



# The IPRS Newsletter

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## Special points of interest:

- First IPRS Newsletter
- New PR Forum
- New PR Leaflet
- Production of Leaflets
- Donations Needed
- International PR Awareness Day

## A New Year And A New IPRS PR Information Leaflet

Happy New Year and welcome to the first issue of The IPRS Newsletter. With the New Year brings new things for The IPRS. This newsletter being the first for the IPRS and hopefully one of at least 6 planned for this year. There have been a lot of new things added to The IPRS Website so far this year if you haven't already checked them out please do so. New additions are a PR Forum, "Great Fun". There is also a copy of the New IPRS PR Information Leaflet on the site. This PR Information leaflet has been created to raise awareness of PR and hopefully with your help we will have a copy in every Drs and Rheumatologist Department. The IPRS wants to raise awareness of PR in the medical and benefits industry. This will not only benefit the people who have a diagnosis but future sufferers who yet have a diagnosis.



Above is an image of the new leaflet further information and a closer look can be found on the IPRS website at:  
[www.pksworld.co.uk/pr](http://www.pksworld.co.uk/pr)

One aim of the IPRS is to raise funds for a separate individual domain name for it's website. Another is to raise funds to produce the PR Leaflet. The way leaflet production costs is the more you have printed the cheaper

each leaflet becomes. Most companies wont produce less than 500 copies. For 500 copies it costs about £400, for 10,000 it would cost about £800. So you see that it becomes significantly cheaper.

Once the leaflets are produced The IPRS wants to celebrate the release with an International Awareness Day. We will then need your help again to distribute the leaflets to your Doctors and Rheumatologist where others can benefit from the information. For further information or to make a secure donation visit The IPRS Website. The IPRS will double the first £100 received in donations.

*This is from my Christmas money and savings, as I believe its really needed to create more awareness, so that is why I'm adding to any of your donations.*

## New IPRS PR Forum

The IPRS have also created a new PR Forum. This forum is an added bonus for the PR community where you can post topics, create polls and reply and comment on other peoples topics. As there are new people getting PR all the time the same questions have to

be answered. Through the PR Forum and IPRS Website these questions and answers can be logged so new members can find the answers they have questions for. The forum offers so much more than a user group and it should be easier to use (at least there won't

be the numerous amount of adverts the web and user groups have to deal with). Visit the PR Forum now it's free, easy to join and use and has a fantastic FAQ which should help you around the forum.



## Families and Friends Need Support Too

We all know or have an idea what each other is going through regarding the unpredictable and painful episodes of PR. What about your family and friends, are they of support to you and your situation? Most people with PR find it hard to understand what they are going through and why, so you can imagine what it is like for them. The IPRS wants to offer an advice and a support group not only for the person with PR but for all those that are affected by PR. If your family and friends join the IPRS they will not only get an in-

sight into what you are experiencing they will also be able to get helpful advice and support for themselves. Surely they need somewhere or someone to talk to who is in their position. Hopefully the IPRS forum will be used by partners, children, families and friends and they will be able to offer support and advice for each other and to help them understand how PR affects us all.

It's all about awareness and informing as many people about PR as we can. If you think anyone else might benefit from

being informed about PR get them to visit, join the IPRS. This may be a carer, employer or benefit or medical professional. The more who know about PR the less you will have to tell and try to explain how you feel or what you are going through.

If there are any medical professionals or benefit experts that are reading this and you could offer support or advice to the people with PR or their families please contact The IPRS by using [iprs@f2s.com](mailto:iprs@f2s.com)

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

## Your Story

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 will include a selection 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](mailto: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.

*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.*

*I hope you have enjoyed this first issue of The IPRS Newsletter. It has been rushed out to inform you of the new changes that a lot of you will of already seen.*

*If you have any comments or suggestions for future newsletters please email [iprs@f2s.com](mailto:iprs@f2s.com)*

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

*Thank you for your continual support.*

## Funds Needed

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 fund-

ing 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).