

# Webinars

# Cutaneous Lymphoma

EuroBloodNet  Topic on Focus

Patients' Organizations

## Impact of Treatments on Quality of Life

**Speaker Keturah Harris with Susan Thornton**

CTCL Patient

c/o Cutaneous Lymphoma Foundation

ERN-EuroBloodNet

Guelph Ontario –CANADA

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# A bit about me...



- Resident of Guelph, Ontario Canada
- Author, Business Consultant, Caregiver, Patient Advocate & patient
- CTCL Diagnosis: September 17, 2013
  - (pre-2013) Atopic dermatitis since 2007
- (2013) CTCL Mycosis Fungoides Stage 1B + follicular involvement (age 47)
- (2015) Large cell transformation

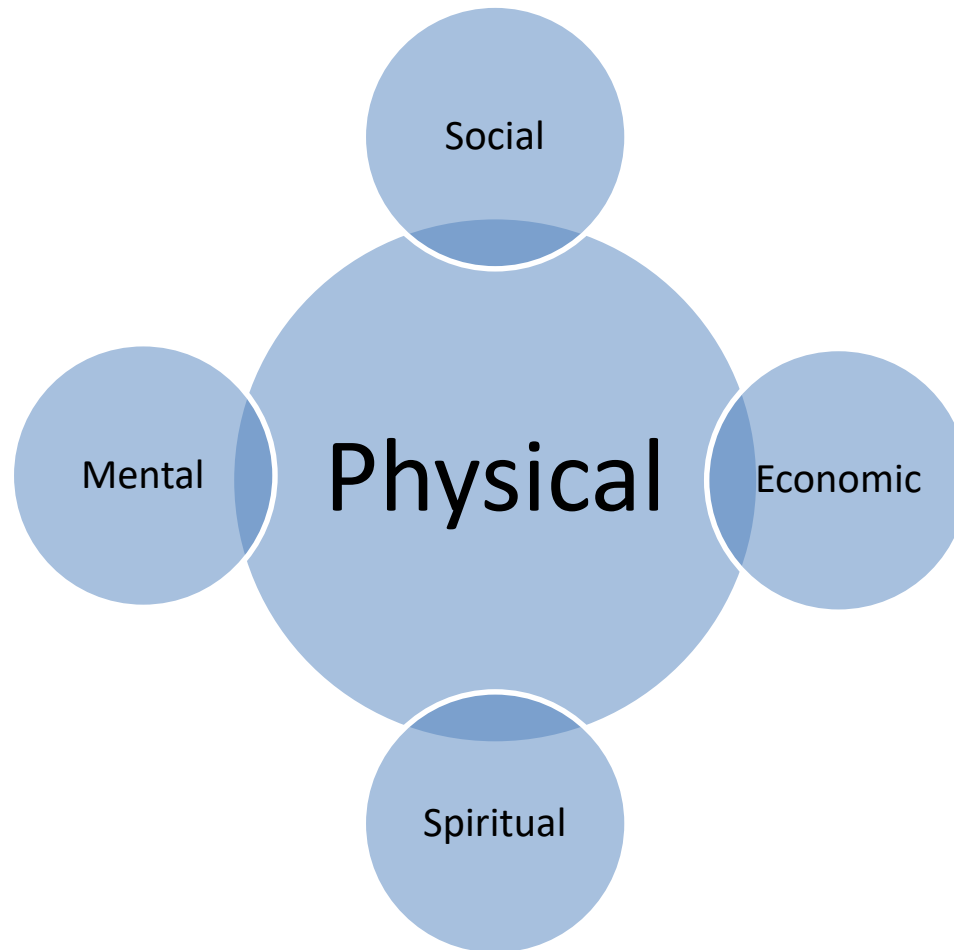
# Treatment History



Pre-diagnosis – “7 years itch” (pruritus) contributing to compromised immunity & sleep deprivation

Skin Directed/Topical	Systemic
Phototherapy <ul style="list-style-type: none"><li>○ PUVA Narrowband 3 x per week (2013 – 2016)</li><li>○ PUVB Narrowband (2021 – current)</li></ul>	Kenalog steroid injections (2013 – current)
Topical Cortisol Steroid Creams (2013 – current)	Immunotherapy Interferon A (2016 – 2021)
Radiation (2015, 2016, 2021)	Retinoid Vitamin A (2013 – 2015) (2021 – current)
Additional Prescribed Medications: Doxepin – pruritus Zopiclone – sleep aid Extra Strength Tylenol – Flu-like symptoms	

# Quality of Life Domains



# Lessons Learned so far...



<b>Physical</b>	Access the best health team you can afford – medical + integrative Aim for quality, stress-reducing lifestyle - diet, exercise, relaxation, recreation Monitor and address other non-CTCL aspects of your health
<b>Social</b>	Connect with a Cutaneous Lymphoma Foundation network Stay consistently touch with close family & friends Seek meaningful or joyful activities that promote inclusion; Reduce stress by creating positive, harmonious relationships
<b>Economic</b>	Connect with local and regional insurance and drug reimbursement specialists Contact regional cancer networks (explore funding, homecare, transportation etc.) Stay engaged in meaningful work and supportive work environments
<b>Mental</b>	Include a mental health professional Learn coping strategies to reduce stress (e.g. yoga, mindfulness, journaling) Join a cancer or CTCL peer-to-peer support group
<b>Spiritual</b>	Explore and deepen spiritual practices (e.g. prayer, meditation, affirmations) Connect with credible spiritual mentors, leaders and communities Give-back to others and the community Practice GRATITUDE

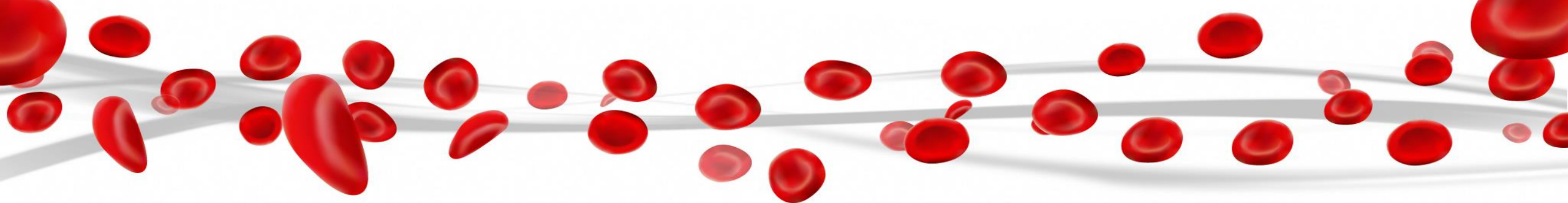


Stay Engaged

Stay Vocal

Stay Hopeful

Stay Blessed & Be a Blessing



## Discussion