



3rd AGM of the BPA 24th October 2004

The AGM of the British Porphyria Association was held on Tuesday 24th October 2004 at Shirley Methodist Church, Birmingham.

There is a considerable change this year to the committee of the BPA, as we added to the new committee:

John Chamberlain (hyperporphyria.org.uk) was elected as the new chairman, and Leigh Treweek (leightreweek@porphyria.org.uk) as the new correspondence secretary.

We also elected the following officers, unopposed: Ann Kesteven (annkesteven@porphyria.org.uk) as Treasurer, Kirstine Chamberlain as elected secretary, Sandy Clark (sandy@bpa.org.uk) as secretary, and Karen Bland as elected monitoring and finance officer for 2005.

It was announced that subscriptions would be collected from all members for the year at the beginning of each year. All members will be receiving a letter in January.

There was discussion regarding getting more staff to offer support to patients on to specialists.

We were pleased to welcome Dr Alex Hoang, who is currently working on research into field disease in EPP patients. He gave an interesting talk about his research. Following this we presented him with a cheque for £2500 towards his research.

Following the formal AGM there were refreshments and a quiz open to all for all the members.



NON-PORPHYRIC SKIN DISEASE IN PORPHYRIA PATIENTS

ACNE: Topical treatments for acne to moderate acne are generally safe in patients with porphyria, though there is scant evidence in the literature. Unfortunately, none of the commonly used antibiotics are safe. Clindamycin, the most effective treatment for acne, is unsafe in the acute porphyria and should be avoided.

ECZEMA: Eczema is often associated with a combination of environmental and internal causes in porphyria. These treatments are generally safe. Moisturisers keep the skin in good condition, which may help to avoid minor injuries and skin splits which may lead to poisoning. Gentle emollient creams as a precaution, given to help reduce itching. Topical glucocorticoids (cortisol and Prednisolone) are safe and considered safe. Most often and if necessary should be avoided. Cortisol top systemic treatment for eczema, if necessary and if a glucocorticoid is both safe in all forms of porphyria. Ciclosporin, another agent occasionally used to treat eczema, is not safe. For subsequent treatment of eczema, see below under psoriasis.

PSORIASIS: Treatment with moisturisers and topical glucocorticoids is safe. Topical treatments such as Calcipotriol, Ointment and coal tar are not known to be harmful. Systemic treatments for psoriasis include: Methotrexate which must be used



with caution. Acitretin and Etretinate are both unsafe. Systemic light treatments are often used together with psoriasis tablets for both psoriasis and eczema, however it should be avoided for patients with photosensitive porphyria. Psoriasis tablet which are known to be unsafe should be avoided by those who have any of the acute porphyrias.

SUN SENSITIVE: Sometimes the skin needs to be protected with sun cream. The diagnosis can be benign tanning or malignant melanoma. This is usually done under local anaesthetic. Most local anaesthetics are safe in porphyria, but Bupivacaine should be avoided.

WARTS: Preparations such as salicylic acid cream or paint are safe but care should be taken since the skin is photosensitive. This is also the case for cryosurgery.

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Daniela Niemeyer

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