



Cutaneous Lymphoma Patient Education Forum

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Thank you

- Judy Jones
- Amanda Kik



CUTANEOUS
LYMPHOMA
FOUNDATION

- Nurses at
PERC



The **New** Women's College Hospital

- Medical
Faculty



DEPARTMENT OF MEDICINE



Goals for Today

- Forum to share information & ideas
- Looking to a better future for the management of skin lymphomas in Ontario
- First meeting of major stakeholders



What is cutaneous (skin) lymphoma?

- A type of cancer that affects certain white blood cells called T-lymphocytes.
- Cutaneous T cell lymphoma (CTCL)
 - Mycosis fungoides – skin
 - Sezary syndrome – skin & blood



What are the problems?

- Skin disease is very upsetting.
- Cancer is very upsetting.
- Itching is horrible.
- Not getting answers is frustrating.
- Getting different answers is worse.
- Not knowing what to do is worrying.
- Not getting better causes desperation.



More problems...

- I never heard of this condition.
- My doctor never heard of this.
- Why did it take so long to make the correct diagnosis?
- Why isn't the treatment I need available in Canada?
- Who is going to help me?
- Who is doing research in CTCL?



Some special goals

- Early diagnosis
- Education of patients and their family, healthcare providers, insurance companies, government
- Equal access to information and resources
- Effective treatments
- Empathic healthcare



Our Hope: Cutaneous Lymphoma Network

- First diagnosis – dermatologist
- Referral to CTCL Clinic (@ PERC)
 - Or to one of the CTCL dermatologists
 - Or to one of the CTCL oncologists
- Diagnosis, tests, treatment plan
 - According to a standard plan
 - Individualized to patient's need

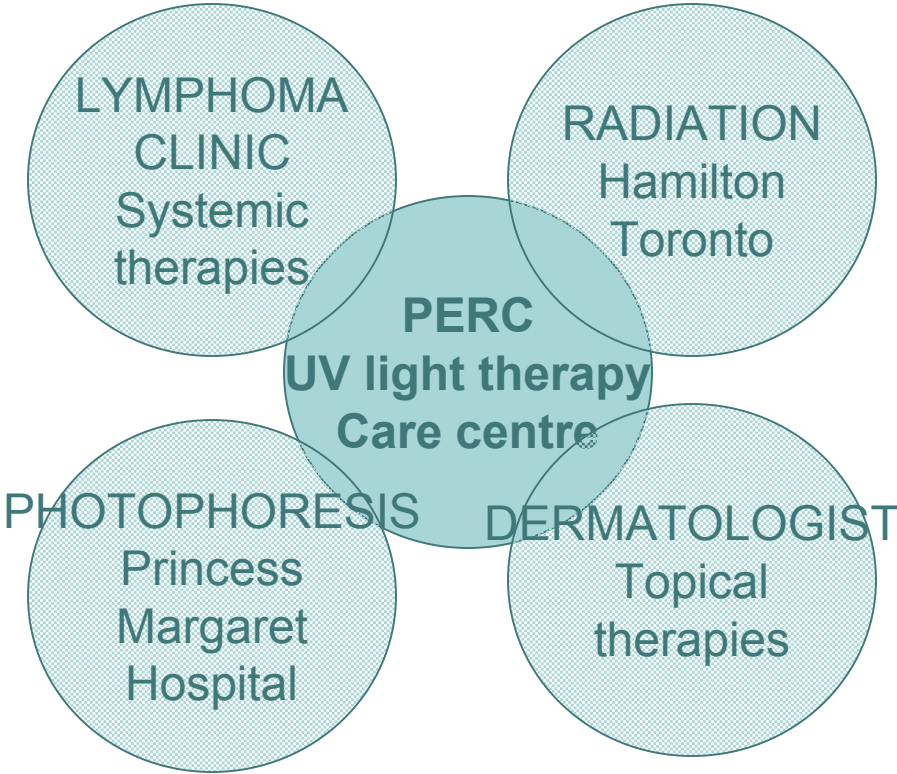


Continuity of care

- Appropriate to severity / staging
 - With dermatology at PERC or other
 - With oncologist at Cancer centre
- Updates on new therapies
- Continual lobbying activities



Special services





Step-by-step

- You have a rash
- Dermatologist thinks of CTCL
- A biopsy is done from the skin
- A skin pathologist needs to “read” this to make the diagnosis and special tests are done to confirm it
- Investigations are done to “stage” the disease



More steps

- You will be seen by a Network dermatologist and a Network oncologist
- You will learn about CTCL and what it means for you
- Treatment options will be discussed