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:
  o CBC, LFTs, creatinine, BUN
  o Fasting triglycerides and cholesterol
  o Blood smear
  o LDH
  o CD4/CD8 ratio
  o HTLV-1 serology +/- HIV serology
  o 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.