PATIENT INFORMATION LEAFLET

LICHEN PLANOPILARIS

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about lichen planopilaris. It explains what lichen planopilaris is, what causes it, what can be done about it, and where you can get more information about it.

WHAT IS LICHEN PLANOPILARIS?

Lichen planopilaris is when a skin condition, known as lichen planus, affects areas of skin where there is hair. Lichen planopilaris destroys the hair follicle and then replaces it with scarring, resulting in permanent hair loss. It is between 2 and 5 times more common in women than it is in men, which usually happens to people aged 40-60 years old.

WHAT CAUSES LICHEN PLANOPILARIS?

The cause of lichen planopilaris is unknown. T-lymphocytes, a type of white blood cell, are involved but we do not know why it starts. The hair follicle (hair root) is attacked by the person's immune system. Both lichen planopilaris and lichen planus cannot be passed to other people.

IS LICHEN PLANOPILARIS HEREDITARY?

No, lichen planopilaris is not inherited. However, there may be genes affecting the immune system responsible for increasing the risk of developing the condition.

WHAT ARE THE SYMPTOMS OF LICHEN PLANOPILARIS?

H Lichen planopilaris typically causes an itchy, painful, burning or tender scalp. The crown and vertex (top of the scalp) are most commonly affected. Areas of hair loss or scarring may be noticed. Lichen planus can also affect the skin, mouth, genitals and nails (for further information, please see Patient Information Leaflet on lichen planus).

WHAT DOES LICHEN PLANOPILARIS LOOK LIKE?

Lichen planopilaris causes redness and scaling of the skin around the base of a hair and blocking of the hair follicle, which may give the scalp a rough texture.

Where hairs have been destroyed, the scalp may appear smooth and shiny. Lichen planopilaris often occurs in patches but may involve larger areas. Face and body hair can be affected.

Other related conditions include:

- Frontal fibrosing alopecia. This is a condition that occurs most often in post-menopausal women. The frontal hairline recedes slowly in a band. Eyebrow and body hair can also be lost. (For further information, please see Patient Information Leaflet on frontal fibrosing alopecia).
- *Graham Little Syndrome (Piccardi-Lassueur-Graham Little Syndrome).* This is a condition in which patchy scalp hair loss happens along with loss of armpit and pubic hair and a bumpy, sometimes itchy rash on the body and limbs.

HOW IS LICHEN PLANOPILARIS DIAGNOSED?

The skin team may do a biopsy (taking a small sample) of the affected area of the scalp to confirm the diagnosis. This may

involve removing at least 2 small areas of affected scalp skin under local anaesthetic and will leave small scars.

CAN LICHEN PLANOPILARIS BE CURED?

Lichen planopilaris is a long-term condition; however, in most cases the condition does eventually become inactive. The loss of hair is usually permanent. Although the condition cannot be cured, treatment aims to help keep the remaining hair and help to control symptoms. Photographs or measurements may be taken in the clinic to help measure disease control.

HOW CAN LICHEN PLANOPILARIS BE TREATED?

Lichen planopilaris can be treated with prescription creams, shampoo and gels, and with tablets. Success rates can be very variable. There is no single proven effective treatment for this condition and some people fail to respond to any treatment. You do not have to have any treatment. You may want to discuss all the options with your GP, family or friends.

Treatments to the skin:

- *Topical corticosteroids*. Steroid-based preparations (for example, lotions, gels, or mousses) can help areas of affected skin. They are applied to the affected areas only. Scalp skin is much thicker than facial skin and tolerates steroid creams better than the skin on other areas of the body. Steroids can cause thinning of the skin if used incorrectly. Topical steroid preparations can help improve itch and reduce the rash (see Patient Information Leaflet on topical corticosteroids).
- *Intralesional steroid therapy*. Steroid injections (known as 'intralesional steroids') into the affected area can be effective treatment for a small area. However, is often painful or uncomfortable, and has a higher risk of causing adverse effects such as thinning of the skin (atrophy) or dimpling of the skin (see Patient Information Leaflet on intralesional steroid therapy).
- *Topical calcineurin inhibitor creams and ointments.* These topical treatments can settle inflammation and do not cause thinning of the skin. Side-effects include stinging to begin with (this usually improves with time). Excessive sun exposure, sunbathing and sunbeds should be avoided while using this treatment (see Patient Information Leaflet on topical calcineurin inhibitors).

Tablet Treatments:

- *Corticosteroids*. A short course of steroid tablets may quickly reduce inflammation in severe cases, with the hope of stopping hair loss. However, side effects such as high blood pressure, diabetes, osteoporosis, and weight gain limit long term use. Sometimes steroid tablets are given as a bridge while waiting for another longer acting treatment to take effect (for further information, please see Patient Information Leaflet on oral treatment with corticosteroids).
- *Hydroxychloroquine*. This drug can be very helpful but can be slow to work. Usually, a minimum trial of 4-6 months is required to see whether the drug is working. If helpful it may be continued until the condition becomes inactive. It is not certain how the drug works to stop hair loss. Very rarely, hydroxychloroquine may damage the retina (the layer of cells in the back of the eye that detects light and allows you to see) particularly in those needing treatment for more than 5 years. The risk of this is generally prevented by keeping the dose low, and limiting the overall length of time on this

treatment. While you are taking hydroxychloroquine annual eye tests may be recommended (see Patient Information Leaflet on hydroxychloroquine for further information).

- *Immunosuppressive drugs.* Several different tablets are used to treat lichen planopilaris by reducing inflammation (i.e. the T-lymphocytes). These are usually safer than taking steroid tablets in the long term, but do have side effects and therefore require dermatology appointments and blood tests. It is not recommended for women to become pregnant whilst on these medications. The immunosuppressive drugs include azathioprine, ciclosporin, methotrexate and mycophenolate mofetil (please see the relevant Patient Information Leaflets for further information).

Other tablets:

- *Acitretin and isotretinoin* are other drugs that have been used; however, isotretinoin is preferred because acitretin itself has a higher risk of causing hair loss. There are important risks concerning pregnancy when taking acitretin or isotretinoin. Please see the relevant Patient Information Leaflets for further information.
- *Tetracycline or doxycycline* are antibiotics commonly used in the treatment of acne but can also be used to treat lichen planopilaris. These drugs have few side-effects and do not require any monitoring by blood tests.
- There is some evidence to show that the off-licence use (using a medication outside of the designated terms of its UK licence) of a diabetes drug called pioglitazone, might also be helpful in the treatment of lichen planopilaris. This is generally well tolerated, but there have been some safety concerns with long term use, including a possible association with bladder cancer.
- *JAK inhibitors* are new medications and trials are underway for their use in a variety of skin and hair diseases. Their role in lichen planopilaris has not been clearly demonstrated yet.

Further treatments:

- Some people who have extensive hair loss from lichen planopilaris will choose to wear a wig or a hairpiece. These can either be bought privately or obtained through the support of the NHS with a consultant's prescription (although they may not be free depending on which country you live in and may be limited to a locally agreed supplier).
- Wearing a hat or scarf is another way of hiding hair loss.
- Once lichen planopilaris has been stable for a number of years it may be possible for permanent areas of hair loss to be removed or reduced in size by an operation, but it is not available on the NHS. Hair transplantation is another option, but only once the condition has stabilised and is also not available on the NHS. Sometimes the disease recurs in the surgical site and affects these new areas.

SELF-CARE (WHAT CAN I DO?)

- Join a hair loss support group (see next section).
- Seek unbiased medical help and be sceptical of online solutions, especially those that offer instant, or quick, remedies.
- Eat a normal healthy diet; no particular food has been linked to lichen planopilaris.

- Consider using techniques to camouflage the problem such as wigs, hair pieces, powders, sprays and hair fibres that are matched to your hair colour.
- Consider using topical minoxidil 5%, available without a prescription, which will improve any expected age related hair thinning and may help your existing hair look thicker.

WHERE CAN I GET MORE INFORMATION ABOUT LICHEN PLANOPILARIS?

Web links to detailed leaflets:

www.dermnetnz.org/hair-nails-sweat/lichen-planopilaris.html
www.nahrs.org

Patient support groups:

Cicatricial Alopecia Research Foundation (US)
Web: www.carfintl.org
Email: manchesteruksupportgroup@carfintl.org

Other websites you may find helpful:

British Hair and Nail Society
Web: www.bhns.org.uk

Most other hair loss support groups focus on alopecia areata, but can offer useful advice for all patients suffering from hair loss.

Alopecia UK
Tel: 0800 101 7025
Web: www.alopecia.org.uk
E-mail: info@alopecia.org.uk

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

BRITISH ASSOCIATION OF DERMATOLOGISTS

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