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**The All Party Parliamentary Group on Skin Call for Evidence: Inquiry into the adequacy and equity of dermatology service provision**

## Home and Away

The Skin Care Campaign (SCC) Experience is now being shared at home and away.

At the time of writing this column Peter Lapsley and I are preparing to attend the BDNG annual conference in Glasgow to talk about the impact of skin disease on people's lives.



Recently, it was also a great pleasure for me to be invited to the Australian Dermatology Nurses Association (ADNA) 4th National Conference in Perth, Western Australia. The programme covered current issues in dermatology with particular reference to the topics of – not surprisingly – skin cancer, psoriasis, social and clinical challenges in providing dermatology services for the indigenous population and for isolated outback communities. I was delighted to join International Skincare Nursing Group (ISNG) colleagues, Dr Steven Ersser (UK) and Noreen Heer Nicol (USA), who spoke about advancing dermatology nursing and advances in atopic dermatitis therapy respectively. My brief was to address the issue of patient-centred care and working together.

Obviously, meeting up regularly is difficult for both patient groups and health care professionals in a country where the journey from one side of the country takes 3 days by train or 4-5 hours by air!

The development of patient support groups and their collaboration with health care professionals is not as well established as in the UK, so I hoped to provide encouragement for our colleagues in the southern hemisphere by sharing the experiences of SCC and demonstrating that there is much to do to improve the quality of life for those people who suffer with a skin disorder and that both patients and nurses can be influential in encouraging change. By describing our background and development, our challenges and our collaborative initiatives with all the individual patient support groups, healthcare professionals, APPGS, government, NHS and pharmaceutical companies it was possible to highlight the importance of grasping any opportunity to lobby for advances in services and health care developments. These opportunities may arise locally, nationally and internationally and in political and professional arenas.

It is hoped that the experiences of SCC will help our Australian colleagues in developing their own strategies – relevant for their country – to raise awareness of the needs of people with skin disease. So it was rewarding to hear from Jan Riley, ADNA President, that:

*"The information that you delivered was very well received and I am pleased to report that you have generated considerable discussion within our group. You have provided well timed patient and political focus for some of our members."*

SCC looks forward to continuing the dialogue with our friends in Australia who live with skin disease.

**Lynette Stone CBE**  
Chairman, Skin Care Campaign

## Looking Ahead

*Peter Lapsley, Chief Executive, Skin Care Campaign*



### QOF for GMS2

'QOF for GMS2' is the typically cryptic abbreviation of Quality and Outcomes Frameworks for the revised General Medical Services (GP) contract. Cryptic it may be, but it is hugely important to people with skin diseases.

When the GMS contract was first published, it made no reference to skin diseases or dermatology, either explicit or implicit. Given the proportion of a GP's time that is spent dealing with skin diseases and the appalling paucity of dermatology training done by GPs, the inclusion of quality and outcome measures for dermatology is essential to improvement of the currently very patchy services they provide for their patients. If such measures were to be included in the contract, the amount and quality of dermatology training received by primary care health professionals would increase dramatically – because, without it, they would be unable to achieve the objectives set by the contract.

The GMS contract was reviewed during the spring of this year, providing an opportunity to rectify the omission of dermatology from it. Working closely together, the British Association of Dermatologists (BAD), the Primary Care Dermatology Society (PCDS) and the Dermatology Workforce Group (DWG) prepared what seems to us to be a very robust case, based on excellent work done by Professor David Gawkrödger, chairman of the BAD/RCP Joint Specialty Committee for Dermatology, and Dr Mark Goodfield, chairman of the DWG. The DWG submitted the proposal on its own behalf and on behalf of the PCDS and the Skin Care Campaign, and the BAD submitted an essentially identical version itself.

The indicators submitted were:

1. Practices will have a register of patients with atopic eczema and a register of patients with psoriasis. (Suggested threshold: 90% for Records.)
2. The percentage of patients with atopic eczema offered a consultation with a trained professional to receive advice, educational material and a review of treatment. (Suggested threshold: 70% for on-going management.)
3. The percentage of patients with psoriasis offered a consultation with a trained professional to receive advice, educational material and a review of treatment. (Suggested threshold: 70% for on-going management.)
4. Practices will have in use a protocol, agreed with the local secondary care provider or appropriate national body, for treatment of patients with acne. (Suggested threshold: 70% for on-going management.)

Recommendation of the indicators was based on the fact that skin disease forms part of 15% of all consultations in general practice; that there are more referrals to secondary care dermatology than to the whole of the rest of general medicine, that 20% of referrals to dermatology are due to the three major inflammatory skin diseases: eczema, psoriasis and acne; that eczema alone accounts for 70,000 referrals a year to dermatology units in the UK; and that the

majority of prescriptions by nurse prescribers are for skin diseases.

The proposal explained that, in spite of the high impact of skin disease on the health system, education for GPs is sub-optimal and patient management can be poor. It said, also, that education for patients with chronic skin disease and easier access to skin care treatment when necessary could significantly reduce the social and psychological burden of skin disease.

The proposal pointed out that atopic eczema affects over 15% of infants in the UK; that, as is the case with other atopic diseases, the incidence of atopic eczema has risen over the past few decades; and that 10% of referrals to secondary care are for eczema.

It noted that psoriasis affects 2% of the population and that 5% of referrals to secondary care are for psoriasis.

It noted, also, that acne affects 80% of teenagers; that, in people in their mid-twenties or older, it affects 1% of men and 30% of women; and that 5% of referral to secondary care dermatology are for acne.

In economic and social terms, the proposal pointed to adult eczema as the second commonest cause of absence from work after musculoskeletal disease, and to the four million working days lost each year as a result of skin disease with a resultant loss to industry of hundreds of millions of pounds. It said that the rising incidence of atopic skin disease with associated sleep disturbance has a negative effect on children's ability to learn and a profound effect on family life. And it pointed to recent evidence which suggests that early intervention in the treatment of atopic eczema can reduce the risk or severity of other atopic diseases.

The proposals for amendments to the GP contract are being collated by a team at Birmingham University who will then pass them to the main negotiating plenary which consists of NHS Employers, General Practitioners Committee, Department of Health (England) and the devolved administrations.

We shall be discussing our proposals with appropriate people during the course of the review process. The revised Quality and Outcomes Frameworks will come into effect in April 2006 and we hope very much that our proposed dermatology indicators will be included in them. If they are, that will be a giant leap for people with skin diseases. If they are not, the two-year review process begins again, also in April 2006, and we shall continue to hammer on the doors of those who matter until they let us in!

### Primary Care Dermatology Course Up-date

Readers will recall that, strongly supported by the British Dermatological Nursing Group, the SCC acted as the catalyst for the development by the School of Nursing and Midwifery at the University of Southampton of what was then seen as a dermatology course for nurses in primary care. I say 'what was then seen as' because there has been a growing belief that the course could well provide the basis for training GPs in dermatology, too.

The SCC having arranged funding for development of the curriculum, the Department of Health found a similar sum to

develop the course materials and for a pilot programme.

The initial advertisement for the pilot study, published in *Nursing in Practice*, attracted 120 enquiries.

The pilot programme ran from September 2004 to February 2005.

Thirteen students embarked on the course, most of them working within the area covered by the Hampshire and Isle of Wight Workforce Development Confederation. Two, both health visitors, were subsequently withdrawn by their employers when their roles were changed.

The pilot programme consisted of four half-day study sessions, associated workbook and CD-Rom activities and supervised practice time.

Overall, feed-back from the pilot programme was very positive, 87% of the respondents saying they would recommend the course to a friend.

Students were asked to identify the factors that motivated them to undertake the course. 'Improved patient outcomes' was the leading motivator by quite a long way, followed by career objectives and self-motivation.

With the exception of the CD-Rom, which had sound and editing problems and which is being re-filmed, the course materials and lectures were well received.

Skills for Health, who have taken over responsibility for the Dermatology Workforce Group from the Department of Health, are providing the necessary funding for the re-filming of the CD-Rom.

We expect that the final 'tidying up' work will have been completed by the time this issue of Campaign News is published. The University of Southampton has begun marketing licensing of the course to other universities throughout the UK but will retain the copyright on it with which goes responsibility for regular review and up-dating. The course, which should be available from a growing number of universities from the late summer of this year, is expected to cost just under £800 per student. That is a very modest sum for PCTs to find given that it can provide primary care health professionals with the background they need successfully to manage far more skin disease themselves, rather than referring it into secondary care. At least as important as this, though, is that it should go a long way towards the provision of proper support for the self-management of inflammatory skin diseases, which is what patients want and which offers huge potential benefits to the NHS.

Great credit is due to Rebecca Penzer, who developed the course curriculum in collaboration with Dr Steve Ersser, to Annabel Smoker who managed the pilot programme and has responsibility for the course, and to Steve for his overall supervision of a most successful project.

## **UK Primary Care Working Group on Skin**

The Skin Care Campaign welcomes the development of the UK Primary Care Working Group on Skin, a joint initiative by the Primary Care Dermatology Society (PCDS) and the Royal College of General Practitioners (RCGP).

The Group is intended to be balanced. Although it will include four committee members of the PCDS and will work closely with the RCGP, the British Association of Dermatologists, the British Dermatological Nursing Group's (BDNG) Primary Care Sub-Group

and the Skin Care Campaign (SCC) have all been invited to nominate representatives. We have suggested that the Group might also consider inviting the Dermatology Workforce Group to do the same.

The Group's remit includes:

- Furthering the appropriate development of General Practitioners with a Special Interest in Dermatology (GPwSIs) by taking forward the best models of care while, at the same time, learning lessons from the past;
- The production of a more structured training and accreditation programme for GPwSIs;
- Improving the education of all groups of primary care health professionals in the management of skin disease, both locally and nationally;
- Ensuring that the more serious skin disorders are seen in secondary care and that the funding is available for secondary care to manage such disorders. Included within this remit is consultation with Primary Care Trusts to encourage them to support the funding, where appropriate, for new drugs such as the 'biologics' for psoriasis.

All of these aspects of the Group's work are important.

Given the clear need to remove much dermatology into primary care, the SCC is strongly supportive of the concept of GPwSIs in dermatology within the overall context of integrated primary and secondary care dermatology services. At present, there appears to be great variation in the competencies of GPwSIs, ranging from those who have gained diplomas but have relatively little clinical experience, through those who are well qualified and have spent many years as clinical assistants, to a very small number who have effectively given up – or would wish to give up – general practice to become what could be termed 'community dermatologists'.

As yet, training is variable and there is no requirement for a GPwSI to be formally accredited. We would see as logical that there should be, and believe that it would make good sense for the PCDS to become the accrediting body in close collaboration with the BAD and the RCGP.

At least as important as the demarcation line between primary and secondary care dermatology, is the need for Primary Care Trusts to understand the respective roles of GPwSIs and consultant dermatologists and to recognise that both are needed.

At present, there is evidence to suggest that some PCTs believe that consultant dermatologists can be replaced with GPwSIs, which is wrong. Some of them seem also to be oblivious to the Department of Health's guidelines for the appointment and employment of GPwSIs.

No matter how well trained or experienced GPwSIs may be, there will always be complex and difficult cases the diagnosis and management of which should properly be done by consultant dermatologists. Much essential clinical research can only be done in secondary care. And GPwSIs themselves need to be trained, mentored, supervised and appraised – all clear roles for consultant dermatologists.

In short, there seems to us to be more than enough work for everyone, and we look forward to the development of an integrated system of dermatology service delivery in which consultants, specialist dermatology nurses, GPwSIs, GPs and pharmacists all work together in partnership for the benefit of patients. We shall work with the UK Primary Care Working Group on Skin, and with other relevant bodies, to achieve that objective.

## Patient Groups Get Together



Following a suggestion from Gladys Edwards of the Psoriasis Association, the Skin Care Campaign organised a day long session where we could all meet to discuss common problems and learn from each other. Several of the Action on Dermatology (AOD) pilot studies involved nurse-led clinics in primary care, and the generic patient pathway that has been developed by the Dermatology Group draws heavily on that work.

It was held on the 28th April at the St Albans Centre, off Grays Inn Road, near Holborn. This was a new venue for many of us and is smart, compact and central.

Gwen Banford put the day together in her usual friendly and efficient way and the event was well attended and lively. Peter Lapsley kicked off the proceedings by telling us the history of the Skin Care Campaign and what it has achieved so far.

Then we split into three groups for a brainstorming workshop session. For many this was probably the most useful aspect of the day. There are so many issues of common concern that it was not possible to cover everything but the different groups covered largely different ground and some key subjects were:

- recruitment of trustees and volunteers
- websites – how they help us to get our message out but also cost us members
- web based forums – advantages and disadvantages
- helplines
- funding
- relationships with the pharmaceutical industry
- membership services, prices and retention

- PR, media coverage and campaigning

The last session before lunch was an introduction to different types of communications from Carys Thomas of Ash Communications Healthcare, who has worked closely with the SCC for several years now and plays a key role in getting our messages out to the professional and consumer media. She told us that part of Ash's remit is to help and advise all patient group members of the SCC when they have a message to put out, or a news story to rebut.

Lunch provided a further opportunity to network and confirmed Gwen's skill in choosing a good venue, as the food was excellent. We were given the useful exercise of finding out something different or positive that another patient group was doing that we weren't.

The afternoon was divided into three sessions, one from Karen Whiteford of Dermal Laboratories who provided a useful insight into the pharmaceutical industry and the help some charities may be able to call on. Peter Lapsley then brought us up to date on health policy and the current thinking of the Department of Health. The day was concluded with a talk from Jessica David of Portcullis Public Affairs who gave us a practical guide to public affairs and how groups can benefit from the work of the All Party Parliamentary Group on Skin.

Everyone agreed that it had been a very productive event and we decided to hold another one later in the year, before Christmas: not too close to the festive season to make attending difficult, but close enough to allow a few mince pies to be on offer, and maybe paper hats for Gwen, Peter and Carys!

All members are welcome. There will be no charge and travelling expenses can be reimbursed. Beat that for value!

**Nigel Scott**  
Vice Chairman, Skin Care Campaign

## The Management and Treatment of Skin Conditions: An Open Learning Course for Pharmacists

An open-learning course dealing with the management of common skin conditions has recently been published by the Centre for Pharmacy Postgraduate Education (CPPE). The package, devised in response to the APPGS call for improved training in dermatology for healthcare professionals, is a 180-page manual with self-assessment exercises and multiple choice questions. Originally conceived as the first of two parts, this course covers the common conditions that are likely to be encountered in the community pharmacy. These include eczema, acne, psoriasis and common infections.

This course is just one of a wide range of courses designed for

pharmacists and available at no cost through the CPPE ([www.cppe.man.ac.uk](http://www.cppe.man.ac.uk)).

It is widely-recognised that pharmacists can play a significant role in the management of skin disease - particularly in helping the large numbers of people with skin complaints who never visit general medical practitioners. Two other factors are also important here. First, over the past few years a number of useful medicines have been reclassified from Prescription Only Medicines (POMs) to Pharmacy (P) medicines, and there are more in the pipeline. Pharmacy medicines must be sold under the supervision of a pharmacist and so these "POM to P" moves make a wider range

of medicines available in community pharmacies. Second, pharmacists with appropriate training are likely to be given the authority to write repeat prescriptions, to vary prescriptions within certain categories of treatment and to prescribe certain treatments. All of this means that community pharmacists will be better positioned to help people with skin complaints and the need for the underpinning training will be all the greater.

This course has been designed in such a way that it can be used as a complete course or can be used section by section to tackle specific learning needs. It also includes background information and references that can be the starting point for more detailed studies. Like most health care professionals, pharmacists are expected to undertake (and record) their continuing professional development activities and this course can be used as part of these. This course requires a total of 10 hours of study.

The chapters are generously illustrated with high-quality, clear photographs of skin lesions. They also contain numerous practice points and tips to equip pharmacists to help patients to get the best out of their treatments. Many of the embedded exercises are case studies designed to introduce common practical problems.

“Signposting” – that is, the capacity to guide patients to appropriate services and specialists is an important element of the current community pharmacy contract. Once again, this course provides useful background information and contact details for patient support groups that will help pharmacists to do this effectively.

For the future, a web-based e-learning package is envisaged. This will allow material to be updated regularly and may be an easier way for many professionals to manage their continuing education.

The course will not make pharmacists into dermatologists and it

has not been designed with this in mind. It will, however, help pharmacists to understand some of the problems faced by patients with skin diseases and show how pharmacists can make their contribution to multidisciplinary patient care. It should also help them to differentiate more clearly between the problems that can appropriately be managed with OTC treatment and those where referral is indicated.

This course has been written by Christine Clark and Diane Langleben with additional input from Allan Melzack and Rod Tucker. All the authors are pharmacists with a particular interest in skin diseases. Many of the photographs were provided by Dr Derek Barker from his personal collection. The final draft was reviewed by Dr Alex Anstey and Dr Tim Mitchell, both of whom provided many helpful comments and suggestions. Finally, it was piloted amongst a group of nine practising community pharmacists who provided additional feedback. Several of the pilot pharmacists commented that they intended to keep the draft document for reference in their day-to-day work.

Community pharmacists can play an important part in supporting and reinforcing the work of the dermatology team and in helping patients to undertake self-management more effectively. This open-learning package provides not only the underpinning knowledge but also a framework for further development. We hope that there will be a wide uptake of this package so that the addition of pharmaceutical expertise to the dermatology team can further improve services for people with skin diseases.

**Christine Clark**

*Research Fellow in Clinical Therapeutics, School of Pharmacy, Bradford University*

## Dermatology Nurses / Nurse Specialist Questionnaire

**A national survey looking at psychosocial assessment and support for individuals with skin disorders**

People with skin disorders may experience a range of emotional and social problems resulting from the illness. Home life, work, relationships, leisure; indeed all aspects of living can be adversely affected. Evidence has emerged that psychosocial distress may not only decrease the individual's quality of life but may also affect disease severity and its response to treatment. Conversely dealing with the psychosocial stressors may improve treatment outcomes and improve life quality. In recent years there has been an increasing interest amongst dermatology nurses and other professionals in providing psychosocial assessment and intervention.

The survey seeks to:

- Examine the frequency and forms of psychosocial assessment
- Clarify the range of psychosocial interventions / support in use, including complementary therapies

- Identify the range of professionals providing this support and referral resources
- Look for evidence of benefits of such interventions.

Nurses working in the field of dermatology are invited to complete the on-line questionnaire (a paper version can be down loaded) by visiting [www.beyondtheskin.org](http://www.beyondtheskin.org).

The ultimate aim is to improve the psychosocial care of patients with dermatological conditions.

**Mr Terry Adams**

Senior Lecturer  
School of Nursing and Primary Care Practice  
Liverpool John Moores University  
79 Tithebarn Street  
Liverpool L2 2ER  
Email: [t.a.adams@livjm.ac.uk](mailto:t.a.adams@livjm.ac.uk)  
Tel: 0151 231 4096

## The Nottingham District-wide Emollient Formulary

We read with interest Lynette Stone's article in the Skin Care Campaign News (February 2005 Issue 29) with regard to "An end to sampling". The article states that some pharmacists are crossing out prescribed treatments and are substituting an alternative to save costs. This takes away patient choice and also the original prescriber's understanding of the required treatment. This practice is often the case with regard to emollients.

At the dermatology department at the Queen's Medical Centre (QMC) in Nottingham, we were determined to ensure that patients were given choices in managing a skin condition. Patients have been major players in being part of the team in developing a formulary with regard to emollients therapy. It was essential that emollients were not only beneficial but also cosmetically acceptable.

Whilst in the department patients can try a wide range of emollients from a display as suggested in the article. Once the patient has received an educational session on emollients and their application the patient tries the emollients for personal preference. The nurse then arranges for the most appropriate access to the treatment via the following routes: NHS prescription, Patient Group Direction or a request letter to their GP. Patients are also given the opportunity to purchase emollients over the counter if they prefer.

However, once the patient has moved from the hospital to the community, the continuity of care may become disrupted as the chosen emollient may not be prescribed due to formulary differences and often purchasing restrictions. To avoid this an approach to a district-wide emollient formulary was discussed.

The emollient formulary was reviewed by the dermatology department at the QMC to include patients. A working party was then set up with the community to include the tissue viability team, community nurses and community pharmacists. After several meetings and changes the formulary was established, giving wide choices and directions for use. The formulary was presented to the Drugs and Therapeutics Department at the QMC.



*Dermatology team, tissue viability lead, continence advisor, community pharmacist and pharmaceutical representatives*

When the formulary had passed that process it was sent to the Drugs and Therapeutics in the Community. We now have a district-wide formulary for emollients that includes the two main hospitals and the four PCTs.

A well-publicised launch took place to introduce the formulary and laminated copies, with the guidelines for use on the back, were given to all district nurses, health visitors, GPs, hospital wards, pharmacists and nursing homes. Pharmacists were asked to ensure that full stocks were available. It is hoped this joint commitment to a formulary will ensure the patient can receive the emollient they have chosen.

300 Questionnaires will go to patients within the next six months to ask their opinion of this joint formulary.

**Coleen Gradwell**, *Clinical Nurse Specialist, Queen's Medical Centre University Hospital, Nottingham* and **Suzanne McGarvey**, *Tissue Viability Lead, Nottingham Secondary and Primary Care*

## Non-Consultant Career Grade Doctors: A Hidden Resource?

Non-Consultant Career Grade Doctors (NCCGs) working in dermatology form an important part of the workforce providing care for a large number of patients with skin disease. Some are employed in secondary care and work predominantly in dermatology (associate specialists, staff grades, trust grades, non-GP clinical assistants and hospital practitioners). Others work mostly in primary care (GP clinical assistants and hospital practitioners) doing one or two dermatology sessions weekly.

Over recent years it has become clear that there is very little information about this huge hidden workforce. A database has been compiled and so far over 800 NCCGs have been found. 180 of the doctors are not GPs. NCCGs are doing well over 1500 sessions weekly and see over one million patients annually.

Since the publication of the NHS Plan in 2000 there has been much emphasis on the development of General Practitioners with a Special Interest (GPwSI) in dermatology. The NHS Modernisation

Agency Action on Dermatology (AoD) programme funded pilot site studies of dermatology GPwSI services. Many NCCGs expressed frustration that they had not been included in considerations of new ways of working to improve dermatology services. By 2004 the AoD programme was keen to explore other models of service delivery involving NCCG doctors working in dermatology and to get their views. They decided to fund a new study. A suitably designed questionnaire was circulated to these doctors.

The purpose of the first section of this survey was to collect contact details so NCCGs could be included in appropriate educational and social events. By compiling a group Email it also meant they could be informed of changes that are going to take place in their new contract and pay and conditions.

The next section was to find out NCCGs willingness to do more sessions (general clinics / minor operation sessions / waiting list initiatives) in hospital and / or the community. It was hoped that this information would be useful to dermatology units looking for staff. It is planned that the information obtained is circulated to British Association of Dermatologists (BAD) regional representatives and also that it is put on the BAD website so that consultants and managers looking for staff can find doctors interested in increasing their sessions. In this way it is hoped that this group might be able to make an even bigger contribution to the dermatology workload than they are already doing.

The third section was about new models of care. Data from 202 dermatology NCCG doctors was analysed: 120 respondents were non-GPs and 82 were GPs; 28% were associate specialists, 19% staff or trust grade doctors and 53% clinical assistants or hospital practitioners; 84% were part time with 93% undertaking all their dermatology sessions in secondary care.

Over half of the respondents said they would be willing to increase their sessions. 44% would prefer to work mainly in secondary care but with some sessions in primary care as against 33% who would prefer to work in secondary care only. 78% of the 202 respondents (GP and non-GP) said that they would be interested in the development of a new role working across primary and secondary care.

The survey showed that over three-quarters of this group of doctors were involved in teaching health professionals including GPs, GPwSIs and nurses. The rest said that they would like to become involved in teaching. 82% were prepared to improve their teaching skills. 19% were involved in research and a further 26% would like to be. Nearly one in four dermatology NCCGs were considering leaving their post. Reasons given were poor pay, to become a GPwSI, retirement, career progression, lack of recognition and post under threat due to PCTs withdrawing money from secondary care.

Dermatology NCCG doctors are an important, experienced resource that should be actively involved in stakeholder groups when designing and commissioning dermatology services across a health community. Dermatologists and commissioners should consider developing the new role of an 'intermediate dermatologist' based in secondary care but providing services in primary care. There are a group of experienced NCCG dermatologists who are ready and waiting to do this work. GP and non-GP dermatologists have worked together successfully in secondary care for many years. There is no reason to think that they couldn't do this in primary care as well.

**Sue Jackson**  
Associate Specialist in Dermatology

## British Journal of Nursing Clinical Practice Awards – Dermatology

The above awards were recently announced for the dermatology category. The three papers short listed were:

1. Gillian Godsell, Skin Cancer Nurse Specialist at the Queen's Medical Centre, University Hospital, Nottingham, for her paper on **"The development of the nurse biopsy role"** which highlighted how expanded nursing roles can greatly enhance the care received by patients with skin problems.

2. Diane Joseph and Jane Day, Dermatology Specialist Nurses from Addenbrooke's Hospital in Cambridge for their paper **"Evaluation of a telephone line for patients with chronic dermatological conditions"** which demonstrated the usefulness of a telephone line for patients with dermatological conditions.

3. Sandra Lawton, Nurse Consultant Dermatology, also from Queen's Medical Centre, and Amanda Roberts and Colin Gibb, both parents of children who have atopic eczema, in affiliation with the Nottingham Support Group for Carers of Children with Eczema for their paper **"Supporting the parents of children with atopic eczema"** which illustrated how this could be achieved through the setting up of a support group in Nottingham.

**Winners:** Sandra Lawton, Amanda Roberts and Colin Gibb.

**Highly Commended:** Gillian Godsell, Diane Joseph and Jane Day.

The papers will be published in the British Journal of Nursing.

## The All Party Parliamentary Group On Skin (APPGS)

The All Party Parliamentary Group on Skin (APPGS) has been re-formed following the General Election, with the appointment of parliamentary officers at the Group's inaugural meeting in June. Whilst activities to recruit new MPs to the Group are ongoing, work has also begun on the APPGS's next report, which will look at the adequacy and equity of dermatology service provision.

A Specialist Advisory Group, made up of representatives of patient groups and health professional bodies, has been appointed to lead the report, chaired by Lynette Stone. The Advisory Group met for the first time in May and discussed the sorts of issues that the inquiry should address. This discussion formed the basis of a call for evidence, which began on 1st June and will run until 1st October 2005 (see insert).

Based on the evidence received, the report will consider dermatology services from the patient's point of view and will follow the journey through primary and secondary care. In doing so it will look at changes and developments since the APPGS's first report in 1997 – including service models developed under the Action on Dermatology Programme and more recent work on the patient journey, being undertaken by the Dermatology Workforce Group.

The inquiry will also seek to gain evidence on how wider changes in the NHS such as the development of National Service Frameworks, new working contracts for health professionals, and policy initiatives such as Patient Choice have affected dermatology services. Furthermore, it will look at new and

emerging issues impacting on dermatology including the cost of new treatments and the need to expand academic research.

It is intended that the report should not focus heavily on health professional training – this area having been discussed more fully in a review by the APPGS in 2004. Instead it will address the roles of the various groups of health professionals involved in providing dermatology services and seek to gain evidence on best practice and new ways of working.

As well as looking at policy changes and the structure of dermatology services, the Advisory Group agreed that the inquiry should also consider the role of patient groups and other information sources in supporting people with skin diseases. The report will discuss how external groups can work with health services to promote better self-management and better outcomes for patients.

The report on the inquiry is due to be published in the early part of 2006. We hope that it will make a significant contribution to the ongoing dialogue with Government about the means to improve dermatology services: highlighting the work that has been completed so far and emphasising the enthusiastic desire that exists for further change.

Should you require any information about the ongoing work of the APPGS or would like to enquire about becoming a member of the Group please contact the Secretariat on: 020 7591 4833.

**Jessica David**  
Administrative Secretary, Portcullis Public Affairs

## Skin Lesions may indicate Fabry Disease

Angiokeratoma corporis diffusum is common in patients with Fabry disease – a rare lysosomal storage disorder. The rarity of Fabry disease, however, means that patients are frequently misdiagnosed and receive inappropriate treatment, often for many years. It is therefore important to raise awareness among dermatologists of the possibility of Fabry disease in patients presenting with angiokeratomas.

### What is Fabry disease?

Fabry disease is a rare X-linked genetic disorder caused by deficient activity of the enzyme  $\alpha$ -galactosidase A. This produces progressive storage of the enzyme substrate, globotriaosylceramide (Gb3), in the lysosomes of cells throughout the body, leading to organ failure and premature death. The average life-span in affected men and women is reduced by some 20 and 15 years, respectively, mainly because of renal failure, stroke and heart disease.

### Key points

- *Angiokeratomas are common in patients with Fabry disease – a life-threatening lysosomal storage disorder.*
- *Dermatologists have an important role in the early diagnosis of Fabry disease.*
- *Enzyme replacement therapy may prevent and even reverse the decline in organ function seen in untreated patients.*
- *Specialist centres provide a multidisciplinary approach to treating patients with Fabry disease.*

The most frequent early clinical symptoms in children are neurological (e.g. agonizing and burning pain in the hands and feet) and gastrointestinal (e.g. diarrhoea and abdominal pain). Angiokeratomas also usually first appear in childhood in both boys and girls.

### Cutaneous manifestations

Accumulation of Gb3 in vascular endothelial cells in the skin causes swelling and a focal increase in pressure. As damage increases, angiokeratomas develop as small (up to 4 mm) dark-red macules and papules that may gradually become hyperkeratotic. Although they may occur singly and discretely, clusters are more often found. Some individuals may have very few angiokeratomas. In others they may cover a large area of the body. They most commonly occur in the 'bathing trunk' area, incorporating the thighs, buttocks, groins and lower abdomen. In many cases the lesions are more angiomatous and exhibit little or no hyperkeratosis.

Angiokeratomas can be removed by laser therapy. In the event of intense hyperkeratosis, an ablative laser (e.g. an ultra-pulsed CO<sub>2</sub> laser) is recommended, followed by a vascular laser that targets the haemoglobin.

In addition to angiokeratomas, patients with Fabry disease may also present to a dermatologist with:

- telangiectases of the lips, oral mucosa, palms and soles; these may appear early in the course of the disease, and are often mistaken for the lesions of hereditary haemorrhagic telangiectasia
- hypohidrosis (reduced ability to sweat) or even anhidrosis (absent ability to sweat), due to accumulation of Gb3 in eccrine glands.

### Importance of early diagnosis

Early diagnosis of Fabry disease is now more important than ever, as enzyme replacement therapy has recently been shown to prevent and even reverse the decline in organ function seen in untreated patients. As angiokeratoma is an early manifestation of Fabry disease, dermatologists have a key role in referring anyone suspected of having the disease to one of the specialist centres in the UK that have experience in diagnosing and treating lysosomal storage disorders.

Once such centre is the Lysosomal Storage Disorders Unit at the Royal Free Hospital, London. Headed by Dr Atul Mehta, this is one of the few specialist centres in the UK treating Fabry disease, and has been at the forefront of research into enzyme replacement therapy with agalsidase alfa. Reflecting the multidisciplinary approach necessary to manage patients with Fabry disease, Dr Mehta is supported by a team of consultants all with a specific interest in Fabry disease, including nephrologists, cardiologists, neurologists, ophthalmologists, audiologists and, importantly in the present context, dermatologists.

### Further information...

Further information and support for patients with Fabry disease can be obtained from the Society for Mucopolysaccharide Diseases (the MPS Society), 46 Woodside Road, Amersham, Bucks HP6 6AJ. Tel: 01494 434156; e-mail: mps@mpsociety.co.uk or christine.lavery@mpsociety.co.uk

**Dr Cate Orteu**

*Department of Dermatology, Royal Free Hospital, London*

## New NHS health check from 2006

The Healthcare Commission exists to promote improvements in the quality of healthcare and public health in England.

We are currently developing new ways of doing this, in partnership with practitioners and health service managers.

31 March 2005 saw the publication of a new way of assessing healthcare services in England. Following a 12 week consultation, which prompted more than 1100 written responses from groups, including patients and those working in healthcare, the Healthcare Commission is looking to revolutionise the way healthcare services are regulated.

We are required, by statute, to provide an annual performance rating of every NHS organisation in England. As many of you are probably aware, the performance (star) rating system has always provoked strong feelings in the NHS, drawing criticism for not reflecting patient interest, ignoring clinical priorities and focusing too much on a small set of targets. Star ratings do not paint as true and rich a picture of performance as we would like, but they have played a significant role in measuring and improving performance. Against this improvement we judge it is time to develop a new system that will tell more of the story.

The new health check will continue to measure performance against targets, increasingly focusing on local ones. It will also take account

of the new healthcare standards published by the Department of Health in July 2004. These standards cover the basics that healthcare providers should be meeting now ('core' standards) and improvements needed for the future ('developmental' standards), designed to increase the quality of care.

Our aim is that the assessment of performance, and the way information is provided by the process, will promote improvements in a range of ways. It will help people to make more informed decisions about their care, lead to healthcare professionals developing more effectively and sharing information on good practice, provide organisations with clearer expectations, enable managers to focus on areas of concern and learn from good practice, and tell us all more about the quality and equity of healthcare services provided.

We are also aiming to align the assessments of the healthcare provided by the NHS with those of the independent sector, and to present our findings to the public in a similar way. This will be particularly important as more NHS care is commissioned from the independent sector.

We know that some previous reviews of NHS services routinely involved large teams of inspectors spending several days on site, and imposed obligations on trusts to collect large volumes of data. The new approach will be different, pioneering the

approach to regulation advocated by the Chancellor in his Budget statement, identifying and responding where services are at risk.

We expect to cut regulation costs for health services, particularly for the best performers and estimate that about 20 percent of trusts will face a visit or spot check on core standards each year, typically lasting two days.

The new system aims to deliver more improvement and less red tape. To do this we will make better use of information provided by other inspectorates, by trusts themselves, and from our work on complaints and investigations. This information will be used to target our visits and interventions where there is cause for concern. Where standards are slipping, our interventions will be robust. For organisations demonstrating good performance and effective leadership, we'll apply a 'lighter touch'.

However, we will make unannounced visits and carry out spot checks to ensure the data we receive is accurate. And we will have much better 'surveillance' information, so we can respond quickly when things seem to be going wrong.

We will be looking to see if trusts have complied with core standards, met existing and new national and local targets, and used resources effectively, as well as what progress they are making in meeting developmental standards. These components will be assessed and reported on separately, and brought together for each trust's annual performance rating.

As public confidence grows that the core standards are being met, we will focus more on assessing developmental standards to promote improvement.

Developmental standards point to the improvements that the Department of Health expects all NHS trusts to make, so patients receive treatment and quality of care that is always improving. We will be assessing the performance of NHS trusts in working

towards new national priorities and targets for improved outcomes and better experiences of healthcare for patients. Over time, we will be assessing the performance of trusts in working towards local targets.

Improvement reviews, which will look at the patient's experience across and between healthcare organisations will be carried out to assess progress on a small number of priority areas each year. Some of these will focus particularly on disadvantaged groups, such as the elderly and those who use mental health services. They will measure compliance with standards, recognise good practice and identify areas for improvement. Where appropriate, we will incorporate assessments from improvement reviews directly into the scores for the annual performance rating. For some issues improvement reviews will provide national reports on progress and best practice in particular areas, or will focus on a sample of relevant healthcare communities.

Our approach in assessing whether healthcare organisations are meeting standards is to realise that they are not ends in themselves. Their purpose is to ensure that healthcare organisations can best serve the public and patients. We will be keeping this purpose in mind throughout the process.

We are confident that this new system will provide a richer picture of NHS organisations than ever before. However, we are aware that this is just the first step in our journey promoting improvements in health and healthcare, and we look forward to developing our approach in the light of experience.

For further information, or to download "Assessment for improvement: The annual health check", go to [www.healthcarecommission.org.uk](http://www.healthcarecommission.org.uk) or telephone the Health Commission helpline on 0845 601 3012.

**Stacey Adams**  
*Head of Communications, Healthcare Commission*

## Patient Group Focus



### Who are we?

The Scleroderma Society was founded in 1982 at the suggestion of a young rheumatologist who felt that people with this rare condition and no known cure needed fellow patient support, which is still true today. The doctor, Carol Black is now Dame Carol, Professor of Rheumatology and the President of the Royal College of Physicians but still finds time to support the society she founded all those years ago. The prevalence of scleroderma is approximately

1 in 10,000 people affected in the UK and is one of the rarer connective tissue conditions. The Scleroderma Society is relatively small in size and many people say it has a family feel to it.

Our mission statement is probably very similar to other charities, **to help patients and their families who suffer from the disease, to raise awareness of the disease and to support research and medical investigation.**

### How we support patients

One of our most important roles is offering support to people who may feel isolated or have questions that they may feel are too trivial or non-medical for their doctors and specialists. This is where our telephone helpline, which is manned by 4 people who

have scleroderma. Each helpline person will be responsible 1 week in 4 which seems to work very well. When we receive calls asking for information we have at present 12 user information leaflets that cover some of the complications. If we are asked a specific question that requires professional medical input we advise the caller to contact one of the nurse specialist helplines or contact his or her own doctor.

Our website, which is small and compact and hopefully user-friendly, attracts enquires from people all over the world. As a general rule we do not send anything by post overseas except to members of the Society, however we will respond to each enquiry and if possible send information (i.e. information leaflets via the internet). We also have a message board and frequently asked questions section. There is a list of physicians who belong to the **UK Scleroderma Study Group** so that patients can find the specialist closest to them. The diversity of specialities in the group represents the complexity of the disease. Any specific medical questions are answered by one of our medical advisors.

Another of our roles as a user support group, in addition to providing information, is to try and put people in contact with one another if they wish to do so. When a new member joins the Society, if they have indicated that they want contact, we send a contact form for them to complete and, upon receipt of this, we send them a list of members in and around their area. We also have a list of members' email addresses in our quarterly newsletter *Scleroderma News*.

### Funding

We are a voluntary support group with just over 500 members who consist of patients, family members, friends, the medical profession and pharmaceutical companies. There is a small annual membership fee to cover administration costs, which is presently £5 per annum and membership is open to anyone.

We have a working committee of 12 volunteers who work as a team. We receive no core funding and rely solely on donations from our supporters. Our annual income for March 2004 was just over £71,000, which included some large bequests. It is usually between £15,000-£30,000.

As we are a voluntary society our costs are minimal so most of the funds that we receive from our members and supporters will go towards research after administration costs such as postage and printing are deducted. Donations come in various sizes from £5 to £26,000 and the average preliminary research project is generally around £20,000-plus. We also receive educational grants from a small number of pharmaceutical companies towards printing costs for our user information leaflets and travel expenses to enable us to attend the BAD and BSR Annual Meetings. We design our own Christmas cards, which means that after the cost of printing and envelopes the profit comes directly to the Society and for the first time we are trying tee shirts which we hope will raise awareness. The greater part of donations we receive are from bereaved

relatives and friends of people with scleroderma, and various fundraising events held through out the year including marathons, parachute jumps, sponsored walks over fells and mountains, one young boy whose Mum has scleroderma managed to be silent for a week! And this year we have received over £300 from various people including pharmaceutical companies who sent donations to us in lieu of sending Christmas cards.

### What we spend the money on

As mentioned previously we fund research and medical investigation from clinical and scientific professionals. Each request above £1,000 is sent for peer review to 3 independent reviewers before a decision is made regarding funding. As a small charity we will quite often fund basic preliminary research which, if found to be positive, will then attract much greater funding from larger organisations. We also support the International Scleroderma Workshop. This is a biannual meeting for medics and scientists from all over the world to meet and discuss their latest findings. This pooling of knowledge in research and clinical trials will hopefully stop unnecessary duplication worldwide.

### Raising awareness

One of the most frustrating things about running the Scleroderma Society is having to hear from successive callers that they have been suffering with various symptoms for years before eventually receiving a diagnoses of scleroderma. Then, all too often people are told, "We are very sorry, this is an awful condition and nothing can be done to help you." True, there is no cure for scleroderma but there are a tremendous variety of treatments that may be able to help stop the progression and improve quality of life, even when the disease has progressed. In view of the rarity of the condition and the treatments available, we attend the BAD and BSR Annual Meetings to ensure that as many doctors and health professionals as possible are aware of our existence.

We are also members of umbrella groups including the Skin Care Campaign, the Arthritis and Musculoskeletal Alliance (ARMA), the Health Coalition Initiative and the Rare Conditions Alliance.

Our logo was designed by one of our committee members, Roy Sanders, when member Sue Garber suggested that living with scleroderma was like balancing on a tightrope. Sadly Sue died before she could see her idea put into practice but I'm sure she would be very proud that her idea is helping to spread awareness.

For more information about the Society and scleroderma please contact:

The Scleroderma Society  
3 Caple Rd  
Harlesden  
London NW10 8AB

## News Round-Up

### British Association of Skin Camouflage (BASC)

The BASC were delighted to welcome two overseas delegates to their Skin Camouflage Training Initiative held in May. The first, a lady plastic surgeon, flew in from Moscow. She has been treating the children maimed during the terrorist attack in Beslan last year, and wished to increase her knowledge to also offer the option of skin camouflage. The second, from the Groote Schuur Hospital, Cape Town, had been given "carte blanche" to set up a clinic and hopefully a subsequent training programme (BASC are in further negotiations concerning training in South Africa). Our grateful thanks go to all the camouflage suppliers, distributors of creams, lotions and potions (and the like) for kindly advising us which products would, or would not, be available in Russia and South Africa. This information was gratefully received by the delegates.

Finally, the BASC have successfully trained 42 delegates this year, and the next event (September) is already nearly fully booked!

### The British Skin Foundation

As the only charity dedicated to supporting research into skin disease, the British Skin Foundation (BSF) aims to help the 8 million people in the UK with a serious skin condition. We enjoy a close relationship with the British Association of Dermatologists who put their administrative resources at our disposal. This means every penny we raise goes straight to supporting skin disease research.

Every spring, we announce that funds are available for skin disease research and invite applications for grants. We receive many requests for funding, and the process of judging which projects to support is given to the British Skin Foundation Grants Advisory Committee. This panel is made up of leading skin scientists and non-medical professionals. Following the review process, the BSF grants are awarded to the successful applicants in early December.

Over the years the BSF has funded research into many well known skin diseases such as eczema, skin cancer, acne, psoriasis and vitiligo; as well as the lesser known ones. Last year alone 18 projects were funded by the BSF to a total value of almost £500,000.

For example, we want to help the hundreds of thousands of children and adults in this country who suffer from eczema. We funded a project in Nottingham that identified a link between where young sufferers live and an alarming rise in eczema cases. Work like this will help us to understand and address the causes of eczema, and work towards a cure.

The BSF also aims to educate the public about staying safe in the sun. Skin cancer is on the increase, with 69,000 new cases registered in UK in 2000 and many people dying as a result. The

BSF recently awarded funding to the University of Manchester where non-surgical treatments are being developed for existing skin cancer sufferers. With our help researchers can carry on developing treatments and finding new ways to slow down the alarming rise in skin cancer.

One of the main income streams for the BSF is corporate donations. To support their own research, many leading companies now approach the BSF for an independent view. BSF dermatologists visit these companies' laboratories, discuss skin health issues with their scientists and are given full access to product research and data. In return for our support, some companies assist us in our campaign of promoting healthy skin for all by giving us a donation.

Looking to the future, our first major fundraising event will be taking place in next year. This will be a series of BSF sponsored walks in eleven locations across the UK to raise awareness and funds for skin disease research.

Between May 13th and May 21st 2006, we aim to get 5,000 people walking in London, Liverpool, Nottingham, Leeds, Southampton, Birmingham, Newcastle, Bath, Cardiff, Edinburgh and Belfast.

The walks will take place at a variety of stately homes, visitor attractions and country parks. Participants include health care professionals and their families, skin disease support groups and the general public.

To find out more about us, our work or offer your support, please contact:

The British Skin Foundation

4 Fitzroy Square

London W1T 5HQ

Tel: 020 7383 0266

Fax: 020 7388 5263

Email: [bsf@bad.org.uk](mailto:bsf@bad.org.uk) or visit: [www.britishskinfoundation.org.uk](http://www.britishskinfoundation.org.uk)

### Herpes Viruses Association

One of the perks of the Skin Care Campaign, at least for those of us who are London based, or within a short commute, is the chance to attend meetings of the All Party Parliamentary Group on Skin. This organisation has been at the forefront of lobbying for improved dermatology services and its meetings are held in one of the committee rooms at the Houses of Parliament. Expert witnesses are always keen to attend – the proximity of the 'corridors of power' acts like a magnet.

The Group has to reconstitute itself for every new parliamentary session and a combination of at least twenty MPs and Peers have

to join or rejoin before it can continue. The APPGS has 48 parliamentary members including the Chair, Rt Hon Bruce George MP and Vice-Chairs Frank Cook MP, Cheryl Gillan MP and Baroness Masham of Ilton DL.

It gave me particular pleasure to be able to persuade my own new MP to join. I have been campaigning and delivering leaflets for her for the best part of ten years now, so when we finally succeeded in getting her elected it was payback time! I insisted that one of her first parliamentary activities should be signing up to the APPGS, which she was more than happy to agree to.

**Nigel Scott**

*Herpes Viruses Association*

## National Eczema Week 2005

### Living with the Enemy – Eczema and the Family

Recognising the impact eczema can have on the family is the focus of this year's National Eczema Week (September 17-24).

Healthcare professionals are being encouraged to take advantage of the free information available through the National Eczema Society's professional membership scheme to help them help patients cope with the psychological and practical effects of eczema.

Recent statistics show that 52% of carers of children with eczema feel they have no control over their child's condition, 23% never get a good night's sleep and 15% feel the whole household is disrupted<sup>1</sup>.

While the person with eczema can do nothing to stop themselves scratching and has to live with painful, cracked and often bleeding skin, carers can be left feeling helpless, guilty and exhausted through lack of sleep and worry.

Andrew Finlay, Professor of Dermatology at Cardiff University, advocates 'treating' the whole family when one member is diagnosed with eczema. "The immediate family needs to be educated on the realities of eczema, from practical management and what improvements to expect, to coping strategies for dealing with the impact it will have on daily life.

"Not all health care professionals have the necessary training to advise families on the wider implications of living with eczema and time constraints mean extended consultation can be difficult in a busy clinic. However, the long term benefits of discussing ways to integrate the child's care with normal family life are immeasurable."

To mark its awareness week, the Society has produced a new introductory booklet in FAQ format on Childhood Atopic Eczema, which is available free in the run up to National Eczema Week, by contacting the Society's patient helpline on 0870 241 3604 or email [helpline@eczema.org](mailto:helpline@eczema.org)

To extend the Society's lifeline to your patients, pass on the helpline number 0870 241 3604 open Monday-Friday 8am to

8pm. To find out more about the professional membership scheme, call 0207 561 8230 or email [professional@eczema.org](mailto:professional@eczema.org)

Reference: <sup>1</sup> ISOLATE report (International Study of Life with Atopic Eczema). The largest and most comprehensive study ever conducted into the impact of eczema on patients' lives and relationships.

## The Pseudoxanthoma Elasticum (PXE) Support Group (PiXiE)

PXE is an inherited disorder in which the elastic fibres normally found in the skin, retina of the eyes, and the cardiovascular system become slowly calcified.

**Although PXE is known mainly as a skin disease the main effect is on the eyes in that over 60% of patients lose their central vision.** Having been told I would be blind by the age of 40, I would not accept this. Therefore, in order to help PXE patients I set up the first PXE Support Group in the World in 1984 as I felt alone and suicidal and did want others to feel the same.

After the skin and eye problems, cardiovascular involvement often develops this commonly involves the peripheral arteries in the legs and arms. Bleeding from the stomach occurs in about 10% of people with PXE. In such cases it may be severe and immediate action needs to be taken to get the patient to hospital.

As PXE only affects approx. 1 in 75,000 it can go undiagnosed and this is where I desperately need your help. I would like to be able to set up an awareness campaign so that all specialists can have access to information on PXE and therefore make their lives easier and the lives of their PXE patients. Support groups can provide expertise and gather information centrally which can help the medical fraternity. For example, presently from information we have gained, it appears that Photo Dynamic Therapy on PXE patients should be used sparingly as those who have had 2 or more treatments (per eye) have almost no sight left. The next step being ICG – Feeder Vessel Therapy to detect problems. As with all support groups, we should be working together to exchange information with the medical profession and vice versa.

The PXE Support Group is a voluntary organisation pledged to provide information to all PXE patients and to the medical fraternity. Although PiXiE was the first PXE Support Group in the World it receives no funding, other than that raised by the members. If you can help in any way or would like more information please contact us. Also see the next edition (November) of Campaign News.

Miss Elspeth M. W. Lax  
Pseudoxanthoma Elasticum Support Group (PiXiE)  
15 Mead Close  
Marlow  
Bucks SL7 1HR  
Telephone: 01628 476687  
Mobile: 07810 287266  
Website: [www.pxe.org.uk](http://www.pxe.org.uk)

### XP Support Group

#### Hydro Active Challenge for Women – 4 September 2005

The Flora Run has now been changed to the Hydro Active run and Sandra Webb will once again lead a team of ladies and girls. We have achieved our team for the London event but still have places for the Liverpool and Birmingham runs. You don't have to worry about sponsorship; for everyone that takes part on our behalf we raise £5. The cost to enter is £15 and you can either do this online at [www.womenschallenge.co.uk](http://www.womenschallenge.co.uk) or by sending a cheque made payable to the XP Support Group, along with your name, address and date of birth. For further information please contact Sandra Webb at the XP Support Group UK Headquarters, tel: 01494 890981, fax: 01494 864439, email: [info@xpsupportgroup.org.uk](mailto:info@xpsupportgroup.org.uk)

#### Auction of Promises – 9 December 2005

Our third Auction of Promises and Gifts will take place at St Katharine's, Par Moor, at 7.30pm for 8.00pm. This is a black tie event and tickets are £30, which includes a 3-course dinner and glass of sparkling wine. Lots up for auction include:

- Two nights' accommodation in New York, including dinner at a restaurant and tickets to a Broadway show
- A Chinese dinner party for 6 cooked in your own home
- A signed England Shirt from the 1990 World Cup
- A magnum bottle of Champagne

and many more.

Tickets are now available and can be obtained by contacting Sandra Webb on tel: 01494 890981, fax: 01494 864439, or by emailing: [info@xpsupportgroup.org.uk](mailto:info@xpsupportgroup.org.uk)

## Skin Care Campaign Scotland (SCCS)

It has been a busy period of time for Skin Care Campaign Scotland over the last few months. I am pleased, in particular, to report that we have held a number of briefing sessions in Parliament and been successful in having a motion calling for skin conditions to be recognised as chronic taken forward to a Member's Debate.

The 5 briefing sessions hosted for us by Helen Eadie, MSP, at the Parliament have now been completed. These took place once a month, beginning in January with a session on psoriasis, to be followed by briefings on eczema and allergies, skin cancer, alopecia areata and the impact of the new GP contract. They were successful in their purpose of providing information to Scottish politicians on the nature and scope of skin disease in Scotland and what measures were needed to alleviate the situation. The sessions also provided an opportunity for some patients to give first-hand accounts of the day-to-day effect that living with a chronic skin condition has on a person's quality of life. Patients and members of their families gave moving accounts of their ordeal. We were also pleased that the sessions provided a forum for our committee members and key medical professionals to become known to the Parliamentarians. Follow-up discussions are being planned, beginning with the issue of skin cancer.

On 25 May, Ken MacIntosh, MSP for Eastwood, secured a Member's Debate on the Motion that he had tabled on our behalf. The Motion and transcript of the debate can be read in the Official Report. The focus was primarily to have skin disease recognised as a chronic condition. We were impressed by the contributions of those MSPs who attended from each party political group, as they highlighted so many of the points on which we had briefed them. The Deputy Health Minister gave an interesting and considered response. We were encouraged by her comments. For instance, she referred to the Kerr Report that was published earlier in the same day, in relation to skin conditions, stating that:

*"The definition of "long-term" conditions that is used in the report is wide enough to encompass any persistent and incurable skin condition. There is absolutely no intention to exclude skin conditions from the new approach; on the contrary, the new approach seeks to address all an individual's needs, and the impact that conditions have on the person's quality of life. Given what we have heard today about the impact of skin conditions, the new approach should have particular benefits for those suffering from such conditions."*

We were heartened that she referred to SCCS as an "effective group...which is articulating ably the views of patients with skin conditions" and that she looked forward to working with organisations such as SCCS "at a time when there are exciting opportunities to make a real difference to the lives of people with chronic skin disease."

As for other SCCS news, I am delighted that we have been able to appoint an Administrative and Development Officer on a part-time basis for a six-month contract. Helen Irons takes up the position on 20 June.

Finally, some of our patient groups have a number of events planned for the summer and autumn.

- Eczema Scotland is holding an Information Day on 1 October from 11am-3.30pm at the Radisson Hotel in Edinburgh.
- PSALV is following up its successful public information event that attracted over 100 people to Aberdeen in April. Its next meeting will be in Edinburgh in November with Professor Rees as the main speaker.

**Rosemary Gierthy**  
Chair, SCCS

## Forthcoming Events

2005		
BASC	Training Initiative, Chester <sup>(1)</sup>	26-29 August
BASC	Training Initiative, Chester <sup>(1)</sup>	2-5 September
National Eczema Society	Eczema Study Day <sup>(2)</sup> Hibernian Football Club, Edinburgh	8 September
Herpes Viruses Association	Seminars on herpes simplex and neurolinguistic programming <sup>(3)</sup> for health professionals and general public, London	17 September
Skin Care Campaign	Blackburn Skin Information Day <sup>(4)</sup>	24 September
Primary Care Dermatology Society	South & West Meeting, Marriott St Pierre, Chepstow <sup>(5)</sup>	7 October
National Eczema Society	30th Anniversary Members' Day <sup>(6)</sup> Chessington World of Adventures. Information about eczema and a fun day out.	8 October
XP Support Group	Volunteer Training <sup>(7)</sup> Green Park, Aston Clinton, Bucks	28-29 October
XP Support Group	BBQ and Fireworks. Annual social event, Prestwood <sup>(7)</sup>	5 November
Raynaud's & Scleroderma Society	First Scleroderma Awareness Week <sup>(8)</sup>	7-11 November
Primary Care Dermatology Society	Scottish Meeting, McDonald Cardrona, Peebles <sup>(5)</sup>	12-13 November
Skin Care Campaign	Cambridge Skin Information Day <sup>(4)</sup>	19 November
XP Support Group	Auction of Promises, Parmoor <sup>(7)</sup>	9 December
XP Support Group	Volunteer Training, St Katharine's, Parmoor <sup>(7)</sup>	10 December
2006		
XP Support Group	Volunteer Training, St Katharine's, Parmoor <sup>(7)</sup>	21 January
XP Support Group	Owl Patrol, St Katharine's, Parmoor <sup>(7)</sup>	10-13 February
BASC	Training Initiative, Chester <sup>(1)</sup>	24-28 February
BASC	Training Initiative, Chester <sup>(1)</sup>	19-22 May
XP Support Group	Owl Patrol for teenagers, St Katharine's, Parmoor <sup>(7)</sup>	18-20 August
BASC	Training Initiative, Chester <sup>(1)</sup>	25-28 August

<sup>(1)</sup> Further details, including booking forms can be obtained from Mary Thorp, BASC Secretariat, on 01625 871 129, or by writing to BASC, PO Box 202, Macclesfield, Cheshire SK11 6FP, or by emailing: [basc9@hotmail.com](mailto:basc9@hotmail.com)

<sup>(2)</sup> For further information or to book contact NES NW office on 01925 766877/[jane.eczema@virgin.net](mailto:jane.eczema@virgin.net) or visit [www.eczema.org](http://www.eczema.org).

<sup>(3)</sup> For further information please contact the HVA office on 0207 607 9661 or email: [info@herpes.org.uk](mailto:info@herpes.org.uk).

<sup>(4)</sup> For details on Skin Information Days please contact Gwen Banford, e-mail: [gbanford@eczema.org](mailto:gbanford@eczema.org); tel: 020 7561 8249

<sup>(5)</sup> For further details please contact: Carol Singleton, PCDS, tel: 01923 711678, fax: 01923 778131, email: [carol@pcds.org.uk](mailto:carol@pcds.org.uk)

<sup>(6)</sup> Free family tickets for NES members (professional and patient) available, first come, first served basis. For more information contact NES on 020 7281 3553 / [sbrooks@eczema.org](mailto:sbrooks@eczema.org)

<sup>(7)</sup> For further details please contact Sandra Webb, XP Support Group, tel: 01494 890981, fax: 01494 864439, email: [info@xpsupportgroup.org.uk](mailto:info@xpsupportgroup.org.uk)

<sup>(8)</sup> For further details please telephone 01270 872776 or visit the Raynaud's & Scleroderma website [www.raynauds.org.uk](http://www.raynauds.org.uk)

## Skin Care Campaign Board Members

**Lyn Stone CBE** Chairman

**Nigel Scott / Marian Nicholson** Herpes Viruses Association (Nigel – Vice-Chairman)

**Jane Watts** National Eczema Society

**Alison Dudley / Dr Nick Varey** Acne Support Group

**Jane Freak** The Wessex Cancer Trust's Marc's Line

**Maureen Benbow** Tissue Viability Society

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Copy date for the next issue is **Friday 16th September 2005** .

Please send news/articles/details of forthcoming events to

Gwen Banford: e-mail: [gbanford@eczema.org](mailto:gbanford@eczema.org)

Tel: 020 7561 8249 • Fax: 020 7281 6395

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