



The IPRS Newsletter

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Special points of interest:

- 2nd IPRS Newsletter.
- New Web Address.
- More and More Members.
- IPRS Survey.
- UK Benefits Help.
- Replies from other Organisations prove we are on our own.
- New look web site

The IPRS Goes From Strength To Strength

Welcome

Welcome to the 2nd edition of the IPRS Newsletter. This is a shorter edition than the first as most of the latest news has been added daily to our site.

Our hard work is finally paying off now with more and more members joining The IPRS every week.

This has partly been due to our new website domain name. We purchased the www.palindromicrheumatism.co.uk so it would be easier for people to find us.

Although we have paid for the name we are still sharing web space with my own private homepage some of you might remember the address www.pksworld.co.uk which isn't ideal. When we are able to afford the new web space it will make things a lot easier and less hassle to have

them both together, instead of having to redirect all the time.

We have been adding links to our website on most of the search engines, as well as all the appropriate sites, who are prepared to list us. Not as easy as it sounds, many thanks goes to Peggy for all her hard work in America.

These links and word of mouth are finally getting the message out that we are here, and we are now able to reach more and more people affected by PR.

Survey

The IPRS Survey is proving popular with over 50 completed surveys returned so far. The IPRS is receiving them every day with no signs of them slowing down. Thank you to everyone that has completed and returned

them so far. I know only to well how hard it can be typing etc so many thanks.

The results so far will be added to the site very shortly.

Benefits

We are fortunate in the UK as we have our very own benefits expert as a member who has PR herself so is only to aware of our situation. Her name is Karin Anderson for those that don't know her already and she is willing to help give advice on disability benefit. If you are wanting to claim Disability Living Allowance (DLA) etc or want to know if you can claim anything for financial help drop her a line first. You can either contact her direct through the IPRS Forum or through us at iprs@f2s.com mentioning benefits in the subject title.

Replies From Other Arthritis Organisations

The IPRS sent an email back in January to the main Arthritis and Rheumatoid Arthritis Organisations in the UK, asking for help and advice with our website and publications. The replies are now back. Unfortunately it wasn't the news we were hoping for.

As we are not a registered charity one of the organisation was not able or willing to add our site as a link but did offer to pass on our address if asked by some one suffering from PR.

Nor were they able to supply funds or a grant

for our publications such as the PR Information Leaflet.

One Organisation offered advice by email whilst the other asked for me to ring them. I was told I could cover the cost of the leaflet by charging the IPRS members a fee or... cont.



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print the leaflet in black and white on an A4 piece of paper to keep the cost down. Neither of which is suitable.

They did suggest applying to a drug company for sponsorship however they pointed out this may seem that our information is biased using a drug company for sponsorship.

They did however wish us luck with the development of our site.

So at the moment I am trying all corners but we are running out of places for help.

We have finally received our first donation last month and our thanks goes out to the member that made the donation. We have also received a

small amount of commission from people shopping via the website. So we would also like to thank those who have contributed.

We are still are a long way off purchasing new web space etc so if you can afford however small we would be grateful for your help.

It Only takes one person to make a difference, together we could make a change.

I hope you have enjoyed this 2nd issue of The IPRS Newsletter. It is not easy for me or my family to find time to work on the IPRS website and publications however we continue to do so as there is a real need to educate, inform and help people suffering from PR.

If you have any comments or suggestions for future newsletters please email iprs@f2s.com

You may have seen a number of changes and layout improvements on the web site over the last month or so. We have put effort into trying to make it look more professional and fresher yet maintain that friendly personal feel. We hope you are happy with the outcome, and we intend to keep it evolving.

You need to keep visiting the IPRS Website for updates and additions.

Thank you for your continual support.

Your Story (As The 1st Issue)

We now have one members story added to site, *many thanks Peggy*, but we really need more so I have included this article again incase you missed it first time around. I know there can be a reluctance for people to submit their own story and pictures but there is a need to give a balanced view as well as hope to others in your situation.

The IPRS is looking for your PR Story and photos to use. Do you have a story that might help others with either helpful

information on work, benefits or treatments that has helped you? Maybe you have such a bad case of PR that others will feel better off? The IPRS includes a section for stories that will hopefully cover most cases, male, female, young and old. People who are working with PR, who have a family to look after etc. If you think that you have something that other people with PR might benefit knowing, reading then send the details, photos to iprs@f2s.com and look

out for your story being used in the future. Also If your partners, children and family have a story to tell get them to send it in. New visitors seem to really appreciate the photos and knowing there are others like themselves.

The IPRS has the right to amend, change and alter any information/photos used for it's website to fit in with the context and constraints of the site . But rest assured we will always submit a final draft for agreement before put anything onto the web.

Funds Needed (As 1st Issue)

The IPRS desperately needs funds for it's ongoing website and literature production. As you know the IPRS is a voluntary group that has no government, educational or medical funding or sponsorship. The IPRS is looking into creating funds from the above however they also need donations sponsorships from it's members or the people affected by PR. If the IPRS receives this funding then the service will remain free for all to use. The IPRS wants to have

it's own independent domain name for it's website before the production of The IPRS Leaflet. I know only too well that it's those affected by PR that have to do the work and raise the money. It should be carried out or paid for by others but life's not like that, as we all know. I believe that by helping others we are helping ourselves. By creating awareness of PR it will not only help others get a diagnosis more easily it will also help people claiming benefits etc.

Hopefully if we all stand together *No Pun Intended* then we will hopefully have a voice within the medical community and hopefully more research will be done into PR (or even start doing some research).

Remember I promised to match pound for pound the first £100 of donations, so if you want to see me put my hand in my pocket some more then just put your hand in yours - or even click on the 'donate' link!