



# The Scleroderma News

Spring Issue  
April 2005

## The Newsletter of The Scleroderma Society (UK)

### A Word from Kim

Hi -- Our AGM is on 30<sup>th</sup> July. Please see inside for details including booking form and a Q&A form for anyone wanting to ask the panel a question. This year for the first time we have tee shirts for sale in two colours, blue and white with the society's logo, to help promote awareness of both scleroderma research and the Scleroderma Society. They come in 3 sizes small, medium and large and cost £10. They will be available at the AGM so remember to bring your cheque book with you. We will also have our Christmas cards, so that you can save on postage, and the annual raffle. Hope to see as many of you as possible on the day.

We have a new membership secretary, Steve Holloway, who many of you may have spoken to on the help-line during the past year. Anna Clark, who Steve is replacing, is having an operation in April and felt that her convalescence might prevent her from performing the duties involved with this position. However, she will be running the Christmas Card Mail order service with her husband Peter, health permitting, later on in the year, replacing Carol Todd who had previously organised this for many years. I'm sure you will wish to join me in thanking Anna and Carol for their tremendous help and support to the Society over the years.

I know that I always seem to be talking/writing endlessly about the weather (some might say I'm obsessed) but do hope that we are in for a rather better spring than winter - which has seen most parts of the UK reaching freezing temperatures and unprecedented snow and rain fall.

Until next time,

Lol Kim

**NEWS** The Society attended the launch of the Health Coalition Initiative Framework Document on Partnerships between Voluntary Health Organisations and the Pharmaceutical Industry at the House of Lords on the 2<sup>nd</sup> February.

Baroness Pitkeathley explained that the framework document has been produced by representatives from VHOs and the pharmaceutical industry working together to share experiences, good practice and cautionary tales of poor outcomes when bad practice has taken place. It is hoped that the document will prove invaluable in promoting better understanding between patient groups and the pharmaceutical industry, so that patients and their carers have access to appropriate and relevant information and services.

**ROYAL FREE FAMILY DAY**  
MAY 21<sup>st</sup>

This year celebrates the 10<sup>th</sup> Anniversary of family day for people with scleroderma and their families at the Royal Free Hospital in London. As usual we will have a stand in the Atrium. Please do come and say Hello.

Francis Bain and Kim attended a workshop "Meet the industry/voluntary health sector" organised by the ABPI (The Association of the British Pharmaceutical Industry). The programme consisted of 2 talks from the voluntary sector, 'The Role of the Chair & Board of Trustees', and 'Producing Information for Patients'. And also two talks from the Pharmaceutical Industry, 'Working with the ABPI Code of Practice' and 'Engagement and Access to Funds'. One of the things that struck me was that just as no two people with scleroderma are alike the same could be said of the voluntary sector, with no two charities being the same either. We come in all shapes and sizes but share a common goal, to help and support our respective communities.

*See also article on Page 5*

**THE QUARTERLY NEWSLETTER OF THE  
SCLERODERMA SOCIETY**  
CHARITY REGISTRATION NUMBER: 286736  
The Scleroderma Society 020 8961 4912  
[www.sclerodermasociety.co.uk](http://www.sclerodermasociety.co.uk)  
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*The Scleroderma Society is not responsible for any information, news or views that appear in this newsletter.*

**Please send YOUR articles, etc.** for the next issue to Carol Sanders, The Laurels, Westport, Langport, Somerset. TA10 0BN Tel: 01460 281305  
e-mail [roy4sanders@aol.com](mailto:roy4sanders@aol.com)  
**Closing date for contributions 17th June 2005**

## Edinburgh and East Scotland Group

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Edinburgh.

EH10 6NL

Tel: 0131 477 1122

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### FLYING SOUTH

I took a flight down to London to stay with Kim for a couple of days in February. I thoroughly enjoyed the visit, but unfortunately it turned out to be one of our coldest week ends which is not good for us as scleroderma patients, still we can't control the weather. On Saturday Kim, Caroline and my self travelled to Hampshire to Sally's house as she hosted our committee meeting. It was lovely to meet every one again, and as you can see by the picture we had a good attendance.

Love Frances



## South Wales Group

Contact: Belinda Thomson  
39 St Alban Avenue, Heath,  
Cardiff, CF14 4AS

Tel: 02920 612690

Email: [bigb263@yahoo.com](mailto:bigb263@yahoo.com)

Hello again from Wales. I have been helping on the help line for nearly a year now. It is very interesting and nice to be able to speak to other people with scleroderma.

*The Scleroderma Society*

# Area News

Also it's good to help them with information, but it's surprising how difficult it is - by that I mean giving relevant information.

May 12th is the next meeting in Wales so if you have not had a phone call or email about the meeting, please contact me to let me know if you are coming.

Kim is going to be here (fingers crossed) so she is willing to answer any questions you may have. She is also bringing some lotions and creams for you to try so that you can get them from your GP, if they are suitable. I look forward to seeing you all.

Belinda

Colin Beevor has kindly sent the directions:-

On entering QA take lifts to D level (1st floor). Walk towards D4 & the seminar room is on the right-hand side, after entering D4 main entrance.

Looking forward to seeing you.

All best wishes,

Liz and Steve Holloway

## London & South East Group

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Tel: 020 8965 4094

Email:

[info@sclerodermasociety.co.uk](mailto:info@sclerodermasociety.co.uk)

We had a splendid meeting on the 17th March, with a very informative talk about taking part in clinical trials. I'm sure that most readers with scleroderma will have been asked to take part in a trial at some time or other. You can read Jane's article on page 3.

Please let me know what talks you would find enjoyable in future meetings and I will try and find a speaker for our meetings. Date of the next meeting to be confirmed in the Summer edition of Scleroderma News.

Hope to see you soon

Kim

## Other Contacts

### Glasgow and West Scotland Group

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## Clinical Trials

Choosing to take part in a clinical trial is an important decision. It is something that you may wish to discuss with your family, friends, and even your GP. You should know as much as possible about the clinical trial and feel comfortable asking the members of the health care team questions.

The following information aims to help you to make an informed choice if you are considering or have been approached to participate in a clinical trial.

A clinical trial (also clinical research) is a research study in human volunteers to answer specific health questions. Carefully conducted clinical trials are the fastest and safest way to find treatments that work in people and ways to improve health. Interventional trials determine whether experimental treatments or new ways of using known therapies are safe and effective under controlled environments. Observational trials address health issues in large groups of people or populations in natural settings.

ClinicalTrials.gov (2003)

### Why Participate in a Clinical Trial

Clinical trials that are well-designed and well-executed are the best approach for eligible participants to:

- Play an active role in their own health care.
- Gain access to new research treatments before they are widely available.
- Obtain expert medical care at leading health care facilities during the trial.
- Help others by contributing to medical research.

However there are potential risks to clinical trials.

- There may be unpleasant, serious or even life-threatening side effects to experimental treatment.
- The experimental treatment may not be effective for the participant.
- The protocol may require more of their time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements.

[roswellpark.org](http://roswellpark.org) (2005)

All these things should be considered and should be discussed when taking informed consent.

### Informed Consent

The participant should be given enough information in a way that he/she can understand completely and that allows him/her to make an informed decision to participate in a trial.

The three main elements of the informed consent process are:

1. Consent for participants in research is voluntary only if it is given without any direct and indirect coercion or inducement.
2. Participation in research should be based on an informed decision after sufficient information about the study has been provided.
3. Informed consent for participation in a research project should involve participants giving written consent. If the participants are unable to give written consent, oral consent in the presence of a witness is acceptable.

Piper (2004)

The dignity, rights, safety and well being of participants must be the primary concern in any research facility.

### Eligibility Criteria

Each study's protocol has guidelines for who can or cannot participate in the study. These guidelines, called eligibility criteria, describe characteristics that must be shared by all participants. The criteria differ from study to study. They may include age, gender, medical history, and current health status. Eligibility criteria for treatment studies often require that patients have a particular type and stage of the disease.

Enrolling participants with similar characteristics ensures that the results will be due to what is under study and not other factors. In this way, eligibility criteria help researchers achieve accurate and meaningful results.

These criteria also make certain that people who could be made worse by participating in the study are not exposed to the risk.

[roswellpark.org](http://roswellpark.org) (2005)

### Types of Clinical Trials

There are many ways of organising clinical trials. The most common terms are included here.

In **randomised trials** participants may receive either the best available treatment or the new one under study.

To make sure that one treatment isn't favoured over the other, the treatment each patient receives is decided by a process called randomisation. This means that the treatment is not chosen by the patient or their doctor but by a computer. There is usually a 50/50 chance of receiving either treatment.

A **double-blind trial** means that neither the participant nor the hospital staff will know which treatment is being given. A special code is used and this is broken at the end of the trial to analyse the results. [Cont'd P.4.](#)

Continued from P.3. The advantage of the code is that it prevents the staff from favouring one treatment or the other when assessing the benefits or side effects. The code is always available and can be broken to identify the treatment, if necessary.

A placebo is an inactive substance, such as chalk, salt or sugar. It is made into a tablet or injection identical in size, shape and colour to the treatment. The patient won't know if they are receiving the treatment or placebo. A **placebo-controlled** trial may also be double-blind. A proportion of patients will feel better even though their illness isn't directly affected by the treatment they are given - the so-called "placebo effect". It's thought that this happens because we believe a new tablet or injection must be better, even though there has been no change in our health. This effect must be separated from that of the actual treatment, which should give better results than the placebo if it works. If the treatment doesn't work, the results will be similar to the placebo.

[www.royalmarsden.org](http://www.royalmarsden.org) (1999)

### Useful Questions

Below are a number of useful questions that you may wish to consider when thinking about taking part in a clinical trial.

- What is the purpose of the study?
- Who is going to be in the study?
- Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?
- What kinds of tests and experimental treatments are involved?
- How do the possible risks, side effects, and benefits in the study compare with my current treatment?
- How might this trial affect my daily life?
- How long will the trial last?
- Will hospitalisation be required?
- Who will pay for the experimental treatment?
- Will I be reimbursed for other expenses?
- What type of long-term follow up care is part of this study?
- How will I know that the experimental treatment is working?
- Will the results of the trial be provided to me?
- Who will be in charge of my care?

[ClinicalTrials.gov](http://ClinicalTrials.gov) (2003)

### References:

An introduction to clinical trials. (2003) [www.clinicaltrials.gov](http://www.clinicaltrials.gov); Information for patients: clinical trials (1999) [www.royalmarsden.org](http://www.royalmarsden.org); What is a clinical trial? (2005) [www.roswellpark.org](http://www.roswellpark.org); Informed consent research. (2004) Johanna Piper. South London & Maudsley NHS Trust. London SE5 8AF.  
Jane Eagle - Research Nurse, Royal Free Hospital

### OBSERVATIONAL STUDY OF TREATMENT OUTCOME IN EARLY DIFFUSE SCLERODERMA (Systemic Sclerosis)

Research is currently ongoing throughout the UK, observing patients with early diffuse scleroderma within 3 years of onset of skin thickening. All rheumatologists in the UK are encouraged to include patients. The aim of this research is to compare the safety and efficacy of different treatment protocols in early diffuse disease. Clinicians select the treatment of their choice for each patient following normal practice. Involvement in this research does not affect normal treatment. This research involves observing patients' disease progression over the course of 3 years, with clinic visits every few months.

The study focuses on patients whose skin involvement extends beyond the forearms, lower legs and face, as they often receive different kinds of treatment. We are looking at patient who are >18 and < 70 years of age and have had skin involvement of less than 3 years.

The study has been running now for over 4 years and approximately 120 patients have been included. We are very grateful to the Scleroderma Society for funding this research.

Donna

**If you are a patient or a clinician and would like some more information about this research, please contact Donna Taylor-Fesler (study co-ordinator)**

**ARC Epidemiology Unit, The University of Manchester Tel. 0161 275 7146.**

[donna.taylor-fesler@manchester.ac.uk](mailto:donna.taylor-fesler@manchester.ac.uk)

### 23rd AGM/CONFERENCE

July 30<sup>th</sup> 2005

THE ROYAL FREE HOSPITAL

LONDON NW3 2QG

Provisional Programme

Physiotherapy and Occupational Therapy in Scleroderma

Mary Hanania and Phoung Quach

Living & Working with Scleroderma

Sally Saunderson

Professor Carol Black (Topic to be confirmed)

Questions & Answer Session

Co-Chairs Prof. Carol Black/Dr Chris Denton

Many representatives of voluntary health groups have told us they believe that the public should have much greater access to the results of clinical trials of medicines. ABPI agrees with that view.

In May 2003, the ABPI launched a website publishing details of clinical trials of medicines involving UK patients:

<https://www.cmrinteract.com/clintrial>. This launch was the result of an ABPI policy to encourage its members to voluntarily provide details of phase III trials involving UK patients on a publicly accessible website. The trials would be registered three months after marketing the medicine in a first major market. We believe this was the first industry specific clinical trial register to be made available to the public. Currently it contains 116 trials.

Subsequently, discussions began on developing a worldwide website for registration and publication of industry-sponsored trials. In the meantime, a number of other initiatives to provide information to the public have been put in place (e.g. some specific company websites and, in America, the development of [www.clinicaltrials.gov](http://www.clinicaltrials.gov)).

The major pharmaceutical trade associations in the world, including the ABPI, have been discussing how to provide the public with more information on clinical trials. On 6 January 2005 an international industry agreement was announced whereby the global pharmaceutical industry proposes to register, at inception, all its clinical trials that are designed to investigate the therapeutic benefit of a medicine. They will provide a summary of the results, whether positive or negative, within one year of a medicine being first marketed. These proposals will come into fruition during 2005 and ABPI will keep you informed of developments.

To see the ABPI press announcement on its recommendation to the House of Commons Health Select Committee inquiry on the pharmaceutical industry's influence, click on

[http://www.abpi.org.uk/press/press\\_releases\\_05/050113.asp](http://www.abpi.org.uk/press/press_releases_05/050113.asp)

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I was diagnosed with Scleroderma in 1997 and after the initial shock of having a disease, that I, my family (apart from one son who is a doctor) and my friends had never heard of and also suddenly becoming clinically depressed I decided that the only person to take control of my life was me. So I came off the Seroxat, with the help of acupuncture, and decided to do some exercise. I found out that walking halved the risk of developing coronary heart disease and strokes. It can help prevent mature onset diabetes and bowel cancer, it reduces the decline in bone density, lessening the risk of osteoporosis and helps arthritis. It improves muscle strength, balance and co-ordination and can increase confidence, stamina and energy levels. It can help combat anxiety and depression and improve the quality of sleep - so I started walking. I then found out that my local authority, the London Borough of Richmond upon Thames, organised health walks. The concept of Health Walks established itself with the "Walking the Way to Health" initiative that was funded by the Countryside Agency, the British Heart Foundation and The New Opportunities Fund. It involves regular supervised walks led by trained volunteers and attended by people who would like to do more walking but prefer the safety of a group and the knowledge that there is a trained walk leader on hand. The aim is to encourage more people to walk regularly in their own communities, especially targeting those who do little exercise. So I volunteered and became a Health Walk Leader! 70% of men and 80% of women are not active enough, 48% of men and 40% of women are overweight, 80% of the population incorrectly believe that they are fit. The biggest improvements to health are gained when people who are inactive start doing a modest amount of exercise. Walking is ideal, requiring no equipment or expense. Find out from your local authority if they have a health walk scheme and if not why not. Alternatively, with some friends, organise walks yourself now that the lighter evenings are here a 30/40 minute walk once or twice a week and you will definitely feel the benefit. I know that I have and I now feel so much more positive about life and what it throws at me. Do consult your medical practitioner or consultant before venturing out.

If you would like more information please do not hesitate to contact me, my email address is in this newsletter.

The Walking the Way to Health Initiative (WHI) has a website [www.whi.org.uk](http://www.whi.org.uk) Caroline Walker

### ONLINE SURVEY

CARE 111 Conference aims to develop further the research agenda for the assessment and management of rheumatological conditions – focusing on team care and non-drug treatment. The CARE 111 International Conference group consists of rheumatology researchers in Europe and N America. The next conference will be in Canada in May 2005. The CARE 111 team have constructed an on-line survey to investigate the views of people with arthritis and musculoskeletal conditions related to non-drug treatment. To access and complete the survey on-line at the Arthritis Society of Canada website takes around 10 minutes.

<http://www.arthritis.ca/look%20at%20research/surveys/default.asp?s=1>

### RAISING AWARENESS

If you want to be exhausted, hear ghastly things said about your appearance all day, I thoroughly recommend being a patient on an MRCP course or examination. You may wonder why you would put yourself through this ritual humiliation several times a year; quite simply it goes a long way to raising awareness about our complex condition in the medical profession. The Doctors taking these examinations are the next generation who will be treating us or others who have scleroderma in the future. The more examples of different types of scleroderma they can see whilst training and in practice can only improve their chances of both diagnosing the condition and seeking specialist help regarding treatment for us. In turn this will improve our treatment options and long term prognosis. I wish I could say that long gone are the days when Doctors tell someone who is newly diagnosed with scleroderma that they are very sorry but there's nothing that can be done, I still hear these dreadful stories from time to time! But hopefully the 200 or so trainees who pass through the Ealing PACES course will remember seeing people with scleroderma and different complications and how we cope with them. Seeing us as people rather than just a list of symptoms in a textbook will stick in their minds. They also learn, I hope, that there are more pleasant ways to describe, in front of us, some of the features that they are looking for. The features will help them determine exactly what condition a person sitting in front of them has, and also to see us as people rather than just a list of complications or symptoms. A bonus to attending this course was meeting Edna Bryan who has had scleroderma since 1995. Edna always has a bag of stamps, a raffle prize or two and news of her many friends for the Society. I have to remember not to overload myself because I always have something to carry home thanks to Edna's kind generosity and support.

Kim

### E-mail addresses of members happy for contact-

## Welcome to Our New Members

Wendy Newman, Jacqueline Sheridan, Lesley Smith, Margaret E Potts, Janet Coe, Lynn Morton, Janie Lewis, Ellinor Coleman, Judith King, Christine Pattinson, Margaret Bacon, Veronica Hurst, Susan Clappison, Usha Vyas, Manjula Patel.

A Warm Welcome to you all.

### PEOPLE LOOKING FOR CONTACT WITH OTHERS

Lynn has limited systemic sclerosis and would like to get in touch with anyone living near her. She lives in Winterslow, Wiltshire, Tel: 01980 863444

Lynn Morton [lynn@dbl.co.uk](mailto:lynn@dbl.co.uk)

A new member, Ellinor Coleman, Norwegian, living near Guildford in Surrey with her English husband has a daughter Kristine, aged 46, living in Caracas, Venezuela who developed scleroderma about a year ago. She has also suffered from Lupus for a number of years.

Ellinor would like to contact, initially via e-mail [brelcol@onetel.com](mailto:brelcol@onetel.com), another mother or patient in a similar situation to understand more how scleroderma sufferers cope and which treatments have been tried, etc.

We have received a request from a member who has limited scleroderma together with coeliac disease. She would be very happy to hear from anyone who has both conditions. Marion also has faecal incontinence due to damage to the nerve endings and is keen to hear from anyone who has had either of the following procedures: a bio plastic augmentation of anal sphincter or sacral nerve stimulation. If you would like to share your experiences with Marion you can contact her through the Society.

### FUNDRAISING

Many thanks to:

Peter and Judith Doyle who ran in the Great South Run in memory of Judith's sister, Carol Clark, and raised £650 and also Zurich Financial Services who matched Judith's sponsorship and donated £290.

The Duck Head Golf Club who raised £800 throughout last year by setting strict fines on the golf course for anything and everything and also for shaving various body parts!

Actelion Pharmaceutical UK Ltd who sent the Society a donation instead of sending out Christmas cards.

Mr Tony Slater who has topped up his life membership once again.

Mrs Shireen Longland who lives in the same village as member Ann Collins who introduced her friend to the Society for which we are very grateful.

Ken Blake who has been saving his small change yet again.

Diane and Richard Horner who run The White Hart Inn, Hawes, North Yorkshire, emptied their collection box and sent a donation from themselves and a friend instead of sending Christmas cards. Many thanks to Mrs Madge West who directed donations in memory of her sister, Peggy Bembridge, to the Society.

Marion Walton has had to give up sewing and has lace, all types of braids and edging, if anyone needs any. Marion is still able to knit and is very happy for suggestions if you have somewhere to sell her knitwear in aid of the Society. You can contact Marion by email:

[mwalton40@ntlworld.com](mailto:mwalton40@ntlworld.com) or telephone 01329 517216.

### SAD NEWS

Many of you will remember Bill Storey's inspirational talk at the Society's AGM at Wexham Park in 2002. Sadly Bill died on 27<sup>th</sup> December, 2004. His family, friends and work colleagues sent donations of £1,200 in his memory. Included in this incredible donation are the winners of the Flitwick Club's quiz night for January and February in memory of Bill. Bill's wife, Val wrote "I can't believe how generous our friends have been and have been so touched by it. Bill would have been thrilled by the size of the donation and so are we, his family". Those of you who had the privilege to meet Bill will know just how special he was.

### CONGRATULATIONS

To Wyn and Mandy, who tie the knot in July, to become Mr & Mrs Williams in Pontardulais!

### NOTE FROM OUR MEMBERSHIP SECRETARY

First, I would like to thank Anna Clark for all her hard work as Membership Secretary.

I am very pleased to be taking over the role.

As Anna would say,

**It's that time of year again!**

Membership renewal date - April 1st. Check the numbers in brackets next to your name on the envelope enclosing the newsletter. If you see (05), then it's time to renew. You will find a form enclosed. If, by the time you read this, you have disposed of the envelope, or you are unsure - do give me a ring.

**Steve Holloway, 023 9237 4176**

## Ask The Expert

**Q.** My mother is 70 years old and is a member of the Scleroderma Society. She has had Systemic Sclerosis and Raynaud's for 14 years. She has recently been diagnosed with a Cataract. Two of the specialists that do laser eye surgery in my country (Iran) say that such an operation is risky for my mum, but another specialist believes that it is OK. Could you please advise us in this matter?

**A.** Cataract surgery should be safe: there is no evidence of excessive scarring after surgery and the patient will gain a substantial improvement in her quality of life.

**Q.** Is there a connection between the menopause and scleroderma? I am 42 and have had scleroderma for 2 years and have just been diagnosed as being on the menopause.

**A.** We don't fully understand the relationships between scleroderma and 'hormones' but there is no definite evidence linking scleroderma to the menopause.

### COMMITTEE MEMBERS

Chair - Kim Fligelstone, 3 Caple Road, Harlesden, London. NW10 8AB 020 8961 4912

Treasurer - Simon Barrell, 11 Connaught Gardens, Berkhamsted, Herts. HP4 1SF

Membership Secretary - Steve Holloway, 15 Carne Place, Port Solent, Portsmouth, PO6 4SY. 023 9237 4176, [stevemail99@btopenworld.com](mailto:stevemail99@btopenworld.com)

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Area Contacts (*details see P 2*) Liz and Steve Holloway, Bill Forman, Belinda Thomson, Frances Bain

## Nurse Specialist Helplines



**Anabel Smith**

Woolmar Hill Hospital, **Aberdeen** 01224 555 403

**Sue Brown**

RNHRD, **Bath** 01225 447997

**Karen Walker** (Scleroderma)

Freeman Hospital, **Newcastle Upon Tyne** 0191 2231503

**Rachael Crackett & Julia De-Soyza** (Pulmonary Hypertension)

Freeman Hospital, **Newcastle Upon Tyne** 0191 213 7418

**Liz Wragg**

Hope Hospital, **Manchester** 0161 206 0192

**Naomi Reay - Sally Smith**

General Infirmary, **Leeds** 0113 3922189

**Steve McSwiggan**

Ninewells Hospital, **Dundee** 01382 633957

**Royal Free Hospital, London**

Scleroderma 020 78302326

Pulmonary Hypertension 020 7472 6354

Lung Enquiries only **Ross Ellis**

**Brompton Hospital, London** 020 7352 8121 (Bleep 7112)

**Sally Marsh**

**Northampton** General 01604 545531

The Nurse Specialist Helplines are part funded by the Raynaud's and Scleroderma Association **Please Note:** These helplines are for general inquiries. Unfortunately it is impossible for any health professional to comment on individual treatment without seeing the patient. If there is no reply, please leave a message with your telephone number.

### NOMINATIONS FOR THE COMMITTEE

At the AGM new committee members may be elected.

If you wish to stand or nominate someone for the committee, please send a letter to Kim, complete with names of the proposer and seconder. Also please confirm agreement of the nominee to stand.