Introduction from the Chair

A very warm welcome to our annual newsletter. Sincere thanks as always to Lisa Buckle for all of her hard work in putting this together.

In the Autumn of 2003 the international CRPS community convened in Budapest in order to consider the diagnostic criteria for CRPS. The work conducted over those two days ultimately became the Budapest Diagnostic criteria, which are now recognised by IASP as the official CRPS diagnostic criteria. In 2003 the CRPS research community was of the size where I, as a doctoral student at that time, knew the ten or so names of the leading clinical academics and of note, only one was a woman, Professor Anne-Louise Oaklander from Harvard Medical School. It was easy to keep abreast of new CRPS research, as so few relevant papers were published each year. Our international meetings struggled to find new research to present because the doctoral student numbers were so few. People with CRPS were research participants only, rather than also being members of the research team where they could help inform the design and conduct of a study.

What struck me, reading this year’s newsletter is how much things have changed since 2003. The volume and breadth of CRPS clinical research presented here is extraordinary, and this is just within the UK. We now have an ever-growing number of highly successful doctoral students working in this field, lots of outstanding female and male clinical academic leaders and an ever expanding international community of patients and healthcare professionals working together to advance our understanding of CRPS.

In September of this year, the CRPS international community met again to discuss the current Budapest diagnostic criteria. Led by Dr Andreas Goebel we considered what works and what doesn’t work with these criteria, and how we can make adjustments to the current text to ensure greater clarity and reproducibility. The results of those discussions will be published in due course. I believe that a doctoral student attending that meeting in Valencia would feel they had arrived into a very large, productive and vibrant community of international researchers, and their reading list of published research would never be complete!

Enjoy the read, and please do keep sharing with us all of your activities.

Best wishes

Candy McCabe
Chair of the CRPS UK Clinical & Research Network
Fiona Cowell and Sharon Gillespie were invited to present “CRPS assist” at the 2019 11th Congress of the European Pain Federation EFIC in Valencia, Spain. This is a free CRPS app for physiotherapists in Europe, targeting those who have little or no experience of the condition. It empowers safe, effective diagnosis and management. The app structure and content was created for EFIC by Fiona and Sharon, along with fellow Network member Dr Andreas Goebel and their colleague Selina Johnson from the Walton Centre in Liverpool.

Dr Nick Shenker was an invited presenter at two events; the Royal College of Psychiatrist’s Annual Liaison Psychiatry Conference, and the Versus Arthritis National Pain Data Group.

Following the successful International Association for the Study of Pain Cork 2017 conference, Dr Dominic Hegarty has been busy setting up the new CRPS Forum Cork website.

The website is aimed at providing support for people with CRPS and their healthcare providers. Features include a clinical screening tool, posters, and a Keep Moving-Keep Using hand exercise video.

http://crpsforumcork.com

Congratulations to Sharon Grieve, who has been appointed to the role of NIHR 70@70 Senior Research Nurse, following a competitive process. This is a three year programme, funded by the National Institute for Health Research (NIHR). It will champion research, innovate and drive improvements in future care. The programme aims to raise the profile of research amongst nurses and midwives.

Professor Candy McCabe was a keynote speaker at the European Pain Federation (EFIC) Congress in Valencia, presenting the David Niv Lecture. She was also an invited speaker to the NIHR Cambridge Biomedical Research Council Distinguished Visitors Lecture Series.
Congratulations to Dr Janet Bultitude, who won an award from the University of Bath for her leadership in engaging people outside of academia in research. She has also been invited as one of three keynote speakers at the 40th annual meeting of the Australian Pain Society in April 2020. Media engagements have included interviews on Good Morning America, BBC Radio Wiltshire and a written piece for The Psychologist (the monthly magazine of the British Psychological Society).

Monika Halicka has been presenting the results of her randomised controlled trial of sensorimotor treatment for CRPS, conducted at the University of Bath, to different clinical groups around the country. She will also present to people with CRPS and their families at an annual patient conference in Bristol.

Going forward, Monika will be preparing her PhD research for publication, before taking up a new job as Postdoctoral Research Associate at the University of Liverpool in March 2020. Many congratulations and we wish her well in her future career.

Funding has been awarded to the University of Cambridge to study EEG changes in volunteers and people with CRPS. Dr Shenker was a mentor to Elsje de Villiers’ successful application for a Pre-doctoral Bridging Programme, relating to a study using Virtual Environments as a rehabilitation tool for patients with Motor Neglect.

The Royal United Hospitals Bath NHS Foundation Trust were awarded funds to support the bid writing of an NIHR Research for Patient Benefit application. This is looking at establishing evidence-based management of CRPS to improve clinical outcomes.

Axel Vittersø (University of Bath) won the Best Oral Presentation award at the GW4 Early Career Neuroscientist Day in Exeter. It was awarded by the University of Bristol’s Elizabeth Blackwell Institute for Health Research for his talk entitled “Representations of the body and peripersonal space during tool-use in Complex Regional Pain Syndrome”.

Monika Halicka (University of Bath) was awarded a prize for the methodological sophistication of her research on sensory changes in CRPS that she presented in a poster at the Pain Research Meeting in Brussels.

Alison Llewellyn (University of the West of England) was awarded the best staff poster, relating to understanding the biopsychosocial aspects of living with CRPS, at the University’s Centre for Health and Clinical Research Conference in Bristol.
University of Bath

Over the past year, a group of researchers have finished data collection for three studies that recruited participants through the Registry. All three studies will shortly be submitted to journals for publication:

- **Why many people with CRPS perceive their affected limb differently.** This study focused on understanding why the feelings that a CRPS-affected limb is an unusual shape or size seems to persist rather than go back to normal. Sensory tests indicated how the arms were perceived during a task using a tool similar to a golf club. Researchers found that the perceived size of arms was more likely to change for people with CRPS than for people without any pain.

- **Bodily changes and sensory sensitivity in CRPS and fibromyalgia.** People with CRPS, fibromyalgia, other chronic pain conditions and pain-free controls were asked to complete a survey. This contained questions on the symptoms of their condition, sensory sensitivity and bodily changes. Results showed that people with fibromyalgia or CRPS report these changes more often than those with other chronic pain disorders. People with CRPS plus fibromyalgia had minimal additional symptoms.

- **CRPS PRISMA trial: Pain Reduction by Inducing Sensory-Motor Adaptation.** This study involved testing use of a prism adaptation treatment for upper limb CRPS and was supported by the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA). It showed that two weeks of prism treatment did not reduce pain or CRPS symptom severity more than the control treatment.
Royal United Hospitals Bath

- **COMPACT-Q**: a multi-centre study to explore the feasibility and acceptability of collecting data for complex regional pain syndrome clinical studies using a core measurement set.

  COMPACT is the acronym for Core Outcome Measurement set for complex regional Pain syndrome Clinical Studies. This international study is testing how practical it is to collect research data from patients with CRPS, using a core set of questionnaires (COMPACT). An electronic data capture system is also being tested to collect and manage the data. Eight international research centres are taking part in this study, which is funded by the Swiss National Accident Insurance Fund (SUVA). Bath is the lead centre.

  Patients are asked to complete the set of questionnaires on two occasions, six months apart. The first questionnaire is completed on paper. The second can be completed on paper or electronically. On the second occasion, patients are invited to complete a questionnaire to provide feedback on their experience of completing COMPACT. Clinicians will use an electronic questionnaire to feed back their experience of data collection.

  The study protocol was recently published in the journal Musculoskeletal Care. The results of this study will inform the final version of COMPACT and the data collection process, which will be recommended for use in future CRPS studies. Using COMPACT in the future will make it easier to compare data across studies. This has long-term importance for the advancement of our understanding and treatment of CRPS.

- **COMPACT-C**: a Delphi study to define internationally agreed core clinical outcome measures for Complex Regional Pain Syndrome clinical research studies.

  This international study complements the previous work undertaken to agree the minimum set of questionnaires (COMPACT) for use in future CRPS clinical studies. It is funded by a grant from the RSDSA.

  Clinicians, researchers and other professionals with an expertise in CRPS were asked to complete two rounds of an electronic survey. They were asked to review a list of clinical outcomes that we know are currently used in CRPS research, and to rate the scientific relevance of each one in relation to the question: What is the clinical presentation and course of CRPS, and what factors influence it?

  The results were presented at a meeting with the study co-applicants in September 2019. Suggestions from the resulting discussion are now being reviewed and will inform a minimum core clinician-reported dataset.
Collectively, Network members have published at least 10 CRPS-related papers over the past year. These cover a diverse range of topic areas, focusing on novel therapeutic techniques, patient experience, treatment standards and guidelines. Our research has also been presented as poster or oral abstracts at various regional, national and international conferences. For full details of all studies and publications, please visit our Network website: [https://crpsnetworkuk.org](https://crpsnetworkuk.org)
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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