



## **Jeff Donovan MD PhD FRCPC**

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### **FOLLICULAR MUCINOSIS (Alopecia mucinosa)**

#### **What is follicular mucinosis?**

- This is a hair loss condition that can occur at any age. In some cases the hair loss is permanent
- It is sometimes referred to as 'alopecia mucinosa'
- The condition must be closely followed as rarely it can be associated with a cancer (such as mycosis fungoides, Hodgkin's lymphoma, etc). If this is going to occur at all, the cancer generally occurs within the first 5 years after diagnosis but can occur later. Therefore, close follow up is necessary and you are advised to always attend appointments at the intervals recommended to you.

#### **Who gets follicular mucinosis?**

- It occurs in all ages
- Men are slightly more likely to get follicular mucinosis than women

#### **What are the symptoms of follicular mucinosis?**

- Itching, loss of sweating in the area
- Lesions affect the face, neck and scalp as well as other areas of the body

#### **How does the doctor arrive at the diagnosis of follicular mucinosis?**

- There are many appearances that suggest the diagnosis, including flesh colored areas, acne like areas
- A jelly-like substance may be discharged from the openings
- There may be increased shedding as well as patchy hair loss
- As part of the examination, your doctor will examine your lymph nodes, spleen and abdomen
- Several biopsies may be taken and sent for special tests (called cell markers and T cell gene rearrangements)

- You may have have blood tests ordered such as:
  - CBC, LFTs, creatinine, BUN
  - Fasting triglycerides and cholesterol
  - Blood smear
  - LDH
  - CD4/CD8 ratio
  - HTLV-1 serology +/- HIV serology
  - Other tests will be ordered if needed (Lymph node sample, bone marrow sample, CT exam, chest x-ray)

#### **How is follicular mucinosis treated?**

- You may be referred to another doctor to evaluate for any associated malignancies
- Your doctor will guide you with treatment. Treatment may be done with topical corticosteroids or pimecrolimus and well as injection of corticosteroids into the scalp
- Other treatments include tetracycline, isotretinoin and dapsone and PUVA light therapy or radiation
- Topical tazorac 0.1 % may be recommended
- A repeat biopsy may be done in 6 months to 1 year.

#### **How long will I be on these treatments?**

- Your disease will be carefully monitored. If the disease does not appear to be spreading, the doses of medications will be reduced and possibly stopped.
- However, if there is any evidence the disease is spreading, increased doses or even new medications may be prescribed.

