



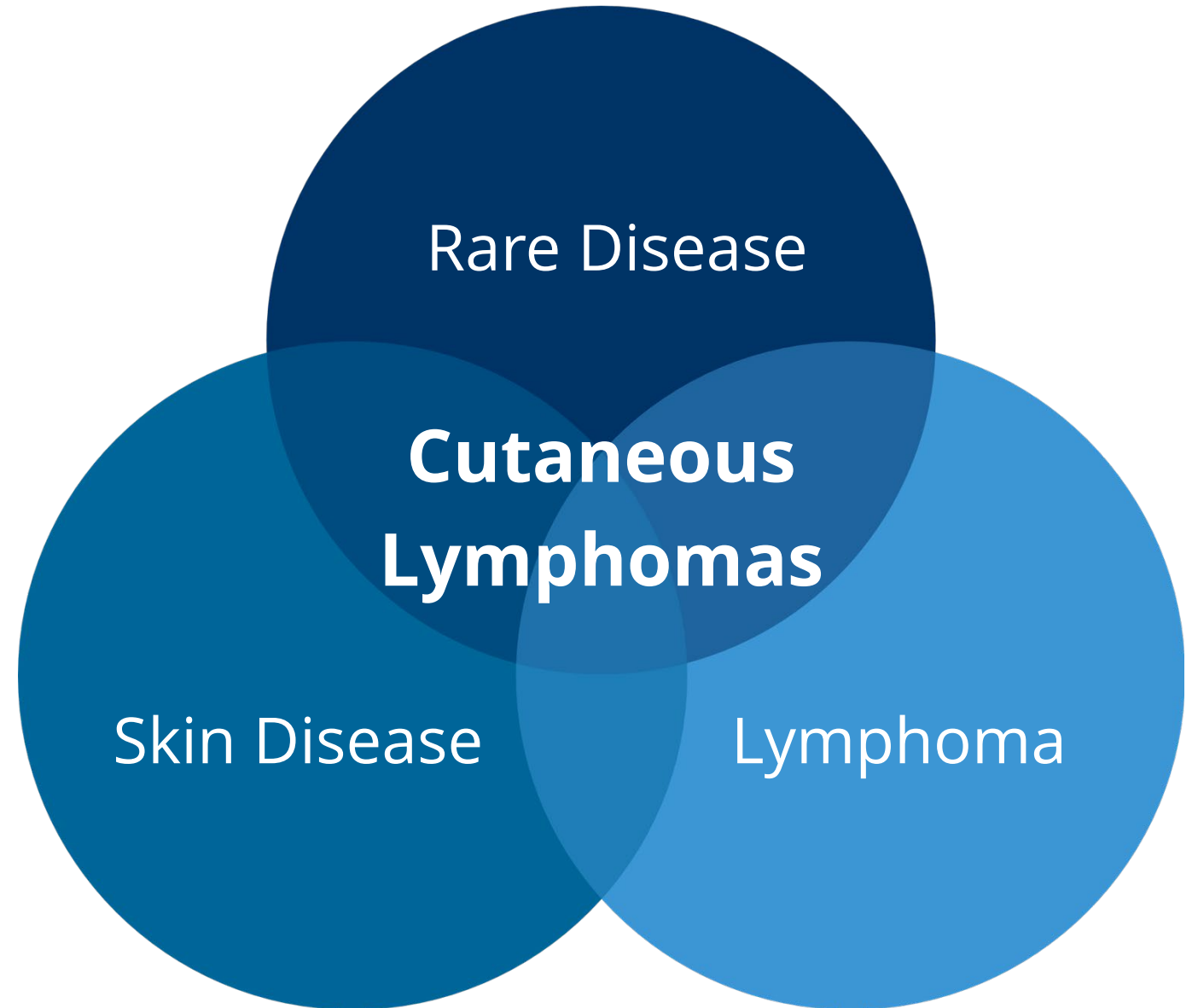
Cutaneous
Lymphoma
International
Nurses
Network

CUTANEOUS LYMPHOMA INTERNATIONAL NURSES NETWORK

The newly formed CLINN is an international group of nurses dedicated to advancing care for cutaneous lymphomas through collaboration and connection. The CLINN, managed through the Cutaneous Lymphoma Foundation, has begun work to develop:

- An international networking platform
- A resource library
- Educational webinars and other training support
- Planning for a clinical meeting

Crossing Disciplines



**Making Change
through
Alliances and
Collaboration**

**Introduction of the
Cutaneous Lymphoma
International Nurses
Network Initiative
(CLINN)**

Global Challenges in CL Nursing Care

Improve	Improve skin integrity
Alleviate	Alleviate pruritus
Maintain	Maintain homeostasis
Relieve	Relieve pain
Prevent	Prevent infection
Address	Address psychosocial needs
Assess/assist	Assess/assist with activities of daily living
Assess/address	Assess/address knowledge deficit (disease process, therapeutic options, chronic disease management)

How It Began: Core Leaders

- Odette Buelens, Skin Lymphoma Nurse Practitioner-Australia
- Claire Lusted, Advanced Nurse Practitioner-United Kingdom
- Sue McCann, MSN, RN, DNC-United States
- Marianne Tawa, RN, MSN, ANP-United States
- Susan Thornton, CEO, Cutaneous Lymphoma Foundation - International Patient Organization



Timeline/History

- Phone call from Australia to the CL Foundation
- First International Nurse Workshop-London
- 2020 World Congress of Lymphoma-Initial discussion
- Followed by renewed discussion post Covid hold
- Regular Zoom calls with core group
- Fall 2022-Survey launched & results analyzed
- First webinar held among CLINN membership-Spring 2023
- Prioritized projects initiated
- Basecamp platform for collaboration initiated
- Early 2025 re-launch

2015-2017

2020-2021

2022-2024

2015

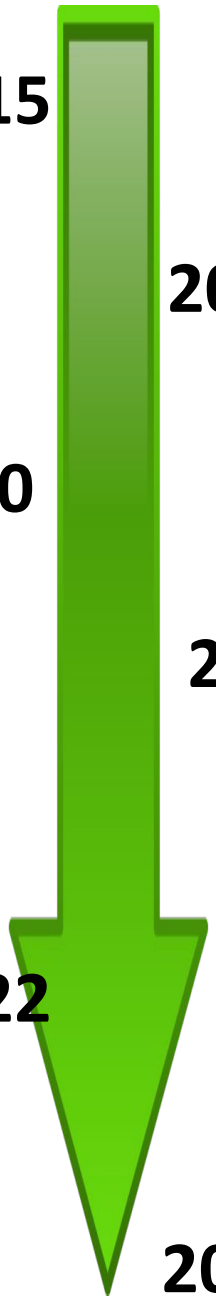
2017

2020

2021

2022

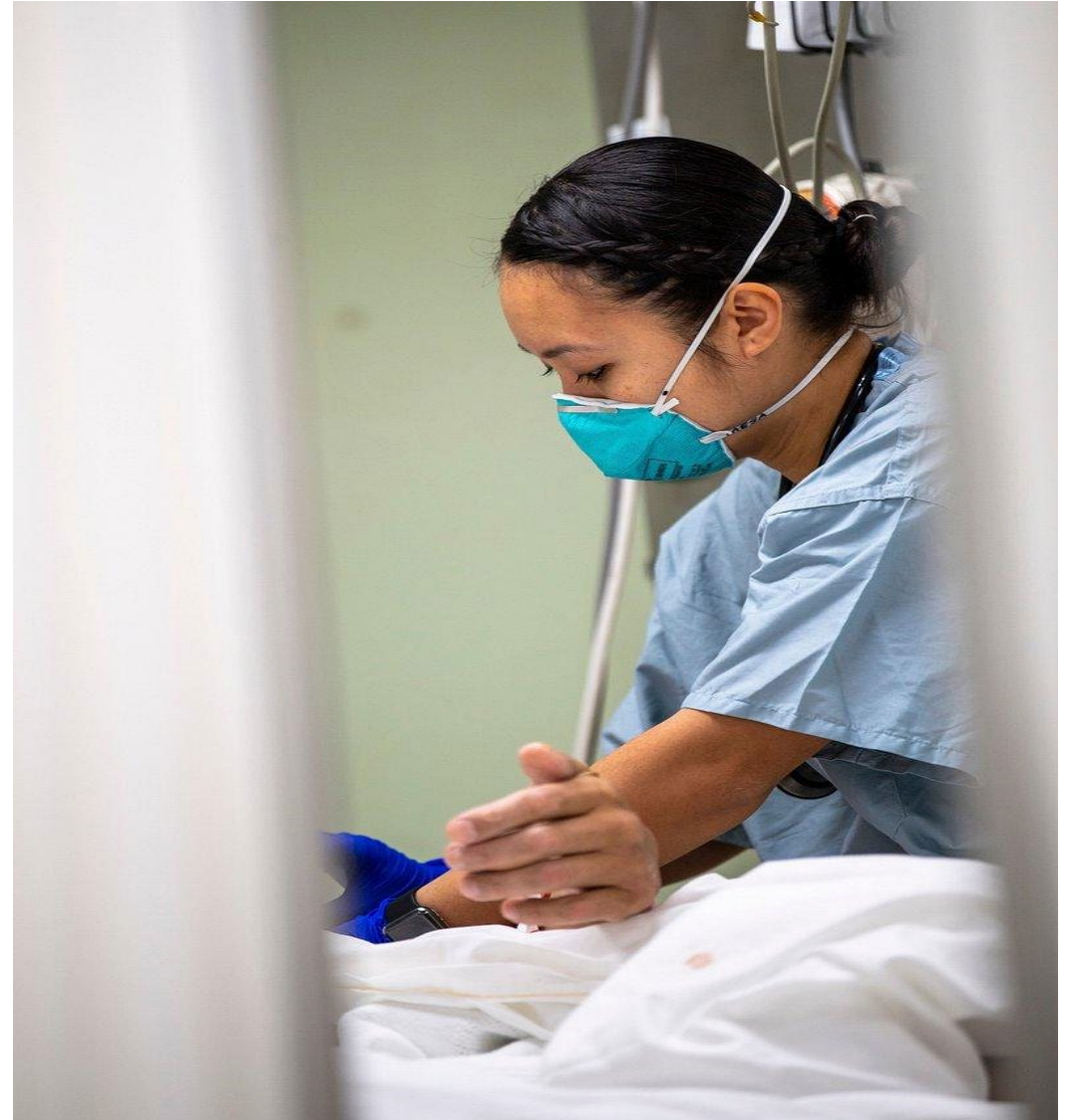
2025



First step: International Survey of CL Nurses

AIMS of the SURVEY

- Gather data on clinical practices
- Understand practices utilized internationally
- Identify gaps in education and needs of nurses caring for CL patients globally
- Determine perceived need for nurses to connect and collaborate with each other to meet the identified needs



SURVEY APPROACH

- Online questionnaire developed by core team over multiple meetings
 - Sensitivity to international nomenclature
 - roles
 - practices & resources
- Used multiple sources to develop database of CL nurses
 - Specialty nursing organizations
 - Pharma partners
 - Cutaneous Lymphoma Foundation



Survey Questions

- Role in the care of patients with CL?
- Venue of specialization?
- Areas of expertise?
- Practice setting (urban/non-urban)?
- Type of setting (academic, community, inpatient, solo)?
- Access to specialty services (type of specialist, infusion, light therapy)
- Level of experience and familiarity with management for CL?
- Percentage of time spent with CL patients?
- Acquiring knowledge?
- What are the unmet educational needs?



Survey Highlights

Total respondents	128
Countries	US/UK/Australia/Switzerland/Canada
Discipline	Dermatology/Hematology/Multi-Disciplinary
Practice Setting	Primarily Urban (77%) and Academic (32%)
Level of Experience	Novice—24 Intermediate—50 Expert--17
Is there an unmet need for nursing education?	73% responded Yes
Would you be interested in attending educational programs?	53% Yes

Areas of Expertise Among CL Nurses

NP/PA-C	26%
Phototherapy	23%
Other (community/medical dermatology; transplant; infectious diseases; topical therapy; chemotherapy)	21%
Acute Oncology/Navigator	20%
Wound Care	19%
Photopheresis/Apheresis	17%
Research/Clinical Trials	14%
Infusion Service	10%
Radiation Oncology	6%
Palliative Care	4%
Psycho/Social Services	3%
Home Care	2%

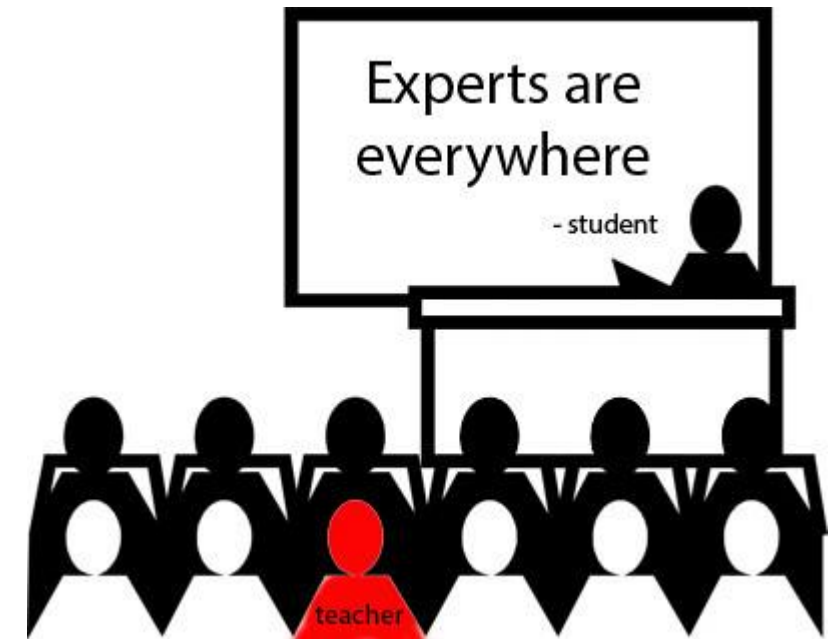
How CL Nurses Acquire Knowledge

Responses (check all that apply)

- On the job
 - ◆ Mentors in clinical setting 48
 - ◆ Physician provided
 - ◆ Nursing provided

- Professional meetings 27
 - ◆ Conferences/seminars
 - ◆ Webinars/On-line

- Independent
 - ◆ Literature reviews
 - ◆ Journals
 - ◆ Other



11 Key Themes Emerged

- SOC treatment options
- Essential disease-related concepts
- Essential nursing care concepts
- Referral issues
- Treatment development pipeline
- Long-term management issues
- Patient education needs/strategies
- General nursing education across disciplines
- Complex disease management
- Access to available physician education/courses/talks
- Acute care setting-from direct care to multi-disciplinary management & referrals

4 Major Educational Themes Identified

- Treatment updates/options/side effects – Country specific
 - SOC, complex care, current research/results, new concepts in treatment
- Primer of essential disease-related concepts
 - Pathogenesis, etiology, diagnosis, staging, prognosis
- Primer of essential nursing care concepts: commonalities world-wide
 - Skin care, wound care, infection prevention, symptom management
 - Long-term and acute-care management
- Education needs
 - Patient education needs/strategies
 - Nursing education in diverse setting & access to available knowledge

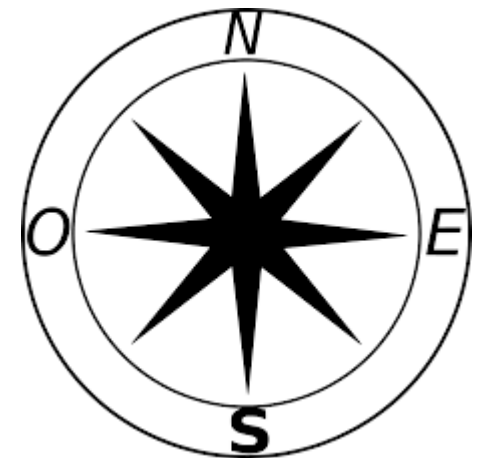
Insights from Nurse Survey: Conclusions

- Need to connect this clinical community
- Educational resources are limited
- Leverage and share skills, knowledge and experience with the treating community



Emerging Directions for Collaboration Identified

1. Essential disease related education
 - Pathogenesis, diagnosis, staging, prognosis, therapies, clinical trials
 - Acute/chronic nursing care: symptom management, skin/wound care, patient education, quality of life
2. Networking and engagement with other practitioners
 - Access to online and in-person educational opportunities
3. Development of nursing clinical practice/education
 - Curate accessible learning modules
 - Wound care



CLINN

Consensus on Next Steps

Careful review of survey responses and feedback from key stakeholders

CLINN priorities fall nicely into place



Collaboration is KEY

- CLINN is endeavoring to connect and collaborate with nursing organizations globally to engage and promote the CLINN projects
- DNA/ BDNG/ Irish Dermatology Nurses Association(IDNA)/ Haematology Nurses and healthcare Professionals Group (HNNHCP) and others
- FUNDING \$\$



Project 1- Repository of Cutaneous Lymphoma Nursing Education

- Agree that there is large and diverse repertoire of CL literature currently available, but not necessarily easily accessed
- This repository has a solid foundation but always in progress to include:
 - collection of CL nursing guidelines
 - evidenced basing CL nursing literature and research articles
 - quick reference guides on symptom management
 - vetted power points on disease state/assessment/management strategies
 - forum for Q&A and problem solving
 - hosting webinars
- Platform for educational resources and connection to accommodate nursing stakeholders is on the CLF Basecamp

Project 2- Wound Care Education Package

- Wound care education tailored to CL patient population
- What literature is available and where are the gaps?
- On-line wound care series with fundamental approaches to the wound care needs of the high-risk CL patient to be developed
- Challenges expected with generalizing content to an international audience given product availability
- Anticipate collaborations between inpatient/outpatient nursing with crossover to WOCN and like partners internationally
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- Current work group consists of NPs from Australia/England/USA