

PRESS RELEASE

February 2017

Scleroderma & Raynaud's UK online test helps over 3,000 people establish if they have Raynaud's.

Scleroderma & Raynaud's UK, the only UK charity dedicated to improving the lives of people with Scleroderma and Raynaud's launched online test that has given 93% of people a result of Raynaud's in less than 60 seconds.

SRUK's research reveals that only 4% are able to identify the symptoms of Raynaud's, yet up to 10 million people are affected by this condition in the UK. Worryingly only 10% of people on average who had Raynaud's symptoms would visit a GP.

Raynaud's is a condition that affects the blood supply in the body's extremities - usually the fingers and toes - and many people living with the condition will regularly experience colour changes to the affected area, pain and discomfort.

The online test has been developed with the support of three consultant rheumatologists specialising in Scleroderma and Raynaud's ensuring this tool follows the clinical diagnosis pathway, giving users a trusted result. Users of the test will answer 5 simple yes or no questions and receive a result as to whether they may have Raynaud's or not. Further information is provided to users who may have Raynaud's including self-management information and for those identified as at risk of having an underlying condition they are being encouraged to see their GP.

If you are affected by any of the 5 symptoms below, take the test today at www.sruk.co.uk/testme

Top 5 signs of Raynaud's

- Cold fingers and toes
- Colour changes in the skin in response to cold or stress
- Colour changes in the affected area to white, then blue and then red
- Numbness, tingling or pain in the fingers and toes
- Stinging or throbbing pain upon warming or stress relief

Other parts of the body can be affected by Raynaud's including the ears, nose, lips, tongue and nipples. Symptoms can last for a few minutes to several hours.

Sue Farrington, SRUK Chief Executive said:

"We are encouraging more people to seek medical help and advice if they regularly experience one or more of the main symptoms which include pain, numbness or tingling in the body's extremities."

"We know that despite a quarter of people saying that they had experienced symptoms, only 10% on average have visited their GP. This needs to change - Raynaud's can be a minor but uncomfortable inconvenience, but for those more seriously affected by Raynaud's or Scleroderma, it's crucial that they seek medical treatment and support as early as possible. We hope with our online test people can self-manage the condition better, seek treatment where necessary but above all know that they are not alone, we are here to support and assist people in coping with the painful and sometimes life-changing effects of the condition"

SRUK's test has revealed that 21% of users may have secondary Raynaud's, which means that the condition may be caused by an underlying medical condition. 1 in 100 people with Raynaud's will go on to develop scleroderma, an autoimmune condition where the body starts to attack itself by overproducing collagen. For scleroderma early diagnosis is imperative as further treatment and close monitoring may be needed.

For more information about Raynaud's and Scleroderma, the signs to look out for, how to manage symptoms and take SRUK's online test, go to www.sruk.co.uk/testme and download a Raynaud's information pack today.

For further information visit www.sruk.co.uk or call us on 020 3893 5998 or email: info@sruk.co.uk

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Notes to editors:

For more information, to arrange interviews with key spokespeople, to review case studies and for relevant imagery, please contact Tracey Spray on 07703 320803 or email tracey.spray@sruk.co.uk with your request.

#RaiseYourHands for Raynaud's Awareness Month

SRUK is tackling this lack of understanding by getting everyone affected to unite and #RaiseYourHands during February. During February we need you to raise your hands and help increase awareness and understanding of Raynaud's and why it is important that everyone know the signs and symptoms to look out for. For further information and how to get involved, visit www.sruk.co.uk/raiseyourhands

What is Scleroderma?

Scleroderma is a rare, chronic disease of the immune system, blood vessels and connective tissue. It is an autoimmune condition, meaning the immune system becomes overactive and attacks healthy tissue in the body. The name of the condition comes from the Greek, 'sclero' for hard, and 'derma' for skin. This hardening of the skin can be one of the first noticeable symptoms of the condition, as the body produces too much collagen. This excess of collagen can affect the skin, joints, tendons and internal organs. It causes scarring and stops the affected parts of the body from functioning normally.

Signs of Scleroderma

- Sore swollen fingers
- Raynaud's Phenomenon
- Reflux or Heartburn

What is Raynaud's?

Raynaud's phenomenon is a common condition thought to affect up to ten million people in the UK. In people who have Raynaud's, the small blood vessels in the extremities are over-sensitive to changes in temperature. This causes a Raynaud's attack where the fingers sometimes change colour, but not always, from white, to blue, to red. A Raynaud's attack can be a very uncomfortable, possibly painful, process. It can also make everyday tasks, like buttoning a jacket or unzipping a purse, very difficult. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose and nipples.

About SRUK

SRUK is tackling this lack of understanding by getting everyone affected to unite and #raise your hands during February.

Information at www.sruk.co.uk/raiseyourhands

- SRUK is the UK's only charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's
- We are a pioneering charity, formed by the merger of the Raynaud's & Scleroderma Association (RSA) and the Scleroderma Society in March 2016

- We're dedicated to providing the best support and care to people with the conditions, while spearheading research in to new treatments and ultimately looking for a cure

Other key findings from SRUK research includes:

- Despite being as common as hay fever and arthritis in the UK over three quarters of people have never heard of Raynaud's or don't know anything about the symptomsⁱ
- Misinformation is rife with 35% of people worried they could pass Raynaud's on, 43% concerned about passing on Scleroderma
- Worryingly, one in five and one in four peopleⁱⁱ would be afraid to touch someone with Raynaud's and Scleroderma respectively; roughly one in five peopleⁱⁱⁱ would be embarrassed to say they had the conditions

For further information visit www.sruk.co.uk or call us on 0207 000 1925

Email: info@sruk.co.uk



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ⁱ55% of people have not heard of Raynaud's and 24% have heard of it but know nothing about it

ⁱⁱ 20% of people would be scared to touch someone with Raynaud's and 24% of people someone with Scleroderma

ⁱⁱⁱ 18% of people would be embarrassed to say that they suffered from Raynaud's, 22% for scleroderma