Unite/CPHVA June 2016

CPHVA Charity of the Month

Scleroderma & Raynaud's UK

Welcome From Unite/CPHVA

I'm pleased to present to you our June CPHVA Charity of the Month member briefing from Scleroderma & Raynaud's UK. Although we are celebrating SRUK as our sixth #CPHVAcharity I want to thank colleagues from the charity for their support in developing the #CPHVAcharity scheme. They were on hand in 2015 to discuss the project and provide valuable advice to how we could support charities in 2016. Please help to support their work by reading this briefing, sharing with colleagues and joining in their #CPHVAtt on 14th June at 7pm.

Dave Munday, Professional officer, Unite in Health
@davidamunday

SCLERODERMA & RAYNAUD'S UK

Unite/CPHVA Member nomination: Jane Beach: "Not many people have heard about scleroderma or know what is involved in living with this debilitating condition. SRUK are doing exceptional work in trying to change this, as well as raising funding for important research. I feel it is important for our members to learn more about Scleroderma and Raynaud's and what support is available from the charity as they may know individuals and families who are affected."

@beach_jane

What do Unite/ CPHVA members need to know about Scleroderma & Raynaud's UK?

Scleroderma & Raynaud's UK (SRUK) is the only charity dedicated to improving the lives of people affected by Scleroderma and Raynaud's. We exist to improve awareness and understanding of these conditions, to support those affected, and ultimately to find a cure.

Despite approximately **1 in 6** people in the UK being affected by Raynaud's, awareness and understanding of the condition is very low. We are determined to change this through research and campaigning.

Our History

SRUK is **the 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. The merger has brought together the knowledge and passion of two charities to form a strong new organisation with the ambition to drive forward understanding and awareness of the conditions.

Our staff and volunteers currently provide emotional and practical support to **over 22,000 people in the UK** living with Scleroderma and Raynaud's and we have ambitious plans to expand our reach – with the ultimate aim of connecting with every person affected by the conditions.

CPHVAcharity

unite the UNION in HEALTH

What is Raynaud’s?

Raynaud’s phenomenon is a common condition thought to affect up to 10 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, from white, to blue, to red. Raynaud’s symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose and nipples.

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 words, ‘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. Scleroderma can cause physical disability and can be a life threatening condition.

Spotting the signs

There are two forms of Raynaud’s:

Primary Raynaud’s is usually a mild and manageable condition. People generally have no other symptoms and only occasionally go on to develop related problems. Symptoms of Primary Raynaud’s include, but are not limited to:

- Cold numb hands and or feet
- Hands that change colour from white to blue and then to red when the circulation returns (not everyone has all 3 colour changes)
- Tingling and discomfort
- Chilblains

Secondary Raynaud’s is where Raynaud’s is caused by another condition, usually an autoimmune disease like scleroderma or lupus. Secondary Raynaud’s needs more investigation and careful monitoring for complications like ulceration. Signs can include the above but also:

- Painful stiff and swollen joints
- Digital ulcers

Scleroderma

The link between Scleroderma and Raynaud’s, is that, although scleroderma is much less common, 95% of those with Scleroderma have Raynaud’s and for around 80% of those that have both conditions, Raynaud’s was their very first symptom. However, it is important to note that if you have Raynaud’s, it does not mean you will develop scleroderma.

If you know someone with Raynaud’s who also has joint pain or swelling, feels fatigued and/or has breathing difficulties or regular reflux or heartburn, make sure they go to their GP for a referral to a rheumatic specialist for some simple tests, in order to rule out any other underlying conditions.

51% of people don’t get diagnosed with scleroderma within 3 years so it’s imperative to spot the signs early in order to get a prognosis quicker.

The early warning signs are often there

SOre Swollen Fingers

RAynaud’s Phenomenon

REflux and Heartburn

Health Visitors Guide To Raynaud's In Breastfeeding Mothers

Caroline Goldstein, 35 from Bristol gave us her account of self-diagnosing Raynaud's when her first child was born.

"My first daughter was born in July 2011. It was not a warm summer, but then toward the end of August there was a noticeable drop in temperature. Living in a poorly-insulated Victorian house meant that we really felt the cold coming in. Still, when I started to have pain while feeding my baby, I didn't understand what it was."

Caroline, like many new mums, had a few little blips with trying to establish breastfeeding but eventually settled into it well. Despite this, during expressing milk in the evenings, she felt very uncomfortable and noticed that her nipples were dark purple.

"I dismissed this as engorgement due to the suction of the pumps" says Caroline "but over the next few days, I frequently felt pain shortly after feeding my daughter or expressing. It felt like very intense spasms in the tips of my nipples and when I thought to look at them, I noticed that they were white. I remember telling my husband about the colour changes, but it didn't occur to me what they meant. All I knew through the general new-parent fog was that it hurt badly enough that sometimes I couldn't help shouting with pain."

Back in 2011, Caroline duly sought medical advice at the health centre. They referred her to a GP who told her that pain during breastfeeding was either mastitis or thrush and it wasn't mastitis so it had to be thrush. Anti-fungal treatment didn't help so she returned to the health visitors and then the GP.

"I insisted on seeing a more experienced GP, which was a very fortunate decision. He said he had only come across this once before and this patient had been treated repeatedly for thrush for several months before losing patience. Finally it all fell into place: cold-induced spasmodic pain of an exposed extremity associated with triphasic colour changes can only add up to Raynaud's, which led to a prescription of Nifepidine."

"It never occurred to me that I would one day be discussing my nipples in public, much less talking about their colour-changing tendencies, but if doing this will raise awareness of a very painful but easily-fixed problem, then I will put my modesty aside and tell everyone I can about my patriotic red-white-and-blue nipples!"

Caroline had experienced Raynaud's in her hands and feet for years, although never had it formally diagnosed, but it never occurred to her that it could happen in the nipples.

"I have spoken to many women who have experienced pain due to breastfeeding, several of whom gave up breastfeeding. I have made a point of mentioning Raynaud's at any opportunity, since it is common but easily missed."

It is thought that many women have undiagnosed Raynaud's of the nipple, which is either mistreated as recurrent thrush or mastitis, causing mothers to take unnecessary antibiotics and often give up breastfeeding. Raynaud's is common, especially in women, so it is strange that so few people involved in caring for newborn babies and their mums seem to have come across it. It is important that women with Raynaud's know it could affect breastfeeding in this way.

"I would like to raise awareness among GPs and health visitors, so that when women seek help with pain due to breastfeeding, this should be something which is considered."

Handy Hints On Keeping Warm

For people affected by Raynaud's or who just feel the cold we have a specific leaflet intended to provide information on keeping warm. An attack will often be triggered by exposure to the cold, any slight changes in temperature or touching cold objects. Emotions, such as anxiety, may also play a part, as can smoking. Cold temperatures or even a slight change in temperature can cause a Raynaud's attack.

Below are a few hints and tips to help with staying warm and averting an attack:

1. Avoid touching cold surfaces and objects such as milk bottles.
2. Always wear insulated gloves before going into the fridge or freezer, silver fibre gloves are great for wearing around the home.
3. Don't have ice cold drinks straight from the fridge - they chill your core.
4. A hair dryer is useful for warming clothes and shoes before going out.
5. After a bath leave the water in while you dress - it will give off enough heat to keep you warm.
6. Use warm air hand dryers in public places to warm your hands when shopping.
7. Keep small heat packs on you ready to install in gloves or shoes in an instant.

Love Your Gloves

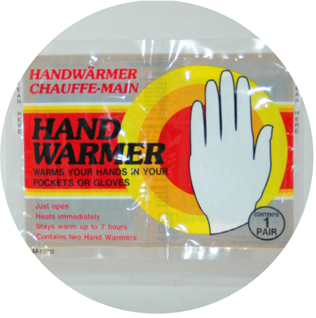
srukshop.co.uk is a charitable retailer where all profits go towards the great work of the charity.

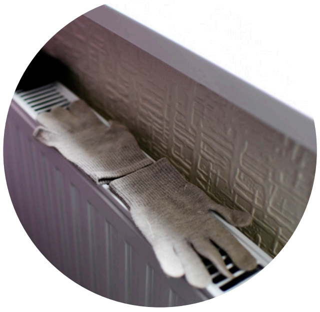
On this website you'll find products recommended by SRUK supporters that have been tried, tested and reviewed. We're bringing you some of the best products for people who have Scleroderma and Raynaud's, people who experience cold hands and feet or just have an active, outdoor or sporty lifestyle and want to stay warm!

From silver fibre gloves and socks, self heating hand and foot warmers, to handy gadgets to make the simplest tasks even easier. We also now have a choice of gifts for all the family with Heat holders Snuggle up blankets and gift sets, there is plenty to choose from, so shop today knowing your money is going towards a great cause.

Check out our website today and recommend us to anyone you believe could benefit from our products.

www.srukshop.co.uk





Raynaud's In Young Adults

Sally Millward, an Associate School Nurse in Redbridge covers around 20 schools in Ilford told us, "I have identified a couple of children with suspected Raynaud's who have gone on to be investigated further."

Sally, who has had Raynaud's since her teens understands first hand the challenges and how easy it is to mistake or simply ignore signs of Raynaud's. "I have had severe Raynaud's since the age of around 14/15. The moment I realised something was not quite right was when I was unable to pick up coins out of my purse due to my fingers being blue, numb and very painful. I remember it was the height of summer and other people were in shorts.

At the age of 18 when I had moved to London from Wiltshire to do my Nurse training, I went to see a new GP as I had a chest infection. He took one look at my blue hands and informed me that I needed to go directly to A&E. I explained that being an asthmatic for some time, that it was normal for me to have blue hands, I knew my chest infection was not severe enough to warrant A&E. The GP was deeply concerned and explained that the chest infection was "the least of my problems" and that if I didn't go straight to A&E I could "lose my hands".

"I went to see my GP who totally dismissed the problem and without any examination of my hands (or any other part of my body), simply said it was a "problem with circulation" and to "keep my hands warm". Therefore, I got used to wearing gloves all year round and thought little of it."

I was seen in Charing Cross Hospital triage, admitted and put on a heparin infusion immediately. Following that admission, where a full examination highlighted other abnormalities such as calcium on my fingers and elbows, I was later diagnosed with CREST syndrome (also known as Limited scleroderma). My example of Raynaud's went on to become something much more serious, so it should never be overlooked or not taken seriously.

"Children with Raynaud's don't just need to wear additional clothing during outside activities but may need to wear gloves during class sessions. Schools can be very stringent about rules and regulations and how they want pupils to dress, so this is where a School Nurse can assist. They can help mediate by outlining the child's requirements, in collaboration with parents and then negotiate with the school Governors' special dispensations, thereby ensuring that every one knows what the allowances are for that particular child."

CJ, age 13 from Sheffield had some issues with her school and her parents had a couple of meetings with the headmaster to discuss her challenges in the hope of support and care from them. "I get very cold, even in summer. I would want to wear gloves all the time if I could but I'm not allowed. I hate gym because I know it's going to be freezing and I'm not allowed to wear any extra clothes."

"CJ's condition is serious enough that we had to go in for a review with the Headmaster. They thought she was playing up and wanting to bend the rules for reasons like 'fashion' but what they didn't realise is that CJ wants to fit in, she doesn't want to be different, so hasn't spoken up before now." says Cindi, CJ's Mum. "Her condition is now so severe it cannot be ignored, we are worried about long term effects on her health and are glad we've been able to work with the school teachers to work on best measures for both".

For information and literature on the condition or for more on spotting the key signs, contact one of the team here at SRUK on 01270 872776.

SRUK Family Day

We're pleased to announce our first-ever Family Day which will be taking place this July in Birmingham on Saturday 2nd July, 10am – 4pm.

This will be a free event for parents of children and teenagers aged 16 and under, who have been diagnosed with Scleroderma and Raynaud's, and will provide informative sessions led by specialist medical professionals along with fun activities for children to take part in throughout the day.

The event will be bringing together families affected by Scleroderma and Raynaud's from across the country, providing a space for parents and children to chat and share stories, as well as receive invaluable information from the top paediatric specialists.

There will be entertainment on the day for the children, so they can meet one another and find friendship.

To find out more and book your free tickets please call our friendly team on 01270 872776.

Help At Hand

Many health professionals only see a handful of cases of Raynaud's and, due to scleroderma being such a rare condition, may never see even one case during their whole career. SRUK have developed a full range of resource literature on all aspects of Scleroderma and Raynaud's in both adults and children. Ranging from a Raynaud's Phenomenon leaflet and Handy Hints on keeping warm, to specific problems such as the affect of scleroderma in the skin, internal organs etc. A full list of publications is available to download from our website www.sruk.co.uk.

To receive your free literature pack simply send your details to info@sruk.co.uk

Going Like Hot Cakes

Wednesday 29th June

CPHVA members can help SRUK by joining in our Hot Cuppa & Cake morning on Wednesday 29th June and raise vital funds to support people affected by Scleroderma and Raynaud's.

Bring together your team, hold an event in your surgery, school or centre, enjoy a hot drink with some freshly baked cakes and raise money for SRUK.

Organising a Hot Cuppa & Cake morning is simple and we make it even easier with our fundraising pack.

Order your pack today by emailing us at fundraising@sruk.co.uk or calling our team on 01270 872776.

Keep In Touch

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Twitter Tuesday

Join in #CPHVAtt

Tuesday 14th June 2016
7:00-8:00PM

Don't miss the joint CPVHA Twitter Tuesday (#CPHVAtt) where Unite/ CPHVA will be joined by colleagues from Scleroderma & Raynaud's UK to discuss the work of the charity and update members further on what they need to know about both conditions.

http//www.unitetheunion.org/CPHVAtt