

Support from our President



Prof Dame Carol Black

Professor Dame Carol Black, the RSA's President, had these words to say in support of the 'Cool Million' project.

"It is a wonderful idea to celebrate the RSA's 30th Anniversary by having a campaign to raise a total of one million pounds for research. The RSA has been crucial to the progress that has been made to date, but so much more remains

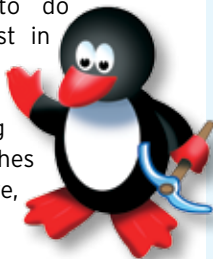
to be done. It is on the common problems, Raynaud's, calcinosis, digital ulcers, bowel problems, bloating, fatigue, sexual dysfunction etc., which so blight people's everyday lives and cause distress and interference with normal activities, that research is particularly needed. This is a great campaign. If we all give a little, whether it be time, money, enthusiasm and/or support, we can get there".

Future Challenges

The work of the Association continues through awareness campaigns to highlight these devastating diseases to both the public and medical practitioners. Facilitating timely and accurate diagnosis benefits patients - this is always the most important aim. Developing the 'informed patient' ensures that they know what support and treatment are available to them. The RSA produces literature that assists patients with learning about their disease as well as providing forums for them to talk to one another. By supporting patients they in turn can challenge their own standards of care.

The Raynaud's and scleroderma community has come a long way, with advances in the provision of expert centres being one notable improvement. There is a need to make sure that all patients when necessary have access to proper specialist centres. Once at a specialist centre, patients should have the best evidence-based treatments available.

In the past the RSA has financially supported much clinical research and will continue to do this, while encouraging others to invest in the development of new treatments, especially for uncommon diseases such as scleroderma. Advancing the understanding of how treatments work, the best approaches to prevention and ultimately finding a cure, are aims for the future.



What is Raynaud's?

Raynaud's phenomenon (usually just called Raynaud's) is a common condition of the blood vessels that supply blood to the skin. During a Raynaud's attack, the blood vessels narrow, reducing blood flow to the hands. They first become white and dead looking. They may then turn blue and finally red and burning when the blood flow is restored. There may be considerable pain, numbness or tingling.

In the UK, Raynaud's is thought to affect as many as 10 million people. However, it is difficult to determine an exact figure for the incidence of Raynaud's because many people with the condition are unaware that it has a name, or that it can be treated. Therefore, they do not go to see their GP until it becomes more than just a nuisance. Raynaud's is much more common in women than it is in men. The condition can affect people of all ages, although it usually develops before a person is 40 years of age.

Diagnosis is usually made from a careful clinical and family history. Raynaud's can be hereditary in which case it is usually mild and seldom has underlying complications. In the majority of cases Raynaud's occurs spontaneously with no apparent cause.

What is Scleroderma?

Scleroderma is an uncommon disease of the blood vessels, the immune system and the connective tissue. The skin, usually of the hands and feet may become thickened, tough, tight and leathery. In addition to affecting the extremities, the fibrosis may spread to other areas and organs of the body. The arms, face, trunk and legs may be involved and movement of the limbs may become limited. Damage to the blood vessels is usually seen in the form of severe Raynaud's, painful pits or scars on the finger tips, telangiectasia and ulcers. These are external signs of scleroderma but internal vascular damage may also occur.

Anyone of any age can develop scleroderma. It is four times more common in females than males and during childbearing years, the percentage rises to ten females to one male. Scleroderma usually begins between the ages of 25 and 55 and is usually preceded by Raynaud's. Although over 95% of people with scleroderma have Raynaud's, the chances of someone with Raynaud's developing scleroderma is very small - it is less than 2% in females and 6% in males.

Raynaud's & Scleroderma Association

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PLEASE HELP US TO RAISE A 'COOL MILLION' POUNDS 2010 - 2012

Since the RSA was founded in 1982, over 11 million pounds has been raised for research and welfare projects throughout the UK. But....this is only the 'tip of the iceberg' and a cure still eludes the researchers.

Mission Statement

The mission of the Raynaud's & Scleroderma Association (RSA) is to provide educational and emotional support for people with Raynaud's and scleroderma and their families. The RSA is committed to increasing awareness of these potentially devastating conditions and raising money for essential research in order to determine cause, enhance treatment and ultimately find a cure.

Our Progress

Since the RSA was founded in 1982, it has not just provided much needed support to patients, their families, and carers, but continually challenged health professionals to improve both the treatment and overall care they provide in the UK. Before the RSA existed, sufferers could find little information, help or advice. By raising the awareness of Raynaud's and scleroderma in a variety of ways, the RSA has helped patients put a name to their symptoms and eased their path through diagnosis and into treatment. The communication between a patient and their doctor is pivotal when providing optimum care. The RSA has empowered patients to better understand their condition, enabling them to have an informed, and so improved dialogue with their treating healthcare team.

Specialist centres provide expert, holistic care coupled with newer medicines, which have led to real improvements in quality of life for patients. The pooling of expert knowledge continues to push the boundaries of current understanding. Due to a focus on the management and treatment of scleroderma, not just life expectancy, but quality of life has improved for patients. Today patients are increasingly living with scleroderma rather than dying from it. The causes of Raynaud's and scleroderma are still a mystery and there is no cure at present. However, incurable no longer means untreatable.

The Need for Research



Prof Chris Denton

Quote from Professor Chris Denton, Consultant Rheumatologist at the Royal Free Hospital:

"I think that you have had a terrific and timely idea. By focusing on research in the UK, this will be a very substantial investment that should yield results. The idea of engaging patients or "users" makes this attractive.

The Raynaud's link is unique and is also an area that compliments other international initiatives. There is growing appreciation that the burden of scleroderma and Raynaud's extends into many important and neglected areas which this initiative can start to address."

The RSA has worked hand in hand with medical practitioners and researchers. This work has led to a better understanding of the development of the disease, which in turn has led to improved treatment. Long-term management of the disease is now a major focus. As treatments have advanced and become more complex, there has been an increase of expert, interdisciplinary medical collaboration.

However, more still needs to be done. Examples of areas of research for which there is no cure, relate to scleroderma in the lungs, the digestive tract (especially the bowels), calcinosis, digital ulcers and Raynaud's. We are therefore inviting everyone who has Raynaud's and/or scleroderma, their relatives and friends, to join us in a united effort to raise a million pounds over two years in the hope that the results of new and ongoing research, will help to improve the quality of life for people with these conditions.



Our Mascot



Hi, I'm Percy Penguin, the RSA mascot. Please help me to reach not just the tip but the top of the iceberg and our target of £1,000,000

How to Donate

For this project we have created a dedicated justgiving page www.justgiving.com/rsamillion and also a section on our website: www.raynauds.org.uk

Alternatively you can use the form below to forward your donation, making cheques payable to: RSA and send to 112 Crewe Road, Alsager, Cheshire ST7 2JA

Payment by cheque or postal order

Full Name.....

Address

Post Code..... Tel No

Email.....

Amount enclosed £

I am not a UK taxpayer I am a UK taxpayer

TAXPAYERS GIFT AID DECLARATION

I confirm that I am a UK taxpayer and I wish that all donations I have made to the RSA in the last 4 years, and all future donations, be treated as Gift Aid. I will notify the RSA if I no longer pay an amount of income tax equal to the tax reclaimed on my donations.

Signature..... Date.....

Together we can make a difference