week. The website promotes a positive outlook to alopecia and is designed to provide much needed support, information and guidance to any individual with alopecia, including their

friends and families. It has also been confirmed that Gail Porter will be the Patron of Alopecia Awareness and that she will have a page on the site where she will add her own input as well as respond to our members, e-mails and letters. We have also adopted our constitution and will be applying for charity status in the next few weeks. We will keep you all posted on progress. Our new website address is www alopecia-awareness.org.uk.

Raynaud's & Scleroderma Association

Anne's Olympic Bobsleigh Challenge – February 2006

In deciding what challenge to take on this year, I tried to think what would capture the imagination of the media and the general public in order to create awareness of Raynaud's and raise funds for research. So what better way than to make it a double challenge – firstly to try and keep warm in sub zero temperatures and secondly to go down the Olympic Bob Run in St Moritz during February, when the winter Olympics were taking place in Turin. Having made the decision back in the summer of 2005, I made the necessary bookings and distributed sponsor forms. My son Andrew agreed to join me and look after me.

Having severe Raynaud's meant that this event would need a great deal of preparation, particularly with regard to what I was going to wear. I only have to go outside briefly in the UK for an attack to occur, so what could I do to ensure that I didn't put myself at risk? I contacted several companies for their support and was delighted to receive the necessary warm and heated clothing for my trip.

Andrew and I arrived in St Moritz the night before and went to have a look at the Bob Run which was close to the hotel. It was very quiet and we stood at the top looking down the track on a beautifully clear moonlit night. I hadn't given too much thought as to what the Bob Run involved because I was more intent on raising as much money as I could. From past experience I knew that once I had a few thousand pounds in sponsorship there was no backing out. Standing at the top of the Bob Run I wasn't so sure! Back at the hotel we watched the two man bob and the luge events on television and tried not to think that we were going to be attempting something similar the next day!

After a good breakfast sitting looking out across the lake, we set off the next morning to be at the start for 9 am. It had taken some time to get dressed and I wasn't sure that breakfast was a good idea before going down the Bob Run! I wore two silver vests, a pair of silver long John's, two pairs of long silver socks, two jumpers, a heated gilet and on top of that a ski anorak and trousers. This was completed by a warm scarf, two hats, including one which Andrew produced as a surprise, printed with the words Raynaud's & Scleroderma Association, Bobsleigh Team 2006, St Moritz, Switzerland. He had a matching one. I also had a sheepskin hat with ear flaps which was wonderfully warm. On the back of my vest I had attached a stick-on heat pack and I put disposable hand warmers inside my trio of mittens which consisted of a silver pair, covered by a woollen pair and finally a pair of ski mitts over the top.

It appeared to be fairly quiet as we walked up to the slope with the sun shining and deep blue sky but as we approached I heard a loud speaker announcing the team from Canada and then from Great Britain, followed by several other countries. What were they doing here? We booked in and were told that we would be going down around 10 am. There were loads of people watching the bobsleighs taking off at the start and the atmosphere was quite exciting. I suggested we went and spoke to the British four man bob team to find out what was going on. Their bobsleigh had just come back up from Celerina at the bottom of the track and we went over to talk to them. They explained that this was the last practice before leaving for Turin. They lifted me onto their Bobsleigh together with our mascot Percy Penguin, for some photos and I explained why I was doing the Bob Run for charity. Five minutes later Lee Johnston, the driver of the British Olympic Team, came to find Andrew and I and gave us autographed photos of the team. I was quite touched and appreciated the gesture.

Having watched several teams taking off down the track it was soon our turn. We were fitted with crash helmets and balaclavas and introduced to our pilot and brakeman. When I saw the brakes on the floor I asked if I was able to use them but was told in no uncertain terms that I wasn't to touch them! Foolishly I had expected there may be seats in the bobsleigh but I guess I should have been grateful that there was a piece of foam on the bottom. The pilot took his position at the front and I got in next and sat on the floor with my legs stretched out on either side of the pilot. Andy sat behind me and the brakeman was at the back ready to run and jump in once he had pushed us off at the start. We were shown where to hold on. This consisted of an elasticised rope along each side but there was no way that my hands could grip it. They started to show concern when I said I couldn't hold on, so I asked Andy to hook the tip of my mittens under the rope and hoped I would OK. It was pretty hard sitting on metal in spite of the thin layer of foam and that was before we hit the ice track. Only our heads and shoulders were above the bobsleigh and with the pilot's head in front of me I felt quite trapped.

An announcement was made and we were off. At first I thought "this is good" but it was only a matter of seconds before we gathered speed and the bob raced downhill then up to the top edge of the run then over to the other side, back again, up again while moving very fast downhill. It was very bumpy but I was determined to keep my eyes open, however, when we reached the hairpin bend we were travelling so fast that even with my eyes open and seeing trees and sky flashing past sideways on, all sense of feeling, time and place disappeared into a blur as we sped at 90 mph towards the finish. And then it was over!

Andrew managed to lift me out of the bobsleigh as I

seemed to be rooted to the floor and hadn't the strength in my arms to push myself up. Our time of 1 min 19.26 seconds was announced and we were given a glass of champagne to celebrate! I then headed for the hot soup which was in a large urn and we sat in the hot sunshine and telephoned the staff at the office to let them know that we had completed the course. I then thought another glass of champagne mixed with a glass of orange would make a nice Bucks Fizz but having poured the glass into the tumbler of orange, I realised that in fact the orange had frozen. I looked up at the illuminated board to see that the temperature was flashing minus 5 degrees. We enjoyed some nibbles and pastries and took some more photos.

All my preparation had worked and I didn't have a Raynaud's attack. In fact I was quite toasty and warm in spite of the nervous energy expended as well as the cold. The snow was crisp and the reflection of the sun on the snow gave a lovely warm glow. I had done what I set out to achieve and I felt good, if a little shaky in the legs, after the exhilaration of the ride. Another challenge completed – so what next?!

Anne Mawdsley MBE, Chief Executive

Congratulations go to Anne who, to date, has raised over £14,000 for the Raynaud's & Scleroderma Association from taking part in the challenge.

XP Support Group

Owl Patrol Celebrates it's 5th Birthday

Xeroderma Pigmentosum (XP) is a rare genetic disorder that causes extreme sensitivity to the sun's ultraviolet rays.

Unless patients with XP are protected from sunlight, their skin and eyes may be severely damaged. This damage may lead to cancers of the skin and eye. XP has been identified in people of every genetic group all over the world. There are about 100 cases in the UK, many of which have still not been diagnosed.

Owl Patrol is an annual night time camp held every February for patients with Xeroderma Pigmentosum (XP) and other light sensitivities. It gives families the opportunity to meet in a safe and protected environment allowing them to socialise, play and learn with others who have the same life experiences. The event takes place at St Katherine's, Parmoor. Parmoor had once been the home of Sir Stafford Cripps who gave the house to St Katherine's Convent of Fulham who had been evacuated there during the war. It has also been the home of King Zog of Albania during his exile. St Katherine's has been adapted to meet the needs of the XP patients. It has a UV protective film or blinds on all the windows of the house. Before families arrive, all light bulbs are replaced with low wattage bulbs, maximum 40W,

and the light switches for fluorescent lights have been taped over so that they cannot be switched on by mistake. Any areas where it has not been possible to adapt have been clearly marked with signs saying 'face masks and gloves beyond this point'.

It all begins on Friday morning where the volunteers arrive to set up camp. This year's theme was world cultures, which involved preparing one of the rooms with huge murals representing USA, Australia, India and China to be painted later by the children. An arts and craft area was created, along with garment making, Scalextric, music area, dance studio and soft play room. Outside basketball, trampoline, football, Connect 4 and the bouncy castle were set up for the activities that would take place after dark. During the afternoon campers arrive, this year saw families not just from the UK, but the United States and Germany as well. In the evening the camp started proper with a welcome party with campers and guests dressed in costumes representing many countries from all over the world.

Over the weekend the children enjoyed the many activities organised for them which included a trip to the Roald Dahl Museum and swimming at a local pool. However camp is not just for the children, it is for their parents and in some cases their grandparents as well. Adults are encouraged to take part in the activities that are organised for the children but there is also a programme of lectures and workshops for them. This year Professor Alan Lehman of the Genome Damage and Stability Centre, University of Sussex and his staff joined us to give a presentation on XP Research and Diagnostics. Alan takes time to explain the genetics of XP in a way that the layman can understand showing strands of DNA as a railway track and the enzymes and proteins as workers. Specialists from the new XP multi-disciplinary clinic that has been set up at Southlands Hospital in Shoreham, were on hand to discuss how the clinic will help in the research and understanding of XP, Cockayne's Syndrome (CS) and Trichothiodystrophy (TTD). These three conditions are all linked to damage on one particular gene; damage on different parts of the gene result in the three different conditions all of which have UV sensitivity. Parents were given the opportunity to talk with a dermatologist, to ask questions they would not normally ask with their children present, a service which the parents valued very highly.

The weekend proved to be in the words of one parent who had attended every camp: "The best ever." There was a sense of joy and friendship throughout the weekend which culminated in a show put on by the children presenting all the new skills they had picked up over the weekend. Even the parents were asked to do their bit and they chose to sing 'Lean on me' because it summed up all that camp was about.

Sandra Webb

Forthcoming Events and Meetings – 2006

Cancer Research UK	National SunSmart Launch ⁽¹⁾	25 April
Cancer Research UK	Sun Awareness Week ⁽¹⁾	15 May
BAD/SCC	Patient Organisation Meeting, London	18 May
BASC	Training Initiative, Chester ⁽²⁾	19-22 May
PCDS	Basic Dermatology, Manchester ⁽³⁾	9 June
PCDS	Half-day Dermoscopy Meeting, Manchester ⁽³⁾	10 June
PCDS	North & Midlands/AGM, Manchester ⁽³⁾	10-11 June
HITS (UK)	Annual Family Event, London ⁽⁴⁾	8 July
XP Support Group	Owl Patrol for teenagers, St Katharine's, Parmoor ⁽⁵⁾	18-20 August
BASC	Training Initiative, Chester ⁽²⁾	1-4 September
NES	Eczema and Me, National Eczema Week ⁽⁶⁾	16-23 September
SCC	Forum, AGM and Board Meetings, London	21 September
PCDS	South & West Meeting, Cardiff ⁽³⁾	6 October
PCDS	Scottish Meeting, Loch Lomond ⁽³⁾	4-5 November

(1) For further details please contact: Genevieve Frisby, SunSmart Campaign Manager, Cancer Research UK, 61 Lincoln's Inn Fields, London WC2A 3PX. Telephone: 020 7061 8396, Email: genevieve.frisby@cancer.org.uk

(2) Further details, including booking forms can be obtained from Mary Thorp, British Association of Skin Camouflage (BASC) Secretariat, on 01625 871 129, or by writing to BASC, PO Box 202, Macclesfield, Cheshire SK11 6FP, or by emailing: basc9@hotmail.com

(3) For further details please contact: Carol Singleton, Primary Care Dermatology Society (PCDS), tel: 01923 711678, fax: 01923 778131, email: carol@pcds.org.uk

(4) For further details please contact: Terri Grant at tgrant@uk.ey.com or tel: 07940 114943.

(5) For further details please contact Sandra Webb, XP Support Group, tel: 01494 890981, fax: 01494 864439, email: info@xpsupportgroup.org.uk

(6) For further information, contact the NES on 0207 281 3553 or helpline@eczema.org, or visit www.eczema.org

Skin Care Campaign Board Members

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Nigel Scott/Marian Nicholson	Herpes Viruses Association (Nigel – Vice-Chairman)
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Gladys Edwards/Ray Jobling	Psoriasis Association
Caroline Walker/Kim Fligelstone	Scleroderma Society
Jane Watts/Margaret Cox	National Eczema Society

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Please send news/articles/details of forthcoming events to

Editor Campaign News: e-mail: infoscc@eczema.org; tel: 020 7561 8249; fax: 020 7281 6395

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