

PAA SKIN 'N' BONES

Issue 10
Summer '98

CONNECTION



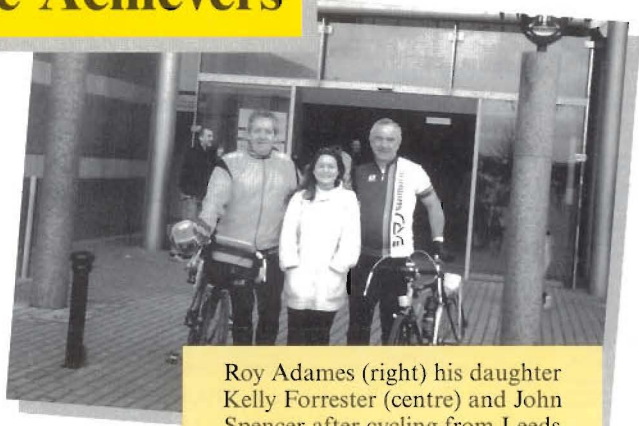
Amanda Rutland (centre) with her mum Hilary (right) receiving a Supporters Award from PAA Co-founder Julie Chandler



David Sadler after completing the London Marathon

The Achievers

Over the years since the PAA's formation there has always been those who have supported us not only in spirit but also through fundraising activities. Here are some recent achievers. To you we are extremely grateful, along with the other unsung heroes that make this organisation possible.



Roy Adames (right) his daughter Kelly Forrester (centre) and John Spencer after cycling from Leeds Castle in Kent to Leeds in Yorkshire

INCLUDED IN THIS ISSUE:

• PAA Conference 1998 • Psoriatic Care Factfile • Diary • Young PAA • Book Review

Let's get into focus

Help us to help you

- Are you good at voicing your opinions?
 - Would you like to influence the manufacturers of treatments?
 - Would you like to take part in research?
 - Would you like to organise a meeting of about 12 people in your area?
 - Would you like to influence the way you receive your treatments?
- and*
- Can you spare 3 hours to attend a meeting?

If you answered **yes** to any of these questions we need you. **Read on.**

We intend to bridge the gap between the medical profession, the pharmaceutical industry and patients. Giving **you** the patient the opportunity to tell us and the those involved in the delivery of your treatments and care what you think about:

- The condition
- How it affects you
- What you expect from clinicians
- Why you feel treatments often don't work and
- How the treatments and delivery could be improved.

With your help we will be able to give a much better picture of living with a long-term chronic condition and thus reflect the true needs of the patient.

The meetings will be titled Psoriatic Patient Focus meetings, and will consist of about 10-15 people. The meetings will come to you and take place at various venues around the UK.

If you would like more information, to take part or help organise a meeting please contact David Chandler at the PAA office on 01923 672837 or write to Psoriatic Patient Focus c/o PAA PO Box 111 St Albans Herts AL2 3JQ.

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This Journal is produced by the Psoriatic Arthropathy Alliance and reviewed by an editorial panel drawn from the board, medical and non-medical advisers.

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The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

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Registered office: Faulkner House, Victoria Street, St Albans, Herts. AL1 3SE

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We also believe that at the time of printing all information is correct but we cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal. All opinions expressed herein are of the contributors and not necessarily those of the PAA. Always consult your own doctors.



Internet address: www.paalliance.org
Registered Charity No: 1051169

This publication was provided with the aid of an Educational Grant from Crookes Healthcare

SKIN 'N' BONES CONNECTION

Psoriatic Arthritis in Children

Arthritis in children

As many as 12,000 children in the UK suffer from juvenile chronic arthritis (JCA). There are three main types:

- **Still's disease**, (accounts for 20% of cases). Starts with a high fever, patchy red rash, enlarged lymph nodes, abdominal pain and weight loss.
- **Polyarticular juvenile chronic arthritis**, in which many joints are affected. Pain, swelling and stiffness affect large and small joints symmetrically (for example, both hips rather than one).
- **Pauciarticular onset juvenile chronic arthritis**, in which only a few joints are affected.

Juvenile psoriatic arthritis is sometimes thought of as part of the spectrum of juvenile chronic arthritis summarised above but others regard it as a separate disease to be distinguished from these, having more in common with reactive arthritis and juvenile ankylosing spondylitis.

The Vancouver criteria for diagnosis of psoriatic arthritis in childhood are a useful guide:

Definite psoriatic arthritis

Arthritis with typical psoriatic rash

Arthritis with three of the four following minor criteria

Dactylitis (pink swollen "sausage" finger or toe)

Nail pitting or onycholysis (splitting and breaking up of nail)

Psoriasis-like rash

Family history of psoriasis in first or second degree relatives

Probable psoriatic arthritis

Arthritis with two of the four criteria listed above

There is a tendency for girls to be more likely to be affected than boys. Simultaneous onset of rash and arthritis is rather uncommon. As in the adult variety the end joints of the fingers are commonly involved. Generally, in juvenile chronic arthritis this does not happen but tendons are often inflamed. Of the joints involved the knee seems commonest in children.

Chronic iridocyclitis, the eye inflammation more usually seen in the form of juvenile chronic arthritis with few joints involved, occurs in 8-17% of cases of psoriatic arthritis in childhood.

In terms of severity, the condition lies somewhere between the forms of juvenile chronic arthritis with few and with many joints involved. No more than 10% of affected children have seriously disabling forms of the disorder.

Using strict criteria, researchers estimate that psoriatic arthritis accounts for up to 8% of cases of childhood arthritis. Using less strict criteria, including a period of five years follow-up during which the psoriasis may appear, they think the real figure may be 20%.

(Source: *Oxford Textbook of Rheumatology*; Madison, Isenberg, Woo and Glass; Vol.2 1993, 677-679 and 714-715, Oxford Medical Publications)

Early diagnosis is important

If your child develops painful joints and there is a family history of psoriasis - even if the child shows no psoriasis at the time - it is worth mentioning the possibility to your doctor and the more so if any family member has psoriatic arthritis. If doubt remains, you should ask for referral to a specialist - ideally a paediatric rheumatologist, but as there are few a paediatrician or adult rheumatologist with an interest in the condition.

Treatment

The main aims of treating juvenile psoriatic arthritis are to reduce joint inflammation, maintain mobility and prevent deformity. Physiotherapy is as important as drug treatment. Daily exercises, hydrotherapy (supervised exercise in a warm pool), and day and night splints are all important for long-term joint mobility.

The aim of treatment is for your child to have as normal and active a childhood as possible.

Useful contact

The Disability Living Allowance has a Benefit Enquiry Line on 0800 88 22 00. See leaflet **DS706 for children under 16**.

Drugs used in the treatment of childhood psoriatic arthropathy

Drug	What it does	Possible side-effects	Comments
Non-steroidal anti-inflammatories such as ibuprofen and naproxen - by mouth - 1 to 4 times a day	Blocks an enzyme to reduce pain and inflammation	Rashes, indigestion, nausea, diarrhoea, increased bleeding	Should not be used in those with asthma or peptic ulcers. May make skin psoriasis worse
Corticosteroid injections into joint or tendons	Reduces joint or tendon inflammation	Allergy, introduction of infection into joint, flushing, small risk of muscle or tendon wasting	Only limited number of injections should be given to any one joint per year
Methotrexate - by mouth once a week with folic acid supplementation	Reduces cell division so fewer cells are made in the skin, gut and immune system	Bone marrow suppression, nausea, liver problems, increased risk of infection, rash	Used in severe cases under close medical supervision
Sulphasalazine - by mouth in tablet coated to protect the stomach; liquid form available - widely differing doses will suit different people due to rate of processing in the body calculated to body weight	A disease modifying agent also used in rheumatoid arthritis and colitis, acts on the chemistry of inflammation to reduce swelling and pain	Headache, nausea, loss of appetite, rash, fever, reduced white blood cell count, mouth ulcers, reduced sperm count in men (reversible), bruising	Regular blood count necessary

Psoriatic Arthritis and the Jaw

Some people with psoriatic arthritis develop problems in the two joints between the skull (temporal bone) and lower jaw (mandible). These are known as the temporo-mandibular joints or TMJs for short.

The temporo-mandibular joint

The TMJs are shaped so that a cylindrical surface on the jawbone sits inside a curve on the skull. Each TMJ contains a disc of cartilage that acts like a washer and also increases the range of movement. As well as opening and closing in a hinge like the elbow, the jaw glides from side to side and can move forwards and backwards during chewing and grinding.

What problems can occur?

The TMJs are lined with synovial membrane, which can become inflamed in some people with psoriatic arthritis. This can cause symptoms of:

- headache
- pain around the face, TMJ or ear
- joint stiffness
- difficulty in opening the mouth
- tender jaw muscles
- pain on opening the mouth wide and when chewing
- clicking as the jaw is opened or closed
- locking of the jaw

If you need to have an operation, always warn your anaesthetist that you have a jaw problem.

Will my dentist recognise the problem?

In the early stages, inflammation of the TMJs may resemble 'TMJ syndrome'. This is a relatively common condition caused by spasm of the chewing muscles. TMJ syndrome is linked with stress, clenching and grinding the teeth or an incorrect bite. TMJ syndrome can also be caused by the habit of holding a telephone receiver between your shoulder and cheek. In more advanced cases, psoriatic arthritis affecting the TMJs will produce changes that show up on x-rays.

What medical professional do I see for advice and treatment?

If you notice problems with your jaw, tell your dentist and rheumatologist that you have psoriasis and are concerned about the possibility of psoriatic arthritis. Remember that people with psoriasis can also suffer from TMJ syndrome, which is the more common condition. If troublesome symptoms persist, your dentist will refer you to a TMJ specialist. You may be offered a corticosteroid injection by an oral surgeon or rheumatologist to reduce the inflammation.

Useful address

British Dental Health Foundation: Eastlands Court, St Peter's Road, Rugby, Warwickshire CV21 3QP. The BDHF offer help and advice and will answer any dental query if you send an SAE.

Y O U N G P A A



Young PAA Friendships

One of the main aims of the young psoriatic arthritis group is to get people in touch with others of a similar age who have PA.

One of the easiest ways of making friends is by penpals. With writing to friends it is a lot easier as you can write when you feel well enough,

transport isn't a problem, you're in control and you can say what you want and write as often as you want.

We met in September of last year at the PAA conference and we have been writing to one another since. Our friendship has grown. It is amazing how much support and friendship can come in one envelope. Soon you find yourself waiting for the post every morning hoping that today is a letter day. With a penpal who also has PA you can share all your worries and problems as well as having someone to celebrate your achievements and talk about everyday things knowing that they will understand.

We hope to set up a penpal network for all young members as soon as possible, but to do this we need all of you to write in to us, so we can send you a form to fill in so, which will enable us to know a bit about you and the ideal person you would like to write to. Well, that's all from us for now, but we hope to hear from you soon with anything you want to tell us.

Take Care, Keep Smiling,

Claire and Eve.

An advertisement for Cocois Coconut Oil Compound. It features a black and white photograph of a woman's face, which is covered in thick, dark, scaly patches. She has a pained expression. The text 'ITCHY, SCALY SCALP?' is written in large, bold, sans-serif capital letters in the upper left corner. Below the photo, the text reads: 'There's an effective treatment that shifts the scale', followed by 'Cocois®' in a large, stylized font, and 'COCONUT OIL COMPOUND' in smaller capital letters. At the bottom, it says: 'Further information and prescribing information is available on request from: Evans Medical Ltd, Regent Park, Leatherhead, KT22 7PQ. Legal Category: GSL Date of preparation: August 1997. 8COC0400.'

BOOK REVIEW

Emollients

Ronald Marks FRCP FRCPATH.

ISBN 1-85317-439-4

48pp; 23 colour illustrations; 210 x 148mm

£4.95

Short handbook covers the definitions, content, use and benefits of emollients.

So You've Got Psoriasis: A Patient's Guide

Richard E. A. Williams BM BS MRCP

B. Roger Allen MB ChB FRCP

ISBN ?

97pp; 36 colour illustrations; 210 x 148mm

£12.95

Topics covered: treatments, ultraviolet light, basics, creams, and living with psoriasis.

The Musician's Hand – A Clinician's Guide

Edited by Ian Winspur FRCS FACS

Christopher B. Wynn Parry MBE MA DM FRCP FRCS

ISBN 1-85317-492-0

240pp; approx. 250 black and white photos and drawings; 246 x 1189mm

£49.95

A practical guide to the special considerations and tremendous advances for patients who are musicians. Music teachers and musicians as well as therapists will benefit from the material on prevention and correct technique.

ALL ABOVE BOOKS ARE AVAILABLE THROUGH MAIN BOOKSELLERS
QUOTING ISBN NUMBERS OR DIRECT FROM THE PUBLISHERS:

Martin Dunitz Limited,
The Livery House,
7-9 Pratt Street,
London,
NW1 0AE.

THE INTERNET

If you have access to the Internet then you may have already seen the PAA Home Page at: www.paalliance.org

We are currently redesigning and inputting new information and need your help.

- What do you think of the site?
- What would you like to see on the site?
- How could it be improved?
- Would you like an e-mail 'pen-pal' list?

If you have answers to any of these questions or any other comments please send them in an e-mail to: info@paalliance.org

Thank you for your help we will ensure that your comments will influence the future of the site.

Lord Irvine's Legal Aid Changes

The Lord Chancellor, Lord Irvine, recently unveiled a new consultation document on proposals to reform Legal Aid, by watering down Legal Aid for civil claims.

For personal injury cases Legal Aid funding will stop altogether, and those with medical negligence cases still qualifying for Legal Aid will only be dealt with by law firms which employ specialist medical negligence lawyers who are members of the Law Society Panel.

For medical negligence work this means that the number of solicitors accredited to perform this work will be greatly reduced and injured plaintiffs will probably have to broaden their search to find a specialist solicitor able to take on the case.

In future any solicitor wishing to take on personal injury work will only be able to do so on a conditional fee basis, more commonly known as 'No Win-No Fee'. However, there are drawbacks to this. Under a conditional fee agreement:

the client will probably have to pay an insurance premium of between £96 and £161 to protect his position;

the client will probably have to fund expensive medical reports; and

most significantly the client will have to pay a success fee to his solicitor from the damages.

By comparison under the old Legal Aid System, the client would not incur the vast majority of costs or deductions which would have been paid for by the Legal Aid Board.

Because a solicitor does not get paid if a case is lost under the 'No Win - No Fee' agreement, he is naturally going to be more cautious when

assessing more difficult cases. Inevitably only strong cases will be taken on under a conditional fee agreement.

As a general guide most solicitors would expect a 70% + chance of success before a conditional fee agreement was offered. Under the old Legal Aid System, the test was only on the balance of probabilities (i.e. greater than 50%).

Useful addresses:

Disability Law Service - Tel: 0171-831 8031:
Helpline offers legal advice for people with disabilities, their families and carers. Topics covered: benefits, employment, discrimination, education, Social Security etc. Address: Room 241, 49-51 Bedford Row, London WC1R 4LR.

Children's Legal Centre Advice Line - Tel: 0171-729 2652: Helpline for children, parents, professionals. Address: University of Essex, Wivenhoe Park, Colchester Essex, CO4 3SQ.

Action for Victims of Medical Accidents. - Tel: 0181-291 2793: Bank Chambers, 1 London Road, Forest Hill, London SE23 3TP. Fax: 0181-699 0632

If you have suffered an injury or harm as a result of:

Inadequate or negligent care * Inappropriate treatment * Misdiagnosis * Lack of informed consent * Failure to provide treatment

AVMA can provide free professional guidance and support and can refer you to the appropriate professional help you need.

HOT NEWS



The PAA are proud to present *Psoriatic Care*

PSORIATIC CARE HAS ARRIVED at a hospital clinic near you!

This project has been two years in the making, from its conception, to finding the funding to do it, being written, printed and agreed by the Plain English Commission, and finally through to launch and

distribution.

Based on feedback from you early on we've made a start on producing topics to go into the fact file and intend to build on these to make the PSORIATIC CARE FACT FILE an essential informative tool for all clinicians. So when patients go to their dermatology or rheumatology out-patients clinics, there will be no excuse for patients not to receive some information on psoriasis and/or arthritis.

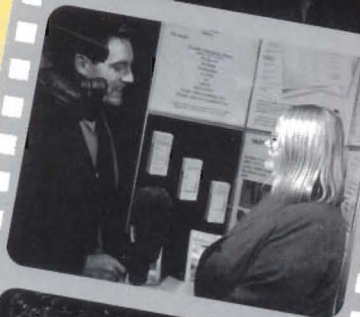
The PAA would like to take this opportunity to thank Evans Dermatology for their kind support and educational grant in making this project possible, with a special thanks to Jacky Ekins at Evans, who along with ourselves put in a lot of time and effort beyond the call of duty to get the Resource File just right – so thanks, Jacky, and congratulations on your new arrival!



We would like to thank Candy Atherton, MP for Falmouth and Camborne, for hosting the launch of the Psoriatic Care Fact File on Thursday 18th June in the Jubilee Rooms at the House of Commons in London. The room was extremely full with well over 100 people attending; this included a large number of interested MPs and Lords.

Candy, as many of you will now know, has both psoriatic arthritis and psoriasis and has only recently decided to speak publicly about how the condition affects her. This will, along with the PAA's, continuing awareness campaign, help to give the condition further publicity.

Here are a few pictures from the launch.



Pharmaceutical R & D

or

Why does it cost so much and take so long?

*We'll drink a drink a drink,
To Lily the Pink, the Pink, the Pink,
The saviour of the human race,
For she invented medicinal compounds,
Most efficacious in ev'ry case*

The Scaffold 1969

"If Lily the Pink was indeed the saviour of the human race, then why did she have to charge so much for her medicinal compounds? What a rip-off!"

"I hear that MegaCorp Pharmaceuticals have a revolutionary new treatment for psoriasis in development. Well why do we have to wait ages for it to be available?"

These are fairly common statements amongst users of prescription medicines (if not actually word for word), especially those suffering from chronic or long-term diseases, and are typical of gripes against the pharmaceutical industry. This article is intended to throw some light on the mystical process of pharmaceutical R & D, or research and development, and perhaps provides an answer to the above statements or even accusations.

However, before that, let's get one thing straight: pharmaceutical companies, by and large, are not philanthropic organisations. Their main aim is to make sufficient profit to satisfy their shareholders, pay their employees, and invest for times to come. In order to do that now and consistently for the future, like any private sector company, they have to constantly develop new products to keep ahead of their competition and to meet their customers' needs. But,

compared to other companies, the processes, or hoops they have to jump through, and limitations placed upon them, are unique.

So, having said that, here are some extracts from the 'Not many people know that' Department..'

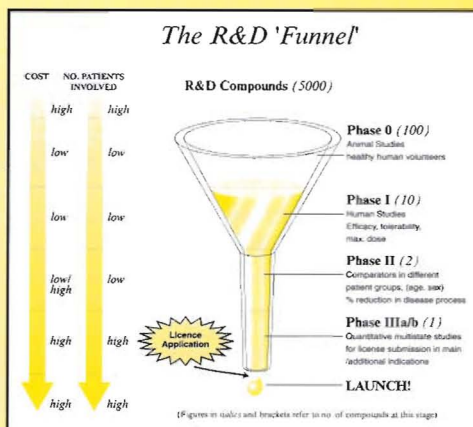
Facts and Figures

- To bring a new chemical entity (NCE) from patent filing to market costs approx. £200m
- The corresponding time may be as long as 12 years
- The drop-out or failure rate for each new compound varies at each stage of development
 - Of over 5000 compounds to reach development stage, only one will reach the market
- There is no guaranteed success once in the market place, or as a return on investment
- For a pharmaceutical company to realise payback, the product must be of global value
- UK pharmaceutical R & D spend is £1451m p.a. (1992) or 17% of sales turnover
- Patent - the unique aspect of a product to which the discoverer has proprietary claim

- Patent protection may apply to
 1. Process of manufacture or
 2. Product, which in turn may apply to the:
 - molecule
 - method of drug delivery
 - mode of action
- Patent life lasts 20 years from first registered manufacture of compound
 - **but it may take the first 12 years to reach the market!**
- Pharmaceutical pricing and promotion is controlled by the government through the PPRS, or Pharmaceutical Pricing Regulatory System, which is a complex formulation based on UK capital employed, research carried out, and several other factors. What it means is that companies cannot charge what they like, nor gain price increases without justification, nor promote the product beyond certain limits.

From Laboratory to Market - the Process

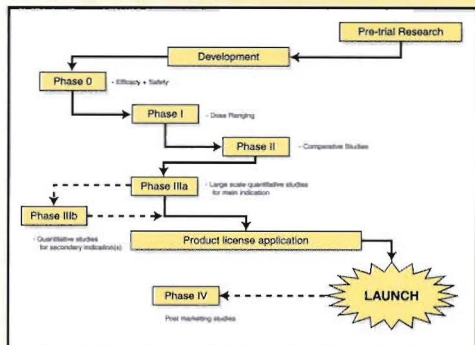
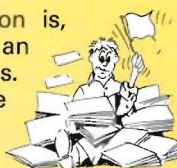
This process comprises a series of recognisable steps which are designed to screen potential compounds using a series of parameters. The system is such that thousands of candidate compounds



may enter at the first stage, but only one may reach the final stage (a bit similar to human fertilisation!).

Phase II is significant as up to this point relatively few numbers of patients are involved, and if the candidate compound has any flaws the development can be stopped without incurring too much expense. Once into phase III, however, not only are large numbers of patients required to prove that the effect of the drug is statistically significantly better than chance, but also this needs to be undertaken in each market in which the drug is going to be launched. Data must be submitted both for the prime indication (phase IIIa) and for additional indication(s) (phase IIIb). Phase III data is required for licence application and may take one to three years to compile, depending on the 'measurable' end point of the disease. Psoriasis, for example, will be longer as there is no or a longer endpoint than, say, conjunctivitis. All the factors of numbers, time, geography etc. equate to very high cost.

Product licence application is, not surprisingly, an extremely fraught process. Backlogs of work and the sheer volume of data being examined by the



licensing authorities mean that most UK product licence applications may take two years and in Japan three!

However, if the drug is deemed of vital importance, the approval time may be shorter, for example it took only 49 days for the FDA (US Food and Drugs Administration) to approve ritonavir, a new class of anti-AIDS drug.

Of course, in practice, no application is straightforward, and licensing authorities may reject or require additional data, all of which means more time and expense.

Launch and beyond

Ah, you may say, now is the time when the pharmaceutical company can start to recoup some of the enormous outlay it has made to date. Wrong! Even before launch, if a licence is anticipated, most companies begin pre-marketing anything up to a year before the actual launch date, especially if the drug is liable to be expensive or will have major impact on the health budget of the purchaser. Most hospitals and many primary health care teams, especially G P fundholders, utilise a formulary, which is in effect a limited list of drugs, that are used to combat the vast majority of diseases faced. To get a product on this formulary usually means that it has to be demonstrably clinically effective and, more importantly these days, cost effective, i.e. it requires a proven health economic argument, or in other words it will save the purchaser money in either the short or the long term. Many purchasers will impose an even stricter requirement, in that before it is considered the new product must be able to displace an old one.

Again, this will all add to the cost as a marketing expense. So, as we now have potential approval by our customers, and the product license has been granted, we can make some cash. Wrong again! Our

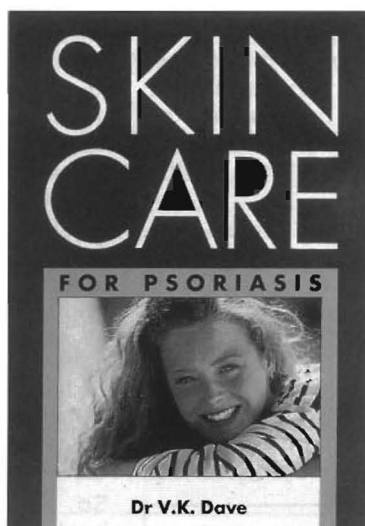
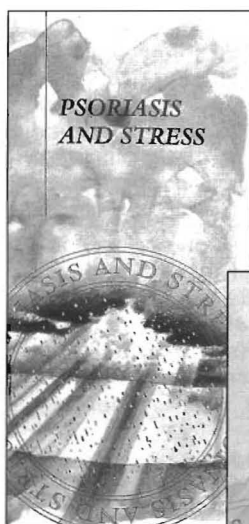
fresh young product is launched, usually with some razzmatazz, to the sales force, all the sectors of the market, and the press (professional and public). Again, these are further big outlays, and what it can only try and anticipate is the reaction of the one big factor outside of the company's control, the competition.

If the product is to be launched into an established market where there are similar compounds, then the competition is likely to be intense. For most companies the most significant item is the sales force. Did you know that it costs approximately £50-60K to keep a G P representative on the road, and to cover the country's G Ps effectively, may cost significantly more. These people will then need promotional materials, including literature, videos, audio tapes, laptop computers and much more to reach their target audience. Other major spend items might include advertising, (press, video, TV, exhibitions), public relations (especially with the press), market research and clinical trials. This last item consists of post launch or phase IV trials. They usually position the product against the competition or test it for efficacy in more unusual or smaller volume indications. For example, a product which is licensed for psoriasis may be trialled to measure its effectiveness in psoriatic arthropathy. Again these trials may incur a six figure spend. All of this activity is designed to establish a brand identity and recognition for the product in the market place. Doctors are just as susceptible to advertising as any consumer, and it is essential that if you want your product to have the image of a BMW, then you don't promote it as a Ford Fiesta!

If the product is new in terms of being a new chemical entity (NCE), this does not guarantee success either. Its credibility still needs to be established with the

continued on page 15

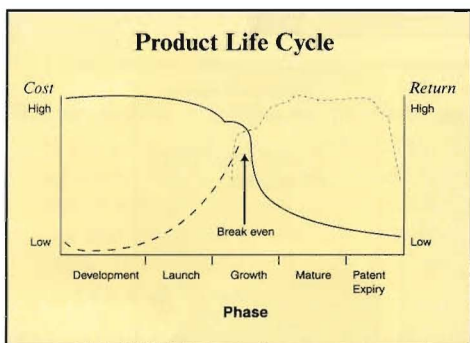
WE ARE PLEASED TO SUPPORT THESE LEAFLETS



— A PRIDE IN —
DERMATOLOGY

purchasers and, increasingly these days, with the end user, the patient. The arrogance of thinking that patients will take what's given them is disappearing rapidly. Informed patients demand a say and, in many cases, particularly chronic ailments such as PA, are at least as knowledgeable as their clinicians. In these cases, patient groups such as the PAA become an important target market sector and are ignored at the company's peril.

It is extremely rare that a molecule is completely unique, and so will invariably face a race to market with several other companies developing something similar. The usual scenario is that whoever gets to market first, wins, gets the major market share, and the rest pick up the pieces. Only one in ten of new products coming to the market will succeed in the long run.



Product Life Cycle

All products have a life cycle which can be illustrated by the graph below:

The return to the company comes when the product is in its growth/mature phase, i.e. where revenue exceeds spend, which may take two to three years, depending on the competition. This period may be telescoped into a fairly short period because, as was mentioned at the beginning, the patent clock is ticking! The patent is designed to ensure that the

company can recoup some of its investment over a fixed period of time. Once the patent expires, the legal protection that the company receives against me-too's, or lookalike products, disappears and generic versions can enter the market. These are unbranded (e.g. ibuprofen instead of Nurofen) and are usually 50% or less of the price of the original. This, of course, collapses the value of the market, and the revenue earning potential of the branded product diminishes.

Companies do anticipate this and can respond in a number of ways which might include new dosage forms, such as sustained release, or some other novel delivery, e.g. transdermal. It may be feasible to switch the product from a POM (prescription only medicine), to P (available through pharmacy), or even GSL (available generally).

So, in conclusion, Lily the Pink's business is precarious indeed. The window of opportunity is relatively narrow. Because of that, the need to pay back all the people with a vested interest (shareholders, employees, banks, creditors) and invest the incredible sums needed to fund research in a more and more demanding environment requires a high return on investment. As a result of this, the critical mass required to balance this equation gets larger and larger. This has led to the current state of mega-mergers in the business (e.g. Glaxo/Wellcome, Ciba-Geigy/Sandoz, Upjohn/Pharmacia etc.), where twice the resource in terms of span of projects being worked on is more likely to produce a result in terms of a successful product.

Basically, it's all just the same as the National Lottery - the more you invest, the more likely you are to get a return!

David Edwards - PAA Adviser

STOP PRESS!

Correction to article which appeared in journal 9

Use of Medication in Psoriatic Arthritis before, during and after pregnancy

DISEASE MODIFYING AGENTS	BEFORE PREGNANCY	DURING PREGNANCY	BREASTFEEDING
SULPHASALAZINE	Safe in women. Causes oligospermia, reducing fertility in men. Fully reversible on stopping.	Safe	Safe
METHOTREXATE	Stop 6 months prior to attempting to conceive	Not safe May damage foetus	Unsafe
INTRAMUSCULAR GOLD	No further injections once pregnancy confirmed	Not safe	Unsafe
HYDROXYCHLOROQUINE (RARELY USED)	Safe	Safe	?Safety
PENICILLAMINE	Withdraw prior to conception	Not safe	Unsafe
AZATHIOPRINE	Caution*	Caution*	Unsafe
CYCLOSPORINE	?Safety	?Safety	Not recommended
CORTICOSTEROIDS			
oral	Safe	Safe	Safe
injection	Safe	Safe	Safe
NON-STEROIDAL ANTI-INFLAMMATORIES (NSAIDS)	Safe	Safe until last 4 weeks. Risk of constriction of ductus arteriosus in baby's heart.	Probably safe, but keep dose to minimum.
ASPIRIN	Safe	Safe until last 6 weeks. Risk of constriction of ductus arteriosus in baby's heart. Increased risk of bleeding of mother and baby at delivery	Probably safe, but keep dose to minimum.
PARACETAMOL	Safe	Safe	Safe
CO-PROXAMOL	Safe	Avoid if possible. Withdrawal effects in neonate.	Safe

D I A R Y D A T E S



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PAA Annual Conference

Saturday 26th September 1998

Woburn Safari Park, Woburn, Bedfordshire



OBITUARY

Professor Verna Wright

Consultant physician and evangelical preacher born December 31st 1928, sadly died on January 31st 1998 of cancer.

His work and tireless efforts led to the development of the internationally recognised research and treatment centre for rheumatism and arthritis in Leeds.

Leeds University was one of the earliest institutions to be set up to search for treatments for chronic pain and disability associated with such diseases as rheumatism and arthritis. He had carried out extensive work on psoriatic arthritis, and research into this still continues today.

He became a research assistant to Professor Hartfall in 1956, who had previously pioneered the use of intra-muscular gold injections in patients with rheumatoid arthritis. Upon Professor Hartfall's retirement, Verna Wright took up appointments as consultant physician at Leeds General Infirmary and Senior Lecturer in the Dept of Medicine. He then began to develop rheumatological services rapidly, establishing a rheumatology and rehabilitation unit from a small house. By 1971 the unit was bursting at the seams with young medical researchers, so expansion was due. Today the unit is recognised worldwide and has more than 30 researchers based there.

Verna Wright became the first person to take up the Chair of the Arthritis and Rheumatism Council.

But it must be said that despite all his achievements Verna Wright's foresight was to have far reaching effects- he formulated the idea of a cohesive group of inflammatory arthritic diseases, the seronegative arthropathies (psoriatic arthritis being one of these). It became apparent through study that the genetic link was a strong one, with many brothers, sisters, mothers, fathers and grandparents being affected by or contributing to such disorders among patients with psoriasis and/or psoriatic arthritis.

Much interest was generated from these theories, giving rise to a strong belief that there was a genetic component to all these diseases, which was later proved with the advent of tissue typing. Research into this theory continues apace today, with several research projects being undertaken into psoriatic arthritis by such doctors as Dr Douglas Veale, who many of you already know is based in Leeds and who is also a very dedicated PAA adviser.

In fact the Leeds Research Centre is continuing to stride to develop and maintain a specialised clinic for psoriatic arthritis patients. Anyone interested in research projects into psoriatic arthritis should contact Dr D. Veale, Dept of Rheumatology, Old Home Leeds General Infirmary, Great George Street, Leeds LS1 3EX. Tel: 0113 292 3956.

We all have a lot to thank Professor Verna Wright for in his dedication and work into psoriatic arthritis because through his efforts our knowledge into psoriatic arthritis can only become greater.

Julie Chandler

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Time	Subject	Speaker
9.00am	Registration, tea/coffee	
10.00am	Welcome and introductions	David Chandler
	OPENING ADDRESS	Guest Speaker
	SESSION ONE – 1 HOUR	Chair – David Chandler
	Making your voice heard	Chris Friend
	Future Remedies – What's new?	Dr Anthony White
11.00am	TEA BREAK	
11.30am	SESSION TWO – 1 HOUR	Chair – David Edwards
	Introducing Young PAA	Eve Baross
	Paediatric PA	Claire Hurstbourne
	Presentation on Psoriasis	Dr Barbara Ansell
		Dr Tony Chu
12.30pm	LUNCH BREAK	
1.30pm	SESSION THREE – 1 HOUR 30 MINS	Chair – Patrick Parker
	Questions & Answers	Medical Panel
3.00pm	AFTERNOON BREAK	
3.30pm	SESSION FOUR – 1 HOUR	Chair – Patrick Parker
	Physiotherapy –Your questions answered	Catherine Buckley
	Complementary Therapies	Dr Virginia Camp
4.30pm	END OF CONFERENCE	

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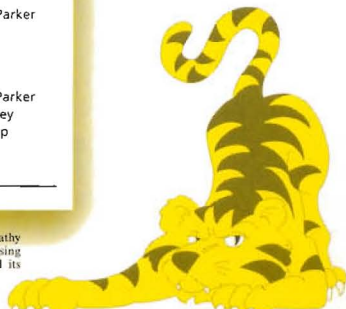
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