A very warm ‘welcome’ to our special edition newsletter to mark the 10th Anniversary of the CRPS UK Clinical and Research Network.

This network was started in 2008 because a small group of clinicians and academics felt passionate about trying to improve the care of people with the potentially life changing condition of Complex Regional Pain Syndrome. We were frustrated by the lack of progress in our understanding of the causes and course of CRPS, and the very limited treatments for CRPS. As a group we believed that by working more closely together we would achieve more. Importantly we were friends as well as colleagues. Communicating regularly with each other was an added benefit of the Network we established. Along the way we have been delighted to welcome new members but friendship, support and a desire to do the best for the people we see in our clinics remains at the heart of our Network.

Over the past ten years the Network community have guided and supported new researchers, and seen the ‘founding members’ progress to senior roles in their careers. We have also published new patient information literature, and celebrated new research funding awards and publications. This activity has been the bustling background to the two largest achievements of our Network: 1. the formation of a national Registry of people with CRPS, and, 2. the publication of the Royal College of Physicians UK Clinical Guidelines on CRPS. We are all immensely proud of these achievements as they have certainly raised the profile of CRPS nationally and internationally. We are greatly indebted to the people with CRPS who have worked with us on these projects. They have helped ensure that our work is focused on the things that matter most to patients.

Ten years is a significant milestone but people with CRPS still spend far too long waiting for a diagnosis, we still do not know the cause and course of CRPS, and we still have limited treatment options. In the next ten years our UK Registry will join with a new International CRPS Registry. This will enable us to work as a global clinical, academic, and patient community. I am hoping this will dramatically escalate our progress in working towards a cure for CRPS.

None of the above would have been possible without the hard work, professionalism and unlimited patience of the three Network Administrators we have been fortunate to have working with us over the last ten years: Yvette Hibberd, Lindsay Davies, and Lisa Buckle. These unsung heroines have kept ‘the show on the road’ and we would have been adrift without them. I would like to say a particular ‘thank you’ to Lisa for putting together this celebratory Newsletter. I hope you enjoy the read and join us again for our future Newsletters.

Candy McCabe
Chair, CRPS UK Clinical and Research Network

Inside this issue:
- Registry Update
- Education Events and Conferences
- UK Guidelines: Revised Edition & Launch
- A Brief History of the CRPS Registry
- Network Research Studies
- Our Members’ Additional Research
- About the Network & Contact Details
The UK Registry currently holds a total of 551 records. 505 people have been recruited onto the Registry more than a year ago, with 81% of these responding to a minimum of one follow-up. At least five years’ worth of follow-up data is available for 24% of these patients.

As is natural for a long-term study, some people choose to opt out of the Registry after a time or may no longer be contacted due to a change in circumstances. However, the drop out rate for the Registry is generally low and currently stands at only 5.8% after a total of 10 years recruitment.

Our main recruitment site is in Bath, but other centres around the UK also contribute valuable data.

<table>
<thead>
<tr>
<th>Recruiting Site</th>
<th>No. Recruited</th>
<th>Last Recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal National Hospital for Rheumatic Diseases, Bath</td>
<td>349</td>
<td>October 2018</td>
</tr>
<tr>
<td>Addenbrooke’s, Cambridge</td>
<td>72</td>
<td>November 2016</td>
</tr>
<tr>
<td>The Walton Centre, Liverpool</td>
<td>38</td>
<td>May 2015</td>
</tr>
<tr>
<td>Derriford Hospital, Plymouth</td>
<td>34</td>
<td>June 2013</td>
</tr>
<tr>
<td>Royal Devon &amp; Exeter Hospital</td>
<td>25</td>
<td>June 2016</td>
</tr>
<tr>
<td>Craigavon, County Armagh</td>
<td>12</td>
<td>July 2016</td>
</tr>
<tr>
<td>Oxford Pain &amp; Rehab Services</td>
<td>11</td>
<td>October 2018</td>
</tr>
<tr>
<td>Solent</td>
<td>8</td>
<td>March 2017</td>
</tr>
<tr>
<td>University College London</td>
<td>2</td>
<td>January 2013</td>
</tr>
<tr>
<td><strong>Total = 551</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Registry Update**

**Education Events and Conferences**

**Award Winners!**

Huge congratulations go to Network member Dr Dominic Hegarty who was one of the lead organisers of the CRPS Cork 2017 conference, which was run by the International Study for the Association of Pain CRPS Specialist Interest Group.

The event won the ‘Best International Association Conference’ award from Fáilte, Ireland. It was also commended as Best Medical Education Meeting at the Irish Healthcare Awards 2018.

The North British Pain Association hosted a successful study day in Edinburgh in 2017. Four members of the CRPS Network were invited as speakers, with approximately 100 people attending the event.

In May 2018, the British Society for Rheumatology’s Annual Conference took place in Liverpool. Dr Richard Haigh gave a presentation on behalf of the CRPS Network, as part of the Pain Special Interest Group session. This gave a brief overview of the Network and the UK Registry, as well as information about the research studies that have benefited from using Registry data.

We have previously held several 2 or 3 day conferences, focusing on updates in recent scientific advances. More recently, smaller scale study days have been organised in collaboration with the CRPS Network. These have offered opportunities for health professionals to learn a range of new techniques for the management of CRPS, which they can then put into practice within their own teams. Members of the Network also attend a variety of regional, national and international conferences – either as invited speakers or to present findings from our own research.
CRPS in Adults UK Guidelines for Diagnosis, Referral and Management in Primary and Secondary Care - 2018 Revised Edition and Launch

In 2012, Dr Andreas Goebel and Dr Chris Barker initiated the development of a national guidelines document for CRPS. A UK panel of experts representing a variety of healthcare professions were involved in creating this nationally important manual for the diagnosis, referral and management of the condition. The guidelines were endorsed and published by the Royal College of Physicians, alongside many other professional organisations.

Fast forward to July 2018, which saw the publication of the revised second edition. Members of the original development panel, along with some new faces, were involved in updating information to reflect current practice and research. The two patient-led charities, CRPS UK and Burning Nights, assisted with reviewing the section regarding long-term support.

The 2018 guidelines were officially launched at the House of Commons on 23rd July, with an afternoon reception hosted by Iain Stewart MP. Representatives from the relevant organisations and charities attended this prestigious event, with a media release being issued on the day.

Ruth George MP was also in attendance, who herself held a successful Parliamentary debate regarding CRPS this year and is working hard to raise the profile of the condition.

On behalf of the CRPS Network, our sincere thanks go to the Royal College of Physicians, the Pain Relief Foundation and Abbot Healthcare for helping to organise and sponsor the launch of these guidelines. Thanks also to Iain Stewart MP and the House of Commons Events Team for making the day a great success.

A copy of the 2018 guidelines can be downloaded from the CRPS Network website, or via the Royal College of Physicians: https://www.rcplondon.ac.uk/guidelines-policy/complex-regional-pain-syndrome-adults

“The 2018 version of the guidelines underlines the need for multidisciplinary support to manage CRPS.”

The 2018 version of the guidelines underlines the need for multidisciplinary support to manage CRPS. It also outlines the ‘four pillars of care’:

- Education
- Pain relief
- Physical rehabilitation
- Psychological intervention

However, more research is still needed into the causes of CRPS and other chronic pain conditions.
A Brief History of the CRPS Registry (part 1)

**2006 – 2008**
A group of specialists representing UK centres for CRPS research and clinical care established the CRPS UK Clinical & Research Network. One of the key aims of the Network was to develop a Registry to encourage collaborative research projects in CRPS and link this to patient care in clinics.

**19th September 2008**
The National Registry for patients with Complex Regional Pain Syndrome was given ethical approval, as a 35 year long-term research study. This allowed approved centres around the UK to contribute data to the Registry using a secure online database system.

**September 2009**
One year on, the Registry had 3 sites actively recruiting patients (Cambridge, Liverpool and Bath), with another two ready to join. Recruited patients were being asked to complete a follow-up questionnaire once a year, to record the ongoing progress and impact of their condition on their lives.

**2010-2011**
Within two years of being established, the Registry held approximately 120 records and had 5 specialist recruiting sites.

A regulatory process was set up that allowed the Registry to be used by approved NHS or University-based researchers to recruit for their own studies.

**2012**
The first application to use Registry data was approved.
A Brief History of the CRPS Registry (part 2)

2013
The CRPS Network website was launched. The Registry now held approximately 270 records, through 7 different recruiting sites.

2014
The first research paper about the value of the UK Registry was published in the British Journal of Pain. The paper concluded that the Registry was “actively recruiting well-characterised patients with CRPS to provide further information on the long-term outcome ……. most continue to have ongoing symptoms and signs of the condition. Analysis demonstrates a well-validated cohort of patients who are willing to engage in being followed up”.

2015-2016
3 further recruiting sites were approved, bringing the total to 10. The Registry held between 350 and 400 patient records. The CRPS Network twitter account was established.

2017
Numbers of Registry patients continued to increase, reaching close to 500 by the end of the year.

2018
After 10 years, the CRPS Network has approximately 40 members and the Registry now holds over 550 records. Follow-up data of at least 5 years duration is held on around 120 patients. A total of 8 different studies have been supported by the Network and Registry so far.

The work of the Network and Registry continues ...........
what will the next 10 years bring?
Network Research Studies

**International Recovery Study**
This study ran from 2012-15, with recruitment of people with CRPS from the Registry during 2013-14. A total of 8 different countries in Europe and North America took part. Participants were asked to complete questionnaires and then rank a set of statements defining recovery into order of importance. This helped the researchers and healthcare professionals to understand what treatment outcomes are important from the patients’ perspective. A paper outlining the findings of the research was published in 2017.

**LIPS Study**
This explored the effectiveness of a new low-dose immunoglobulin treatment in reducing pain for people with moderate to severe CRPS. The study started in 2013-14 and involved 7 specialist pain centres in England and Scotland. A research paper was published in 2017.

**MIRAGE**
Recruitment via the Registry took place in 2013-14. The study explored the effectiveness of using visual illusions that change the size and shape of the CRPS-affected hand to provide pain relief. A virtual reality system was used to create the illusions and test whether repeated exposure had a lasting effect in reducing body perception disturbance. The findings have been analysed and a paper has been submitted for publication.

**COMPACT**
This international project commenced in 2013 and involves researchers all over the world. The first stage recommended an agreed minimum core set of outcome measures for use in all CRPS clinical studies, with a resulting paper being published in 2017. The next two stages are a feasibility study to test collecting patient data using these outcome measures, plus an extension of the recommendations to include clinical measures.

**GEN-PAIN**
Participants were recruited from the Registry in 2014-15. Genetic research is being used (through questionnaires and DNA samples) to look for variations in people who have chronic pain, including those with CRPS.

**Sensorimotor Training**
Recruitment commenced in 2017. Computerised tests and questionnaires are used to explore whether movement therapy can help to relieve pain in people with CRPS.

**CoRe**
This study investigated brain changes in people with CRPS to see whether there is a link with the inability to perceive body sensations accurately. Recruitment took place during 2018. In order to look at brain activity and structure, the study involved a mix of questionnaires, clinical tests, EEG and MRI scans.

**Investigating Brain Networks**
Building on the work already undertaken via the MIRAGE study, this will specifically look at brain activity when someone is experiencing a visual illusion. Recruitment has started in 2018 and the study will compare people with CRPS or osteoarthritis, in addition to healthy volunteers. Use of the MIRAGE virtual reality system, MRI scans and questionnaires will help the researchers to understand more about the brain networks that are related to pain.
# A Snapshot of Our Members’ Additional Research

## 2008-2010
- Exploring how people with CRPS used an online message forum. The study found that it was used as a support resource (both those looking for support and those offering it). Some messages also revealed unrealistic hopes, which helped the researchers to change practice and ensure that people with CRPS were given clearer guidance and what was and was not realistic.

## 2011-2014
- Talking to people who support a relative or friend who is living with CRPS, in order to find out what it was like for them as they tried to make sense of their loved one’s experiences.
- Learning more about patients’ experiences of returning home following a hospital rehabilitation programme and what barriers they faced.
- Asking patients what advice they would give to someone else who was living with CRPS. Many useful tips about putting ‘CRPS second and life first’ were identified.
- A short book explaining what CRPS is and what it is like to live with the condition. The book includes case studies and coping strategies used.
- Randomised controlled trial looking at arm pain treatment options.
- Medical advisory role for a modern theatrical piece developed by a person living with CRPS.

## 2015-2018
- The experiences and attitudes of Emergency Department staff towards people arriving at A&E with chronic pain. This study found that the staff were frustrated, not with the people with chronic pain, but with the system.
- European-based study relating to the drug bisphosphonate.
- Publication of information leaflets to meet support needs. These were co-created with people living with CRPS.
- Comparing limb perception in people with CRPS and pain-free participants.
- Recommendations for clinical practice in reducing the risk of CRPS following a fracture.
- Development of a sensory discrimination training device to help reduce pain in people living with CRPS.
- Using sound to manipulate body image perception.
- Audit work on rapid access pathways and the management of acute CRPS.
- Use of pain portraits - asking patients to draw, name and describe their pain before and after treatment on a pain management programme.

For more information on all of our research projects and links to published papers, please visit our website www.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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