

## SPECIAL EDITION

## NEW PATIENT INFORMATION BOOKLETS

Welcome to a special 6 page edition of the RSD UK Newsletter. We decided to do a mega-issue due to the last issue not being posted out (time/resource constraints) and only being available on the RSD UK website (under news). In this issue we look at fundraising, what is happening in research and services for RSD/CRPS and invite all our readers to consider submitting articles for publication. If you have any feedback we would be happy to hear from you by letter phone or email.

RSD UK and The Neuroscience Research Team at The Royal National Hospital for Rheumatic Diseases in Bath have been working together on a new patient information booklet. Catherine, from RSD UK, has been assessing feedback from the RSD UK Information & Support Line, from email contacts and the online forums with regards to information patients would like to have received at the time of diagnosis. The feedback was assessed then used alongside previous publications and experiences from the Neuroscience Researchers in Bath.



The end result is the enclosed 12 page booklet covering many topics, including signs & symptoms, prognosis and treatments. Most pages include quotes from RSD/CRPS patients; we included these because many patients wanted to hear others' experiences. We are unable to post booklets overseas, however a copy can be downloaded from the website at <http://www.rsd-crps.co.uk/rsdukleaflet.pdf>.

Many thanks to Medtronic who sponsored the full cost of printing the booklets.

## NEW CONTACT DETAILS

Please note that the contact details for RSD UK have changed.

**0845 22 66 008** calls are charged at local rates and the line is open 10:00-

16:00 weekdays. Please note: the helpline is run by volunteers and it isn't possible to have someone available to answer the calls all the time. If you can't get through or hear the answer phone please try again later or the next working day.



**Postal Address:** RSD UK,  
PO Box 7929, Oakham LE15  
7WW

### Website:

<http://www.rsd-crps.co.uk>

### Online forums:

<http://www.rsd-crps.co.uk/phpBB2>

### Email:

For conference information, to order a Patient Information Booklet or purchase merchandise please email Barry—[barry@rsd-crps.co.uk](mailto:barry@rsd-crps.co.uk) and for all other enquiries please email Catherine—[catherine@rsd-crps.co.uk](mailto:catherine@rsd-crps.co.uk)

Please allow 7 days for email replies and 7-10 days for postal information to arrive, we respond as quickly as possible to all contacts.

## THE RSD UK MOBILE PHONE CHALLENGE

Are you tough enough to take up the mobile challenge? Do you have any old mobile phones hanging around? Can you ask friends, relatives, colleagues—anyone you know to donate redundant mobile phones and/or accessories and ask if they can pass on the request for mobiles further a field.

Each mobile phone and each accessory can raise £4.00 towards our funds. If every person receiving this letter sends one phone RSD UK would receive **£5,600** and if every person sent in four the total would rise to a staggering **£22,400**.

**There is a £100 prize for the person sending in the most phones and/or accessories before 31st December 2005 ~ the winner will be notified by post. Please send all phones in one batch and use the tear off slip (page 6) to enter the competition.**

## YOUR CHALLENGE?

**TO HELP US RAISE £10,000 BY JANUARY 2006!**

## LOCAL MEETINGS—ARRANGING AND BEING INFORMED

Many RSD UK members, new and old, have arranged local meetings in various venues around the UK. The meetings have been very successful and to date have been held in Kent, Plymouth, Stirling, Lincoln, Sheffield, Leeds, Huddersfield & Birmingham to name a few. The meetings are informal and are usually held in a pub, restaurant or the eating-type places in large shopping complexes where it is easy to grab a bite to eat and a drink.

If you are interested in arranging a local meeting for your district please give Catherine a call on the low-rate number and she will help you advertise your social meeting. If you would like to be notified of future meetings in your locality please let Catherine know and she can put you on a mailing list. When future get-togethers are planned a letter will be posted to all those in the region of the planned event giving details about dates, times, venues and a contact phone number.

**CALLING THE HELPLINE:** If your call diverts straight to the answer phone it means the line is engaged, please try again later. We are unable to accept messages left on the answer phone due to a quirk with the operator, so please try again later. We try our best to answer calls during the stated hours but please remember volunteers also have RSD/CRPS and may be unable to get to the phone for some reason.

## 2005 RSD UK Conference ~ September 17th, Wakefield

The final planning for the 8th Conference for RSD/CRPS is underway and as ever there is much to look forward to. It is more than a weekend of presentations by professionals, it is a weekend to meet old friends and make new friends.

The weekend begins on the afternoon of Friday the 16th of September with leisurely drinks and chat in the lounge and bar areas. Many of you are meeting friends made at previous conferences or local meetings, but for others this is the first time they have met anyone else with the condition. Meeting others with the condition for the first time can be quite emotional and often people describe this meeting as “overwhelming” because suddenly there **IS** someone else that has the same condition, they **DO** understand and they don’t need explanations of how you feel.

### SPEAKERS:

As ever we can’t give a final list of speakers until the event. The nature of the speakers’ careers means that they may have to cancel last minute. To date speakers include Professor David Blake (Patron of RSD UK), Dr Lance McCracken, Psychologist, Dr Rachel Gorodkin, ARC research Fellow, Holly Wilkins, Disability Rights Commission, Mr Tollafield, Podiatric Surgeon & Sally Wormesley. More to follow!

### THE WEEKEND EVENTS

**Friday** afternoon and evening—socialising and getting to know other delegates

**Saturday’s events** 9:30-17:30 (approx) presentations with breaks for coffee and lunch and question times. Prize Draw and Tombola.

**Saturday night** in the Ocean Suite, a private bar/room for events and socialising, a quiz and other social events organised by delegates.

**Sunday** morning breakfast, coffee and final farewells and home. Don’t forget to swap contact details!

### THE DELEGATES:

Those attending come from all walks of life and include patients, their family and/or friends, carers and medical professionals attend. If you are attending for the first time, want to know more about the weekend or want to attend but are nervous please give Catherine a call and she will go through the weekends events with you and arrange for someone to meet you when you arrive at the hotel. There is something for everyone so it is certainly worth attending.

## RSD UK ONLINE FORUMS

The RSD UK Online Forums are available to anyone with an interest in RSD/CRPS and can be found by going to <http://www.rsd-crps.co.uk/phpBB2>. Joining is simple, just click the “register” button and make an account—it is free and is accessible 24 hours a day. The forums are divided into categories with sections dealing with RSD/CRPS queries, health care teams, news and announcements and a “general chatter” section where members can chat about almost anything and relax with friends. There is a dedicated section to put our non-internet users in touch with other patients or families.

All messaging is done via the website. There are no emails and you can log in to your account on most public computers. If you go away you won’t come back to 100’s of emails as the messages are saved on the web pages. You can dip in to topics as and when you want and any unread messages since your last visit to the forum are highlighted. If you want to join in but feel apprehensive there is no need to worry, members are always ready to help our Newbie’s!

## NON-INTERNET USERS

Since RSD UK started we been putting members in touch with each other by telephone or snail mail. If you aren’t an internet user and would like to contact other patients or parents of RSD/CRPS children please let Catherine know and she will do her best to put you in touch with someone in similar circumstances. We can only put children in touch with each other with the full consent of the parents. However, we can and do put parents in touch with other parents. Contacting other patients may lessen the isolation felt.

## PODIATRIC SURGEON CONFERENCE—GRANTHAM MARCH 2005

During a conference for podiatric surgeons in Grantham earlier in the year a full afternoon seminar on RSD/CRPS took place. The sessions were well attended and included presentations on diagnosing the condition, where to refer the patient to and on-going treatment & support for the patient. Actress, Sally Wormesley performed three sketches with the aid of a “volunteer” to show difficulties in communications when faced with an unusual condition—this was well received by the delegates. Catherine Taylor gave a presentation on behalf of RSD UK to give the perspective of the patient and how the Charity are involved with patients. Following the conference 4 Podiatric Surgeons rang for information and four patients were subsequently diagnosed with the condition. Delegates were given RSD UK contact details and booklets.

We would like thank to Podiatric Surgeon Mr David Tollafield for arranging and hosting the seminar on RSD/CRPS. Not only did Mr Tollafield spend a lot of time researching the condition to make the afternoon useful, informative and fun he also donated his fee for chairing the event. This very generous gesture is appreciated by all at RSD UK.

## CONGRATULATIONS ~ BATH CRPS TEAM WIN NATIONAL AWARD

At the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath is an enthusiastic and innovative team of medical professionals working with RSD/CRPS patients referred from all over the UK.

The British Society for Rheumatology held a competition open to all 1,000 practicing physicians in the UK looking for the team providing best working practices and innovative approaches to patient care and research. All entrants were also judged on availability of services elsewhere and resource implications; and outcomes.

The Team won the award for services and research that have already been established; they work to a carefully tailored and a well established treatment protocol taking patients through a “care pathway” for best outcome for the patient. Within the team are professionals from many different specialties; each with their own experience and knowledge to input which leads to effective patient care. Patients feel understood, believed and are encouraged to take a very active role in their treatment and recovery.

The team members are actively involved in various research projects including work on the “mirror therapy” treatment and the DiPEX project. Because they play the dual role of researcher and clinician any useful findings from research can be directly transferred to patient care. This benefits the patients immensely and is allowing for some very useful and intriguing findings by the team.

Well done to all of you—what a great achievement!

As part of the award from the competition was £500 which the Team have donated to RSD UK. Everyone involved with RSD UK would like to thank the CRPS Team at RNHRD for the donation.

### DR GORODKIN—HOPE

Dr Rachel Gorodkin, an ARC Research Fellow working at the UMIST and Hope Hospital, Salford in Greater Manchester is coming to the end of her research studies. Quite a few of you will have met Dr Gorodkin either through her work or at the Annual Conference. She will be giving a presentation of her results at this years conference.

The RNHRD CRPS team and the Rheumatology team at Hope Hospital are hoping to start collaborative work for RSD/CRPS—it is comforting to know that medical professionals are committed to helping.

## WE NEED YOUR VIEWS

What type of article would you like to see in the newsletters? Would you like to become involved by submitting articles, letters or photographs.

When pain is severe it is easy to become overwhelmed and loose sight of how to enjoy ourselves or achieve our goals. Many RSD/CRPS patients have achieved things they never thought possible after their diagnosis. Could you tell us about your achievement, say why it was important to you and what prompted you to “go for it”? If your story is inspiring it may encourage others to “go for it” too.

## DLA AND OTHER BENEFITS

Claiming benefits is daunting and many of our contacts have difficulties claiming Disability Living Allowance. DLA is payable for two components, personal care and mobility. For help with filling out your forms you may wish to seek advice of agencies that help with this, these include the Citizens Advice Bureaux or DIAL, the disability advice network (<http://www.dialuk.info>) both should be listed in your local telephone directory or found via Yell Online (<http://www.yell.co.uk>). A very good guide to filing in the application form can be found at Barton Hill Advice Centre, download the information guide (if you don't have internet connection ask your local library for help) at <http://www.bhas.org.uk>.

Support while claiming DLA, going through appeals or tribunals is available on the RSD UK Online Forums ~ if you don't have internet access it is worth asking someone you know who has for assistance or contacting your local library.

If you feel you want to talk to someone who has had a successful application, appeal or tribunal please let us know and we can put you in contact with others.

## RSD UK—WHAT WE CAN AND CANNOT DO

### WE CAN :-

- put patients in touch with others, with full consent ✓
- send out patient information booklets
- take telephone calls between 10:00-16:00 weekdays
- give general information regarding clinics
- give general information about treatments
- share information about research and help recruit subjects
- Represent members views at meetings about pain services

### WE CANNOT :-

- give out personal information without full permission ✗
- take calls evenings or weekends
- recommend named doctors/clinics
- give information for legal cases (e.g. doctors names)
- give reports or information for benefits claims (e.g. DLA)
- share data with other organisations
- Use any identifiable data for research purposes

## FUNDRAISING

### PLYMSTOCK SCHOOL

**Lisa Warrilow** applied to her school charity fund to be their named charity last year because her dad, Mark, has the condition. At the conference Lisa very bravely read out the letter that secured RSD UK as the school charity for the year. Plymstock School Fund donated £475. Well done Lisa!

### SCREWS ON TOUR

In May 9 Prison Officers, including RSD UK's Barry Swallow along with RSD UK Trustee Steve Chapman turned their biking holiday in to a fundraiser. The group challenged people to guess total mileage the 10 bikers rode between setting off and returning to Chatham in Kent. They toured Brittany and clocked up just over 15000 miles. Sian Jenkins was the winner of the 50:50 split of the raised funds (before Prison Charity Donation) and she decided to generously donate her prize of over £400 back to RSD UK, thank you Sian!. The Prison Service Charity Fund added £805 bringing the total to **£1588!** Well done lads!

### REGULAR DONATIONS BY STANDING ORDER AND PAYPAL

We would like to thank the following for their regular donations to RSD UK through standing order: **Sarah Norris, Brenda Swallow, Mike and Chris Inwood, Sarah Armit, Helen Fulcher, Mrs R Child, Steve Chapman, Barry Swallow** and **4 anonymous** donators. If you would like to donate in this way from £1.00 per month upwards see back page for detail and S/O Form. To make a donation through Pay Pal online please visit <http://www.rsd-crps.co.uk/donate.htm> and click on the donate button.



### BONUS BALL

This man has become known fondly as "extortionist extraordinaire". **Malcolm**, from Yorkshire is a milkman and his fundraising efforts this year involve extracting money from his customers playing his "bonus ball" game; each customer picks a number, if that number is that weeks Lotto Bonus Ball the customer wins. To date he has raised £1832 with more money being raised weekly. Well done and thank you **Malcolm Blackburn** and his wife Dee



### CHARITY CONCERT

When **Helen Balder** from Coventry realised she knew someone who could perform for a charity concert she wasted no time in organising it. **Claudio Saeiva** helped Helen and husband **Scott** raise £1355. Well done Helen and Scott, thank you to everyone that helped make the night a huge success.

### CHEEROGRAMS

Many thanks to one of our overseas friends, **David Faille** from USA found a novel way to raise money during a hospital stay. He pledged to pay RSD UK for each "cheerogram" sent via email to his hospital bed. A total of \$150 was donated to RSD UK; David is now on the road to recovery.

### BATH HALF MARATHON

Well done, and thank you to **Jenny Lewis** from the National Hospital for Rheumatic Diseases, Bath for raising £200 by taking part in the Bath half Marathon this year.

### TOMBOLA

Thank you to **Marie Wilson** who raised £800 at last years conference with a tombola stall, a great effort from one of our younger members.

### WHITE WATER KAYAKING

**Steve Chapman** will be getting himself the title of "RSD UK Daredevil" after his latest fundraiser was to white-water kayak from Hereford to Monmouth. He may have lost his mobile phone and keys but managed to pick up £2398, partly thanks to The Round Table, and a donation from Veritas, his employer. Well done Steve—what is for next year?

### CONFERENCE RAFFLE 2004

**Valerie Chapman** and **Malcolm Blackburn** organised the 2004 Raffle drawn at the Conference. The prizes were excellent and the total raised was over £1800. Thank you to both of you—they are busy planning the 2005 Raffle; if you can help by donating any prizes please let us know so we can put you in touch with Valerie or Malcolm.

### THANKS ALSO TO

**Mike** and **Chris Inwood** for raising £80 at a table top sale; the "**Dylis Kidnap Fund**" (conference 2004) which raised £65; an anonymous donator for £730; **Wyntec Management** (via **Pete Cheshire**) £50; **Sian Jenkins** for donating her "Screws on Tour" prize of £391.50 and other anonymous benefactors.

We have a template for **SPONSOR FORMS** so if you are wanting to organise an event please let us know so we can design and send out RSD UK with Charity No. and contact details.

**DONATION BOXES** for counters are now available; if you have a trustworthy place where they would be noticed and used please consider asking us for one. They will all be security checked and booklets explaining the condition will be sent with the boxes.

**CHARITY WRISTBANDS** are now on sale at £2.00 each. They are available in adult and junior sizes, in RSD UK blue and bear the wording "REFLEX SYMPATHETIC DYSTROPHY". You can order from the web page, phone or letter and there is no minimum order.



## DIAGNOSIS—WHY IT CAN BE DIFFICULT

## HELPING YOUR GP

Diagnosis of a pain condition can take a long time, be fraught with uncertainties and leave the patient feeling frustrated and sometimes depressed. To diagnose RSD/CRPS set criteria given in Guidelines by the International Association for the Study of Pain (IASP) should be met. This means that the patient must show, or have shown signs and symptoms from a list of recognized symptoms.

There are no tests that can prove a patient has this condition although some tests, such as bone scans and thermal imaging can support a diagnosis; tests such as blood tests, MRI scanning, nerve conduction (EMG) tests and others are used to rule out other condition as an RSD/CRPS diagnosis should only be given when other conditions presenting similar signs and symptoms have been ruled out.

The condition usually follows an injury or operation but many don't appear to have an initiating event. Doctors, physiotherapists and other health professionals are becoming more aware of the condition and we are having contact from a larger percentage of early diagnosed patients. However, many health professionals will never have seen this condition—this means they lack the experience to recognize and diagnose it quickly. This leads to delays in referrals to the appropriate clinic for treatment early in the duration of the condition.

If you do have the signs and symptoms given in the enclosed patient information book but don't have a diagnosis please discuss this with your doctor. Please be aware that many other pain conditions share very similar symptoms and matching signs and symptoms shouldn't be used to self diagnose or treat. If you have any questions about the diagnosis procedure please call our helpline for advice.

Given that during medical training a GP has only 20 minutes of lecture time dedicated to "pain" (source: BPS) it is easy to see why your GP could seem confused about this bizarre condition. There are only 2 GP's specialising in Pain Management in the UK and the other 39,000+ will probably be unaware of RSD until a patient of theirs is diagnosed.

We ask patients to remember that a GP probably isn't familiar with the condition and that some of the peculiar symptoms can appear confusing to even the most experienced doctors. After diagnosis you can request a copy of the Patient Information Booklet to take to your GP (or we can send direct). Think about giving your GP the helpline number as we speak to many about this condition and can offer general guidance about referrals and treatments. They are also welcomed at the conference, so how about showing GP's the booking information?

### DID YOU KNOW?

You may be entitled to **FREE PRESCRIPTIONS** if you are unable to collect your own prescriptions from the chemist without help. Ask your surgery for the "exemption form" and ask your GP to tick the relevant box and sign.

You may be eligible for a 2-for-1 scheme entitling you to use council amenities and cinemas so a carer goes **free of charge**. Ask your local council for details.

If you are in receipt of DLA mobility component you may be entitled to a "disabled persons rail pass" and/or a local Reduced Fair Card. Details at your local transport offices, CAB or DIAL (all can be found in the phone book).

Toll bridges/roads are often free of charge to disabled drivers!

### PHYSIO AND OT SEMINAR—FEBRUARY 2006

A seminar for physiotherapists and occupational therapists is being organised and will take place at the RNHRD, Bath.

This is a 2 day seminar on the 9th and 10th of February and will include presentations, demonstrations of therapies available and observation sessions of the "Mirror Visual Feedback Therapy"; this therapy could benefit many patients seen by Physio's and OT's. The seminar brings together International experts including Lorimer Moseley, Dr Candy McCabe and Professor David Blake.

If you think your health care team would be interested in attending this seminar please ask them to contact Catherine or call Tracey Lee at RNHRD on 01225 448444 for further details and booking forms/information.

### COPING WITH RSD/CRPS—CAN YOU HELP OTHERS TO HELP YOU?

Coping with this condition can put a strain on the most solid relationship; the patient can't always express their pain or frustration and may feel unbelievably or misunderstood. As a patient we can help our family understand by explaining (on a good day!) how the bad days feel. Often writing down how you feel and allowing your loved ones to read it, digest it then discuss it can be a major breakthrough to working as a team for coping together.

When having a good day it is advisable to let others know what sort of help you need (or hate) on your bad days, set out a plan of action and work together to decide when medical help is needed, when peace and quiet is needed or how you would like your family to respond to the tearful or angry days. Good planning for the bad days can save a lot of upset and make your relationships stronger with more understanding between you.

If you don't have access to a pain psychologist you can ask for a referral from your consultant or GP. Other organisations such as MIND and SANELINE can be invaluable sources of support (numbers in phone book). We can't expect others to anticipate how we feel, or how we want to be treated—it takes trust, talking and understanding.

Remember, your health care team are there to help, if you are not coping or any depression feels worse let your GP know as help may be available. Some patients do become suicidal—if you care for someone you feel is suicidal or may become suicidal please seek urgent medical help. Most health authorities have access to a "Crisis Team" of Community Psychiatric Nurses.

## MOBILE PHONE CHALLENGE FORM

I WOULD LIKE TO ENTER THE MOBILE PHONE CHALLENGE.

I HAVE COLLECTED (enter number) \_\_\_\_\_ MOBILE PHONES (any make, any age)

I HAVE COLLECTED (enter number) \_\_\_\_\_ ACCESSORIES (chargers, headpieces, car chargers etc)

NAME: \_\_\_\_\_

ADDRESS \_\_\_\_\_ POSTCODE \_\_\_\_\_

TELEPHONE: \_\_\_\_\_ AGE (IF UNDER 16) \_\_\_\_\_

Please send your completed form along with all mobile phones and accessories to:

**THE MOBILE PHONE CHALLENGE, RSD UK, PO BOX 7929, OAKHAM, LE15 7WW**

If you have family, friends, colleagues or other contacts who would also like to enter the mobile phone challenge please let us know and we can send out a form, otherwise, please feel free to photocopy this entry form.

## HOW DO I SET UP A STANDING ORDER FOR REGULAR DONATIONS?

To make a regular donation by standing order please fill out the form below and send it to your bank; alternatively you can set a standing order up via internet or phone banking if your bank has these facilities. Please note, you may cancel a standing order at any time. We are grateful for all donations, even 50 pence a month can make a big difference to someone we help.

PLEASE SEND THIS **TO YOUR BANK**.

I would like to set up a standing order using the following details

Please can you transfer £ \_\_\_\_\_ (enter amount) on the \_\_\_\_\_ (enter date) of each month to

ACCOUNT NO 40420358

SORT CODE 09-06-66

ACCOUNT NAME RELFEX SYMPATHETIC DYSTROPHY UK

My account details are

NAME: \_\_\_\_\_

ACCOUNT NUMBER \_\_\_\_\_

SORT CODE \_\_\_\_\_

Charity Information:

Registered No. 1100140

PO Box 7929

Oakham

LE15 7WW

0845 22 66 008

## REQUEST FOR PATIENT INFORMATION BOOKLETS

Please use this form to request extra patient information booklets, or to receive additional copies of the 2005 Conference information and booking forms: alternatively you can call the helpline to order.

NAME: \_\_\_\_\_

ADDRESS \_\_\_\_\_ POSTCODE \_\_\_\_\_

TELEPHONE: \_\_\_\_\_ AGE (IF UNDER 16) \_\_\_\_\_

I would like to order \_\_\_\_\_ (enter number) Patient Information Booklets and/or \_\_\_\_\_ copies of the Conference information and booking form

Please return this form to "Information and Contacts", RSD UK, PO Box 7929, Oakham, LE15 7WW