

CRPS UK Clinical & Research Network

ISSUE 01 – September 2016



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Registry Update

We currently hold 400 patient records on the CRPS UK Registry database. Patients are recruited via 11 different hospitals and NHS Trusts across the UK. During 2015 we have welcomed three new recruiting sites: Solent (incorporating Southampton and Portsmouth), Oxford, and Craigavon (Northern Ireland). An application from West Hertfordshire is in progress.

RNHRD = 260 records (latest added Aug 2016)

The Walton Centre = 38 (latest added in 2015)

Derriford = 34 (latest added in 2013)

Addenbrookes = 25 (latest added in 2009)

Royal Devon & Exeter = 21 (latest added Aug 2016)

Craigavon = 13 (latest added July 2016)

Solent = 7 (latest added May 2016)

UCL = 2 (latest added in 2013)

RNOH Stanmore = 0

Oxford = 0

Welcome to the First CRPS Network Newsletter

The CRPS UK Clinical & Research Network was established in 2006 and is a research collaboration between NHS Trusts and academic organisations with a specialist interest in Complex Regional Pain Syndrome. In 2008, the Network set up the CRPS UK Registry database, which is the only national research database for this condition. This newsletter will provide regular updates and news of the Registry, Network and other CRPS-related information.

If you are interested in becoming a recruiting site, please visit the Registry section of our website: www.crpsnetworkuk.org.

CRPS Network UK 2016 Conference

Clinical & Scientific Advances in Complex Regional Pain Syndrome

Thursday 10th—Friday 11th November 2016

Bailbrook House Hotel, Bath

Registration fee: £275

The focus of this year's Network conference is managing longstanding CRPS, with the programme offering an informative and interactive mix of plenary lectures and workshops.

Topics being covered include:

- Current and future advances in treatment
- Managing refractory CRPS in primary care
- Immune abnormalities and therapies
- Medico-legal debate
- Sensory/perceptual changes
- Practical management of CRPS in the pain clinic
- Central psychophysiology of anxiety, chronic pain and CRPS
- Paediatric CRPS
- Post-Traumatic Stress Disorder and CRPS
- How clinicians can better interpret evidence related to treatment efficacy
- Intimacy issues: how to return to a physical relationship
- How to set up a rapid access CRPS clinic
- Challenging perceptions in CRPS rehabilitation
- 'Question Time style' session re the current provision of care across Europe for CRPS

Keynote speaker:

- Mr Iain Stewart MP (founding member of the All Party Parliamentary Group for CRPS)

Book Your Place Now!

Places are still available, so please visit the events page of our website for more information and to register for the conference. If you have been invited to speak or run a workshop, then you will be individually advised of your registration arrangements.

Poster abstract submissions are also encouraged and a prize will be awarded for the best presentation. Full details are available on our website.

**** Abstract submission deadline extended to Friday 30th September ****



www.crpsnetworkuk.org/Events.php

www.aesculap-academia.co.uk



CRPS Patient Charities Success

Two UK patient-led organisations have been awarded fully registered charity status during 2016.

CRPS UK provide information and support to people with CRPS. They also aim to improve research, diagnosis and treatment, as well as promote awareness of CRPS in primary care. They have an active Facebook support group, which is accessible to members. For more information, please visit their website:

www.crps-uk.org

Burning Nights also offers detailed information and support for people with CRPS, their families and friends. They aim to improve the quality of life for people with CRPS and increase knowledge of the condition on a national and international level. A discussion forum and branded merchandise are available via their website:

www.burningnightscrps.org

Congratulations to both organisations for their achievements!

All Party Parliamentary Group for CRPS

All Party Parliamentary Groups (APPGs) are informal cross-party groups that are run by and for Members of the Commons and Lords.

The APPG for CRPS was established in October 2015 and is chaired by Mr Iain Stewart MP. It was set up to raise awareness of the condition among parliamentarians and lobby the government for increased funding for better research and understanding. They will also support other organisations and groups in the UK who are working to achieve similar objectives.

Attendance at some meetings is restricted to parliamentary members, whilst others will be accessible to Network members and expert patients. Details of open meetings will be circulated to Network members as and when they are available.

CRPS Registry Projects

CRPS UK Registry data has been used to recruit patients for a number of different research studies and clinical trials. These include a study defining patients definition of recovery, a genetic pain study, and research relating to treatment of CRPS through the use of visual illusions.

The data held on the Registry can be accessed by any study, providing that an application is approved by the Registry Steering Committee.

Information on how to apply to access the data is available via the Registry section of our website.

Get in Touch with the CRPS Network

Visit our website: www.crpsnetworkuk.org

Look out for changes to the website coming soon.....

Follow us on Twitter: @CrpsN

Contact the CRPS Network Administrator:

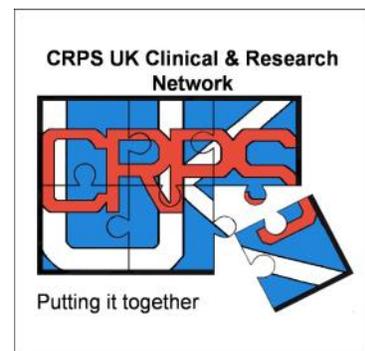
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Next Network Committee Meeting:

Wednesday 18th January 2017;

10.30am-3.30pm, RNHRD, Bath