

CRPS UK Clinical & Research Network



ISSUE 4: December 2020

Welcome to the latest issue of our newsletter

“An especially warm 'Welcome' in these strange times. I do hope this newsletter finds you all well, and gives you a flavour of the warm and productive community that we belong to. I have greatly missed our face-to-face gatherings at conferences, ad hoc meetings and our annual get together as a Network but 2021 is looking hopeful for some of that to start to resume. I can't wait!

It is wonderful to see how, despite a very challenging year, members of our Network have continued to deliver new research, publications, and resources for people with CRPS and chronic pain. It is also great to see how the CRPS registry continues to grow and support our community. You will have received a separate email from Lisa inviting you to participate in a survey about how our registry develops in the future, and how we may want to work with, or alongside the planned international CRPS registry. Please do try to find the time to feedback your views to us via that survey. We really want to hear what you think.

My thanks as ever to Lisa for preparing this newsletter and for so calmly and efficiently keeping the CRPS Network and Registry moving along and growing. We would be lost without you Lisa!

Wishing you all the very best for the holiday season and I look forward to seeing you on February 8th for our virtual Network meeting. Sadly no cake and Rosario's lunch but lots of friendly faces!

Best wishes

Candy McCabe

**Chair of the CRPS UK
Clinical & Research Network**



Sharon Grieve has been successfully awarded her DPhil from the University of the West of England. Her thesis related to improving health outcomes in Complex Regional Pain Syndrome and informing chronic pain practice.

Karen Rodham has published a book entitled “**Self-Management for Persistent Pain: The Blame, Shame and Inflammation Game?**” This explores the problems with current pain self-management approaches, discusses how to improve self-management of chronic conditions and advocates for a more collaborative approach.

Research Update

Network members have published an impressive tally of at least 16 research papers and blogs over the past year:

- Five of these papers directly relate to studies that have used the UK Registry for recruitment, with topics focusing on sensory changes and behavioural intervention techniques
- Other CRPS-focused publications have explored the incidence of the condition after wrist fracture, the role of non-medical therapeutic approaches in rehabilitation, and the influence of pain management programme attendance on patients' decision making regarding treatment options
- A wide range of other pain-related topics have also been covered. These include persistent pain in adult cancer survivors, sensory disturbance in people with fibromyalgia, parental effects on how children manage chronic pain, and the management of hemiplegic shoulder pain that occurs after a stroke
- COVID-19 has offered the opportunity for additional reflection. **Karen Rodham** has written a blog called "**Some bubbles don't burst**", which looks at the impact of lockdown for people with pain.

Whilst the pandemic has inevitably meant that some research studies have been paused, others have been able to continue throughout this challenging time. One such example is **COMPACT**, which is an international feasibility study and is testing the acceptability of collecting data for CRPS clinical studies using a core measurement set. A total of 102 participants were successfully recruited across six different countries and researchers expect that data collection will be complete by early 2021. Alongside this, work has continued to agree the core clinical measures and these are being finalised. Findings from the study will inform the development of a new international clinical research registry for people with CRPS.

Other studies have needed to adapt with the changing situation. Researchers are testing a **Sensory Training System** for people with persistent limb pain. The participant undertakes the treatment themselves at home, so this is now being planned as a remote study with all contact from the study team taking place on a virtual or telephone basis.

Education Update

Prior to the pandemic, **Miriam Parkinson** was a guest speaker for the North West Surgical Hand Society and North West British Hand Therapy Annual Dinner. She gave a comprehensive talk on CRPS assessment and management, before leaving attendees with a question – “**On a scale of 0-10, how confident are you that you would not get CRPS after injury, and why?**” This led to an animated and at times eye-opening conversation!

Miriam is also the co-opted Director of Membership on the current Executive Committee for the British Association for Hand Therapists (BAHT). This role enables her to help raise awareness of CRPS at a national level.

Karen Rodham has been invited to drop in on the **patient-led charity CRPSUK** coffee mornings:

1. To explore coping with CRPS in lockdown
2. To explore coping with CRPS as we come out of lockdown
3. Coping with CRPS in the winter

She is currently working with the coffee morning group to share experiences and create a leaflet on this last topic.

Miriam Parkinson and **Sharon Gillespie** contributed to a live webinar in August entitled “**Complex Regional Pain Syndrome: Assessment, Prevention, Service Outcomes & Development**”, alongside international clinical academic Tara Packham.

This formed part of the BAHT’s ‘Demystifying the Difficult’ series, which has been a replacement for their 2020 conference.

Miriam presented on lessons learned from an audit that looked at local standards of CRPS practice in hand therapy, using the national guidelines published by the Royal College of Physicians.

Sharon Gillespie and **Fiona Cowell** contributed to “**Complex Regional Pain Syndrome: Physiotherapy is the Key**” at the Physiotherapy UK Virtual Conference in November. The focused symposium was presented under the Managing Complex Pain theme of this year’s event.

UK Registry Recruitment

Recruiting Centre	Number Recruited
Addenbrooke's, Cambridge	72
Craigavon, County Armagh	20
Derriford Hospital, Plymouth	34
Oxford Pain & Rehab Services	17
Royal Devon & Exeter Hospital	28
Royal United Hospitals Bath	388
Solent	8
The Walton Centre, Liverpool	48
University College London	2
	Total = 617

UK Registry Follow-up Data

Participants continue to be contacted annually by email or post and are asked to complete a brief follow-up questionnaire.

A total of 162 participants have responded to at least five of these questionnaires, whilst 50 have responded to eight or more requests.

As is natural for a long-term study, some participants have subsequently chosen to opt out of the Registry or are no longer contactable. However, the drop-out rate is generally low and currently stands at 7% after a 12 year recruitment period.

About the Network

The CRPS UK Clinical & Research Network is a research collaboration between a number of UK NHS Trusts and academic institutions with an interest in Complex Regional Pain Syndrome. We aim to raise awareness and understanding of the condition amongst health professionals, patients and the general public. We maintain a national CRPS Registry database as part of a long-term research study.

If you are a NHS health professional or an academic working in the field of CRPS, you can get involved either by:

- **Becoming a recruiting centre** and contributing patient data to the Registry. Ethical approval is required for this
- **Applying to use existing Registry data** or recruit patients for your own ethically approved research study. Applications will need to be considered by the Registry steering committee and a fee applies for accessing the data
- **Joining the CRPS Network** as a member. We meet annually, but keep in regular touch by email

Please contact us to find out more!

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