



The IPRS Newsletter

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Special points of interest:

- 3rd IPRS Newsletter.
- New IPRS Survey.
- Coming Soon User Blog Area.
- Future Plans.

Seasons Greetings To All

A Look Back

Firstly I would like to apologise for not being able to get the 3rd newsletter out before now. It has been a tough year as well as an ever changing and growing year for the IPRS and there was never the opportunity to do it before now, so I have tried to cover all the new additions in this.

Well as we are approaching the end of another year for the IPRS, we thought we would take the opportunity to look back over the last 12 months and then take a look at what the future may hold.

IPRS Forum

The start of the year saw a new addition to the IPRS, the IPRS Forum. This was so important to offering the support and advice needed as well as connecting people with PR from around the world. The forum has gone from strength to strength and has had well over a 100 members in its first year. The forum additions that have been added so far included a calendar, a chat room (to allow instant communication) and a member's gallery which allows members to share images for example of their family, friends or their interests. **News Flash**, to celebrate our 1 year anniversary of the forum and new for 2007 there is going to be a

blog section added to the forum which will allow members to keep a diary/journal of their lives, PR Flares and medication etc or simply just keep friends informed of their day to day activities. You can also keep information private or just allow your friends to read. So 'myspace' watch out as the IPRS does it better. More information on the blog section will be posted in the forum around the release date. We are hoping the blog area will create a real feeling of an online PR community which complements the forum activity.

IPRS Website

As for the IPRS Website, we had a new look website created earlier this year to try and make it more interesting and easier to navigate around. We do however add new additions all the time and do try and keep it up to date and more informative when we can. New additions this year also included other peoples PR Pictures and Stories and a selection of emails received by the IPRS..

Also New

We also purchased this year the following domain names palindromicrheumatism.co.uk, palindromicrheumatism.org and very recently palindromic.org. The new domain name has made it easier for people to find us. Here's how you can

make it easier for people to find us:- Every time somebody puts palindromic rheumatism in a search engine and then visits the link listed, it moves our site further up the list therefore when somebody new comes along to try and find information on PR they will find us first at the top of Google or Yahoo etc, instead of having to go through website after website of companies just trying to sell medication/cures etc or out of date sites. If you just use the IPRS link from your favourites or on the explorer pull down bar it doesn't register on the search engines list. So occasionally use the search engines to keep us at the top.

Also purchased this year was the IPRS's own web-space for the website and database for the forum following the ever increasing use and popularity. **News-flash** We have just purchased even more database space which should cope with the new additions and increasing forum for the next 6 to 12 months. All of these purchases have only been possible due to your generosity and my donation pledge promise of matching the first £100 pound. The new available database space allows the forum to grow and the blog section to be added. So many thanks to those that have helped out by either



Wishing You A Very Happy And Healthier New Year.

A Look Forward

To look ahead for the New Year and The IPRS:

The New PR Survey will be made available and will be the largest survey that I am aware of to be carried out on PR (see below for more details).

I would also like The IPRS in the New Year to extend and grow even further. To reach out to more people and places around the

world affected by PR. Ideas for doing this include, to some how get The IPRS mentioned on TV and radio not only just in the UK in the beginning but hopefully in America, Canada, Australia and New Zealand. Also when I have enough funds, I'm going to look into producing prints of The IPRS leaflet and distributing them through the IPRS members to pass on to their DR's and Rheumatologist who in turn can pass on to new and old cases of PR sufferers.

Also we are going to look into approaching the medical world and research universities regarding future research studies into PR. To find out what is being done and what research will be carried out on PR in the future and to offer our services to them.

Hopefully the future will be more positive for people with PR and together we can make a change.

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

I hope you have enjoyed this 3rd issue and end of year edition of The IPRS Newsletter.

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

Thank you for your continual support.

New IPRS "PR" Survey

I am currently working on a New IPRS PR Survey. This survey is just for people who have been diagnosed with PR (as it is just about people with PR). It will be the largest PR survey I know that has been carried out and will hopefully help the medical world understand more about PR. The results will be available to anyone in the medical world that has an interest in PR or is doing any research into PR. The Survey when ready will be available on the IPRS website for you to complete.

Once we have enough completed surveys we will hopefully start to show some of the results on the website however the survey is anonymous and private information will not be disclosed.

One thing the IPRS is more aware of is PR is different for most people if not everyone with PR however we do have similarities that the medical world don't always recognise as symptoms or characteristics of PR. Hopefully this PR survey will help them to under-

stand the differences but also the problems we suffer with. Hopefully together the IPRS and medical world can work together to fully understand PR and find better treatments and hopefully a cure.

Understanding PR has to start some where and where better than from the people who know the most about PR. So please take the time and complete the new survey. The more completed surveys the more understanding and fuller picture we will have.

Difficult Times.. And Making A Difference.

Although I am finding it continually hard to find the strength and time to work on the website and contribute in the forum I am still doing so. It may take me longer to reply to emails and messages but I intend to get as much done as possible. I want to apologise to anyone in the future in case I don't respond quick enough for you or in the unusual circumstances if I fail to respond at all.

I am constantly getting emails from people who

have PR questions for me and are looking for help and advice with their situation. Although I suggest they join the forum for support and advice from the other members they don't seem to do so at the time and that is their prerogative (maybe they will at a later date?)

I understand that people may not want to or have the time to spare for others but the IPRS will continue to be there and offer help and support where ever it can.

I understand that it is hard for everyone to type and contribute in the forum and thank those that do. **A Big Thanks** to the IPRS volunteers and forum moderators for their time and dedication. Also thanks to all the forum regulars who frequently post and make the forum interesting and supportive. I would also like to thank you on behalf of all the other members that don't post or post as often but always read avidly. I know they enjoy reading your posts as much as me.