

ISSUE 1: Aug 93.

THE PSORIATIC ARTHROPATHY SUPPORT GROUP

136, High Street, Bushey, Watford, Herts, WD2 3DJ.
0923-672837

GROUP NEWS UP-DATE

Since our official launch on April 7th 1993, we are pleased to say that we are steadily and slowly growing in numbers. The recent small article in the Daily Telegraph, produced well over 300 enquiries, from all over the Country, from sufferers, relatives, friends, and a few hospitals and doctors. Small articles over this length of time have also been placed in local newspapers, and these too have generated enquiries.

It is essential that we keep this profile up with regards to the media. So if any of you feel like writing to your local free newspaper or any other newspaper in your area, please have a go, or alternatively let us know the newspapers in your area and the addresses and we will try to approach them.

We hope in the coming months that we will go from strength to strength, but we cannot do this without your help and support, so please join in, no matter how small your participation.

We are working towards a formal committee now, so as to enable us to have more scope with the formation of the group and what we will be able to do in coming months, with a view to giving the group a formal structure leading to the drafting of a Constitution.

Once we have a formal committee and an agreed Constitution, meetings will take place with regard to applying for charity status, so as you can see there is a lot of work to be done!

DONATIONS

Thank you to everyone who have sent us donations and stamps with their subscription fees. These will be put to good use, and are gratefully received.

HOT NEWS !!

LOOK OUT for Womans Own August 16th 1993 issue. There will be a small piece in this issue on Psoriatic Arthropathy, and a mention for the group. Dr A. White, Rheumatologist, has kindly agreed to be on our advisory team, contributed to the article. A follow-up is hoped for later in the year. Good promotional opportunity for the group.

WANT TO GET INVOLVED? JOB OPPORTUNITIES

FUNDRAISING!

Are there any members out there who would like to take up the challenge of becoming fundraising organisers for the group. Please give us a ring. The job besides organising and arranging fund raising events could involve research into sponsorships etc,so the job has scope as well as challenge,depending on how much or how little you would like to do,the jobs yours to develop.

PROMOTIONAL ORGANISERS

Fancy promoting the group and its work. Writing to newspapers,promoting the group on radio? Promoting in other ways. We need you in all areas around the Country.

REGIONAL BRANCH ORGANISERS?

Do you fancy starting a regional branch group of The Psoriatic Arthropathy Support Group,where members can meet,raise awareness in their area of the condition,promotion of the group,fundraising activities,and generally be active. If so let us know and again we will do our best to help you get started. All network branches will be under the direction and guidance of the Parent Branch.

MINUTES SECRETARY

Is there anyone in the group versed in taking minutes of meetings willing to attend future meetings of the committee and take down the minutes and keep records of future committee and other meetings.

RESOURCES

Many of you have kindly offered to help us with services ie photocopying etc. It would be very helpful to us if you could let us know what you could offer specifically,so as we can ascertain what resources we have on offer. Thank you.

MEMBERSHIP PACKS.

We hope you have all received your membership packs,but if you haven't please let us know and we can forward another if necessary.

Packs should consist of the following:-

Psoriasis /Dithro tapes, Dithro booklet (Dermal),Arc leaflets;PA,Arthritis & Drugs,Work related complaints & Rheumatism,Rheumatism and the Weather. Psoriasis booklet (Leo)Key facts about Psoriasis book by Roche,Skin/scalp booklets (Dermal).Canadian Article,leaflets on Psoriasis of the hands,feet and nails,Psoriasis and the nails(Can.Psor.Found),.Pen Pal/Tele Lists where applicable,Polytar leaflet (Stiefel).E45 Clinical Trials,Dithrocream Extract,Aveeno leaflet/price list,Emulsiderm leaflet,Crookes (book) Common Guide to skin disorders,Membership letter.

Samples:

E45 Wash/bath oil satchets,E45 Cream,Aveeno,soap,oatmeal bath additive,Emollient & Moisturizing cream (Bioglan), Capasal shampoo, Emulsiderm emollient(Dermal).

We are always willing to listen to any ideas you might have.

Either to be used now or in the near future.

DECISIONS, DECISIONS, DECISIONS!!!

The NEWS JOURNAL? We need a title. We thought about calling it "The Skin & Bones Connection" or "Skin'N'Bones" mag,journal,rag? What do you think,do you think this is or could be a good title or can you come up with any better ideas. We have brain drain at the moment. We need a title that joins the skin and arthritis conditions together,so please put your thinking caps on.

The Journal is in the process of being put together as we speak,and with abit of luck we hope to send it out to you in September. We were going to produce it earlier but things have been moving faster than anticipated with the group so it was decided to postpone it until September when a more interesting issue could be produced.

It is hoped that we will try and produce two news journals a year,September and April,funds allowing,with periodical newsletters like this one during the course of the year,to keep you more informed of what's going on with the group,it's successes and its failures,hopefully not too many of the latter!

STOP PRESS

We have now received a copy of a tape that we ordered from the American Psoriasis Foundation in America relating to PSORIATIC ARTHRITIS. It is 30 minutes long and the interview is by Dr.Frank B.Vasey,who has done substantial work in the field of PA. Because of copyright we cannot sell you copies of our tape,but we are willing to loan it out to any member who wishes to borrow it on LOAN to listen to and then return it to the office. ALTERNATIVELY,we are willing if there are enough people interested in purchasing a copy of it,to place an order to America for reasonable sized quantities. It is cheaper this way as the cost of money orders is quite expensive. This also goes for any other information,books etc that you would like. Details of these will be in future newsletters and journals.

If you decide to place orders you will appreciate they do take sometime to be received,so there will probably be a wait for them. Don't hesitate to let us know.

CONTACT MEMBERS LISTS:

Please make use of the Tele/Pen pal lists. We know how difficult it is to pick up the phone and talk to a complete stranger,but we are all a nice lot of people with a common interest and a common goal. It seems that we are all waiting for each other to pick up the phone,in which case nothing happens and it defeats the object of having these lists. So please don't be shy.We are a special band of people with a lot of experiences and advice to offer each other,especially as we are at all different levels of the condition,thus we can all learn a great deal from each other,beit bad news or good news. We owe it to ourselves to know what's going on . We each have a gift (although not a pleasant one!!)of experience that can help people,old hands at the condition and new sufferers,who have it all in front of them,so please turn a bad situation around and make it work for a better cause.

If any of you change your minds about either going on or off the Contacts Lists,please let us know

and we can arrange either for you,although we hope you won't change your minds about coming off.

CONTRIBUTIONS!!!!!!

Contributions to the news journals and the newsletters will play a vital aspect of the support group,which we hope you will appreciate. By means of these news journals/letters,it will enable members to learn from each other,feel part of this important group,share your experiences,good or bad,voice your views,have a moan about anything connected with the condition,and to express what you want from the group,and what you would like to see in the way of changes towards your illness by doctors etc. It is for everyone to share their ideas. **THIS NEWSLETTER IS YOUR NEWSLETTER** so please make use of it!!

We need your feedback so as to develop the way you want us to so please don't let us down,we are all in this together.

You do not have to be an expert to do this just try to put down on paper what you feel,so go on have a go.

IMPORTANT: CAN YOU HELP?

PREGNANCY & PA.

This is an important issue that needs to be addressed and we intend to go into this area of PA,and try and find out how it affects women.

But you can help too!!! There are alot members who have experiences in this regard and we would be very grateful if you would be brave enough to share your experiences with us,good or bad,how you felt during pregnancy and after,treatments you received.We know there are many of you contemplating either starting a family or adding to your already existing one,so your contributions in this regard will be invaluable to other members. We will either print your contributions if you would like us to or we will compile the information gathered from you and print the findings,but it would be nice to print readers own experiences don't you think?

Please remember you can either give your name or remain anonymous,just let us know.

FINALLY

A big thank you for your support so far please keep it coming because we really have to make this group something and we can do it with your help,So keep up the good work.

SURVEY

FACT FINDER MISSION!!!!

Now the group is taking shape we feel it's about time we got started on producing some much needed fact sheets, and this is where you come in. Because everyone has different ideas of what they want we feel the best way to handle this is to find out what you all want done first in the way of information, so we need your help with this survey!!

How to complete the questionnaire.

You will see two columns of boxes. In one column please tick the fact sheets that interest you and in the second box please place a number from 1-10 in order of preference you would like to see these produced. Thank you.

PSORIATIC ARTHROPATHY

- | | | |
|-----|--|-------------|
| 1. | Info on PA in general; how it affects the body, genetic factors etc. | [] [] [] |
| 2. | PA and pregnancy | [] [] [] |
| 3. | Juvenile PA | [] [] [] |
| 4. | PA and nail changes | [] [] [] |
| 5. | Fingers | [] [] [] |
| 6. | Hands | [] [] [] |
| 7. | Wrists | [] [] [] |
| 8. | Feet and toes | [] [] [] |
| 9. | Ankles | [] [] [] |
| 10. | Hips | [] [] [] |
| 11. | Pelvis | [] [] [] |
| 12. | Knees | [] [] [] |
| 13. | Neck | [] [] [] |
| 14. | Back/lower back | [] [] [] |
| 15. | Sacroiliitis | [] [] [] |
| 16. | Ankylosing spondylitis | [] [] [] |
| 17. | Jaw problems | [] [] [] |
| 18. | Eye problems (Uveitis) | [] [] [] |
| 19. | Immune System; the part it plays | [] [] [] |
| 20. | Stress | [] [] [] |
| 21. | Diet | [] [] [] |
| 22. | Management and PA | [] [] [] |
| 23. | Physiotherapy and PA ; exercises for various parts of body | [] [] [] |
| 24. | Do's and Don'ts | [] [] [] |
| 25. | Drugs used in treatment of PA (General) | [] [] [] |
| 26. | Side effects | [] [] [] |
| 27. | Specific fact sheets on drugs ; please list below :- | [] [] [] |

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|-----|-----------------------|-------------|
| 28. | PA Other fact sheets? | [] [] [] |
|-----|-----------------------|-------------|

FACT SHEETS ON PSORIASIS:-

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|-----|--|-------------|
| 1. | Hands and nails | [] [] [] |
| 2. | Feet and toenails | [] [] [] |
| 3. | Body parts affected by Psoriasis (general fact sheet) | [] [] [] |
| 4. | Genital Psoriasis and its treatment | [] [] [] |
| 5. | Scalp | [] [] [] |
| 6. | Face | [] [] [] |
| 7. | Management of Psoriasis | [] [] [] |
| 8. | Tip sheets by members | [] [] [] |
| 9. | Creams and lotions used in the treatment of Psoriasis and side effects (if any). | [] [] [] |
| 10. | Steroid treatments | [] [] [] |
| 11. | PUVA | [] [] [] |
| 12. | UVB | [] [] [] |
| 13. | Tar preparations | [] [] [] |
| 14. | Research if any | [] [] [] |
| 15. | Types of Psoriasis | [] [] [] |
| 16. | Psychological aspects of condition | [] [] [] |
| 17. | Stress and Psoriasis | [] [] [] |
| 18. | Immune system and its role | [] [] [] |
| 19. | Alternative therapies : please list below | [] [] [] |

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ALTERNATIVE THERAPIES:-

- | | | |
|----|---------------------------|-------------|
| 1. | Acupuncture | [] [] [] |
| 2. | Faith healing | [] [] [] |
| 3. | Holistic approach | [] [] [] |
| 4. | Hypnotherapy | [] [] [] |
| 5. | Alexander Technique | [] [] [] |
| 6. | Yoga | [] [] [] |
| 7. | Others: please list below | [] [] [] |

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MISC:

Are you happy with the group and its work to-date? Yes [] No []

If not please give reasons:

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Do you still wish to receive samples and product information in relation to Psoriasis? Yes [] No []

THANK YOU FOR YOUR TIME