

**CLL SOCIETY**

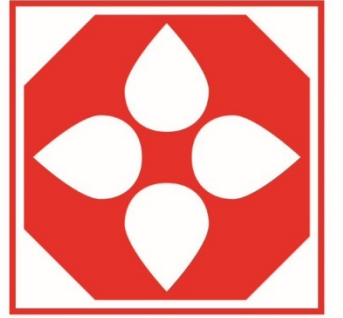
*Smart Patients Get Smart Care™*

# **Beyond the Diagnosis: Surviving and Thriving with CLL / SLL**

**August 21, 2023**

**11 AM PT, 12 PM MT  
1 PM CT, 2 PM ET**

This Program Was Made Possible  
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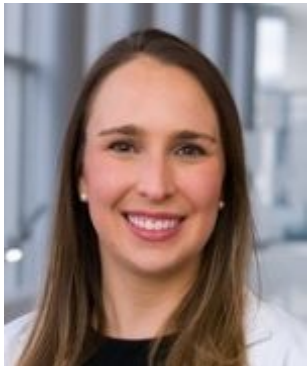
# Speakers



**Moderator**

**Stephen Feldman**

CLL Patient Advocate, Senior Support Group Advisor,  
Member CLL Society's Patient Advisory Board



**Speaker**

**Heather Wolfe, MD**

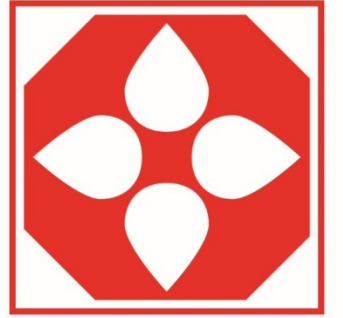
Assistant Professor, Department of Internal Medicine  
Director of CLL Survivorship  
UT Southwestern Medical Center



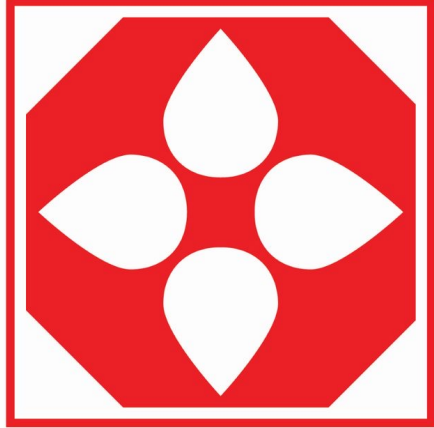
**Welcome**

**Robyn Brumble, MSN, RN**

Director of Scientific Affairs and Research  
CLL Society



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# Beyond the Diagnosis: Surviving and Thriving with CLL

**Heather Wolfe, MD**

Assistant Professor of Internal Medicine

Director of CLL Survivorship

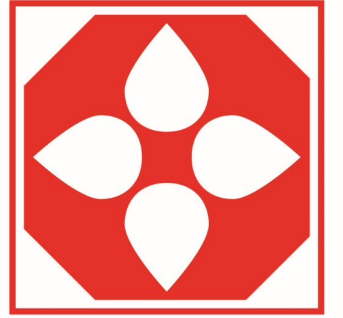
Harold C. Simmons Comprehensive Cancer Center

University of Texas Southwestern Medical Center

**August 21, 2023**

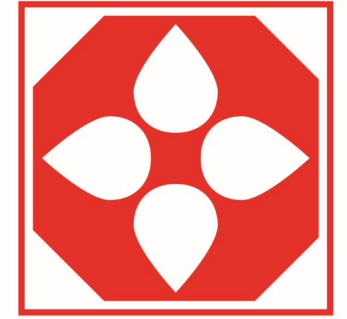
# Learning Objectives

1. Survivorship Care in CLL
2. Infection Prevention
3. Secondary Cancer Screening
4. Cardiovascular Health/Risk Factor Modification
5. Bone Health
6. Mental Health
7. Additional Survivorship Recommendations

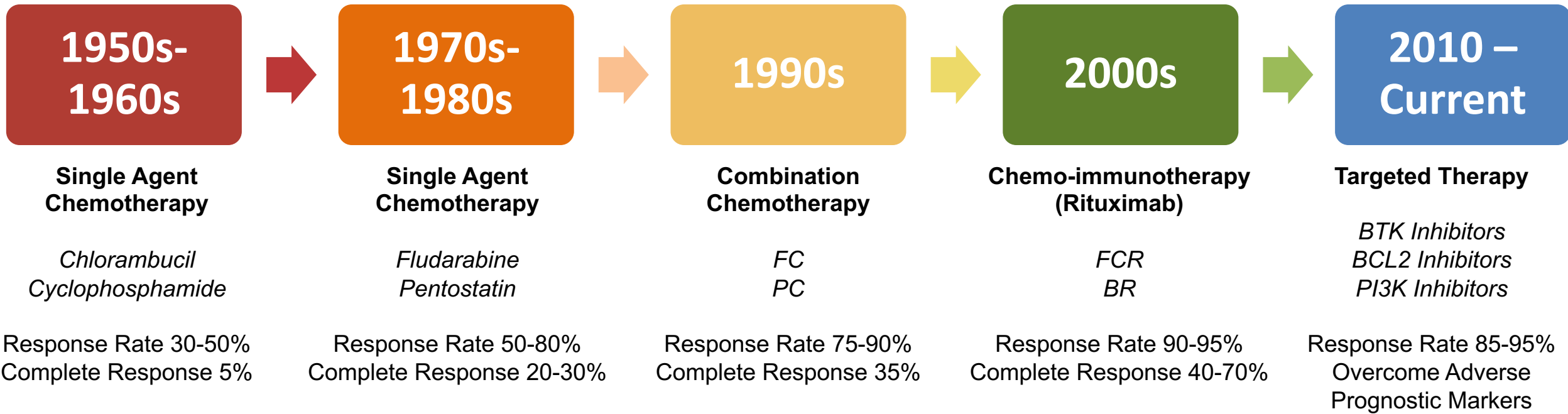


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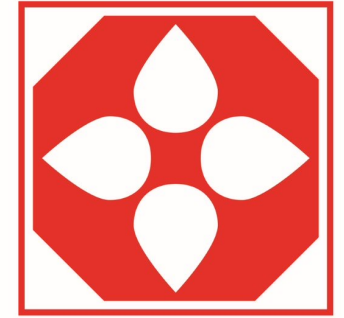
# Advances in Management of CLL



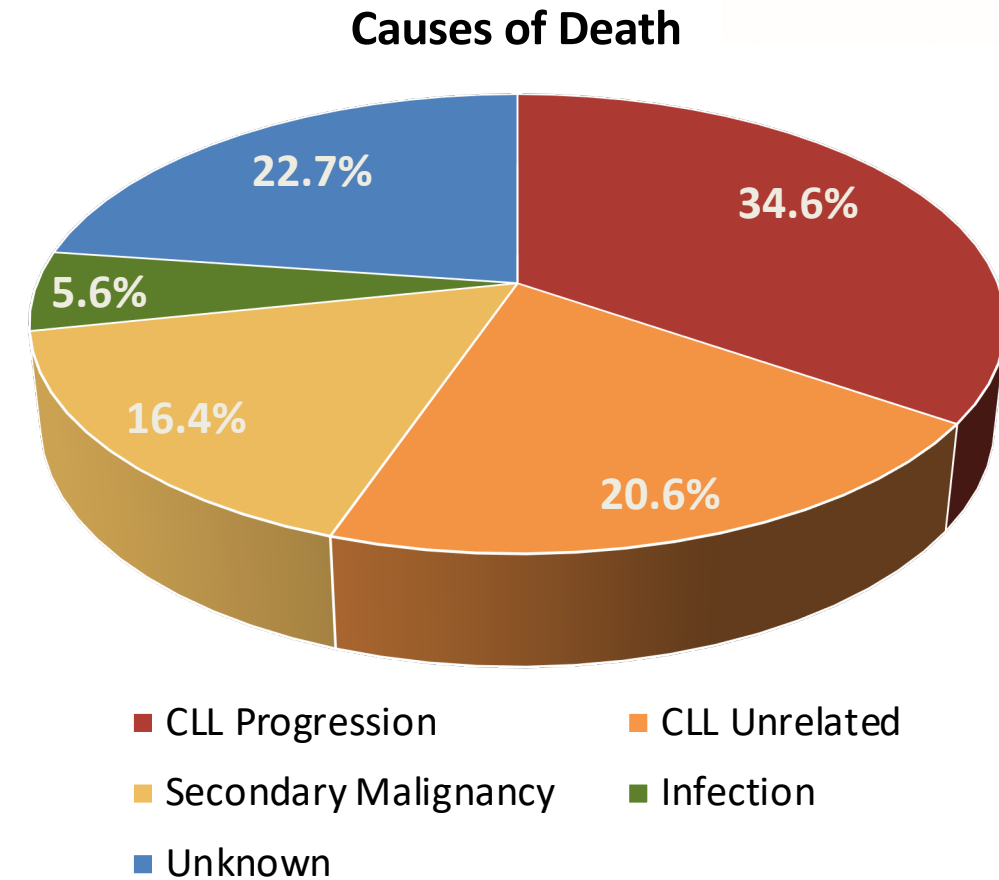
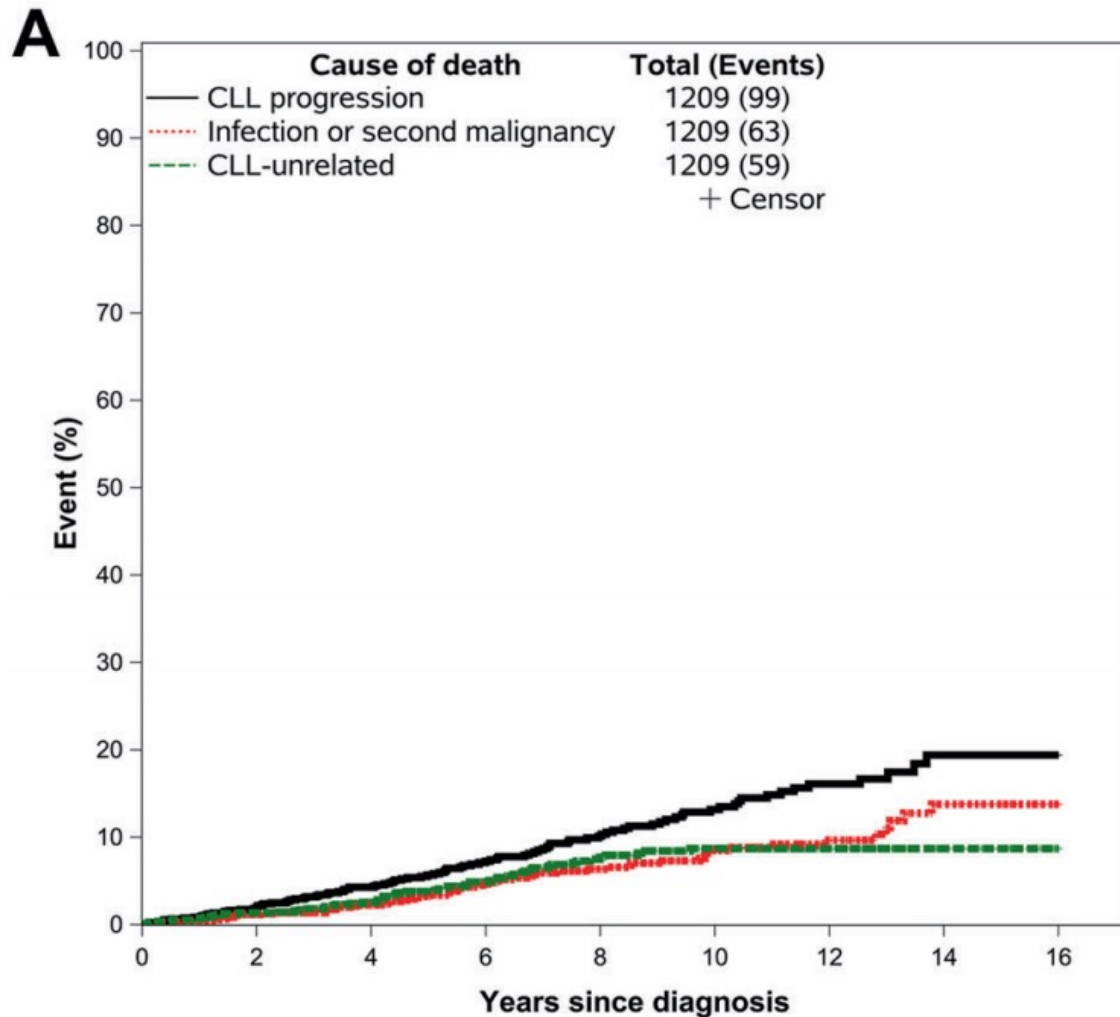
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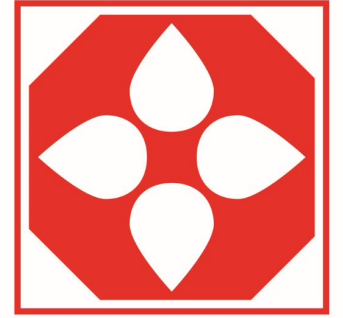
# Outcomes in CLL in 2020s



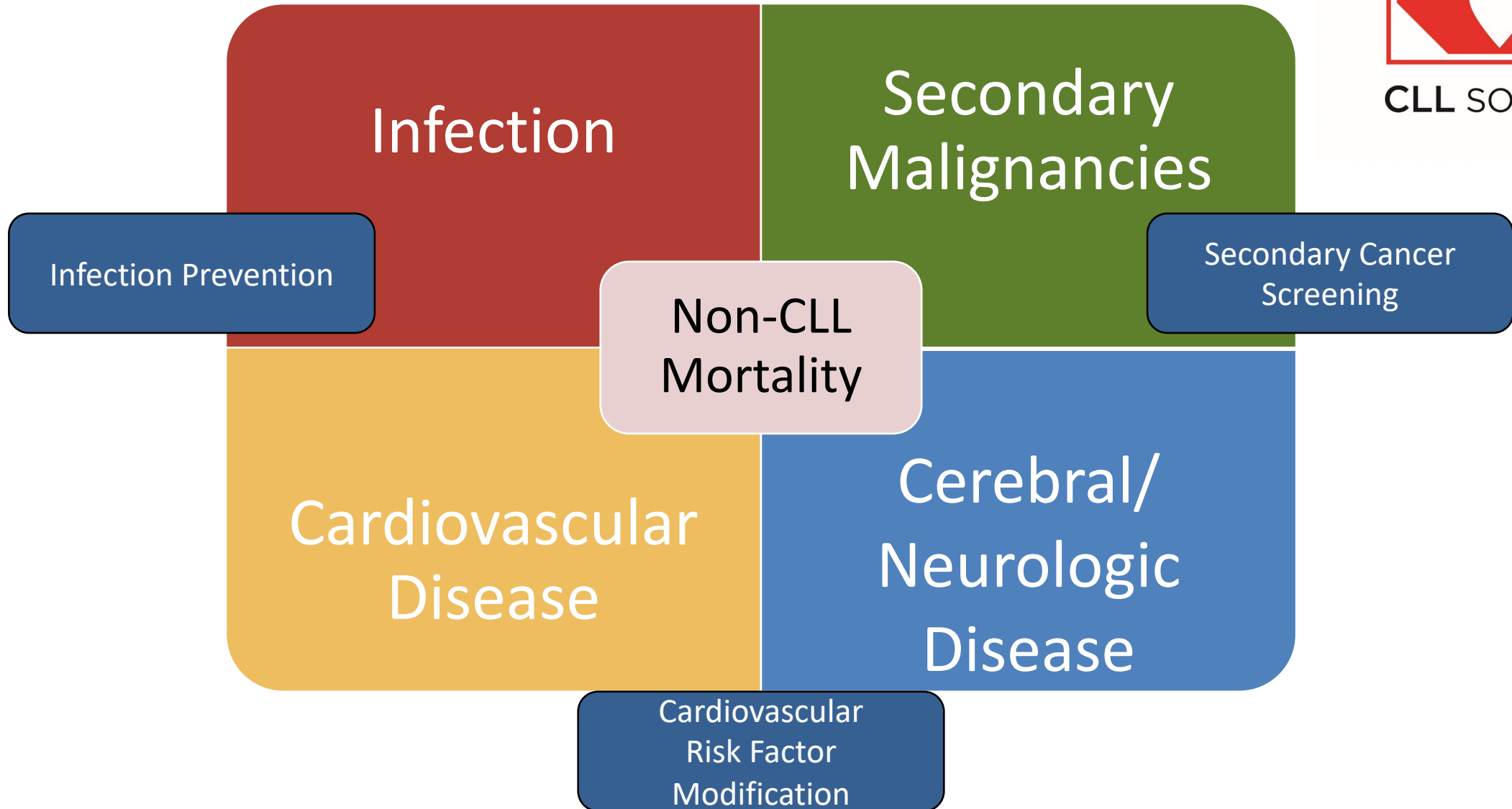
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# Outcomes in CLL in 2020s

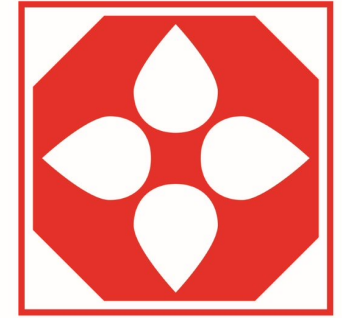


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# Survivorship Care in CLL



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## National Comprehensive Cancer Network (NCCN):

“An individual is considered a cancer survivor from diagnosis, through the balance of life. This includes survivors living with cancer and those free of cancer”

 National Comprehensive Cancer Network®

**NCCN Guidelines Version 1.2023**  
**Survivorship**

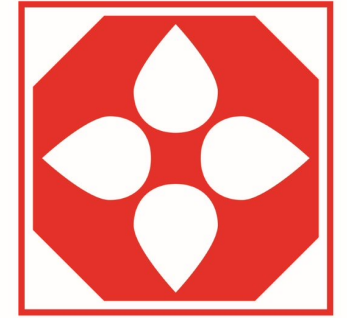
[NCCN Guidelines Index](#)  
[Table of Contents](#)  
[Discussion](#)

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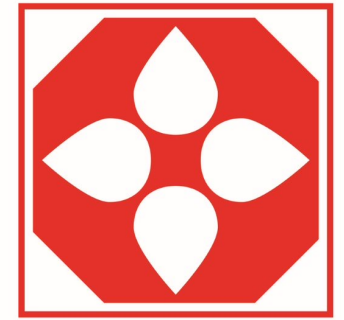
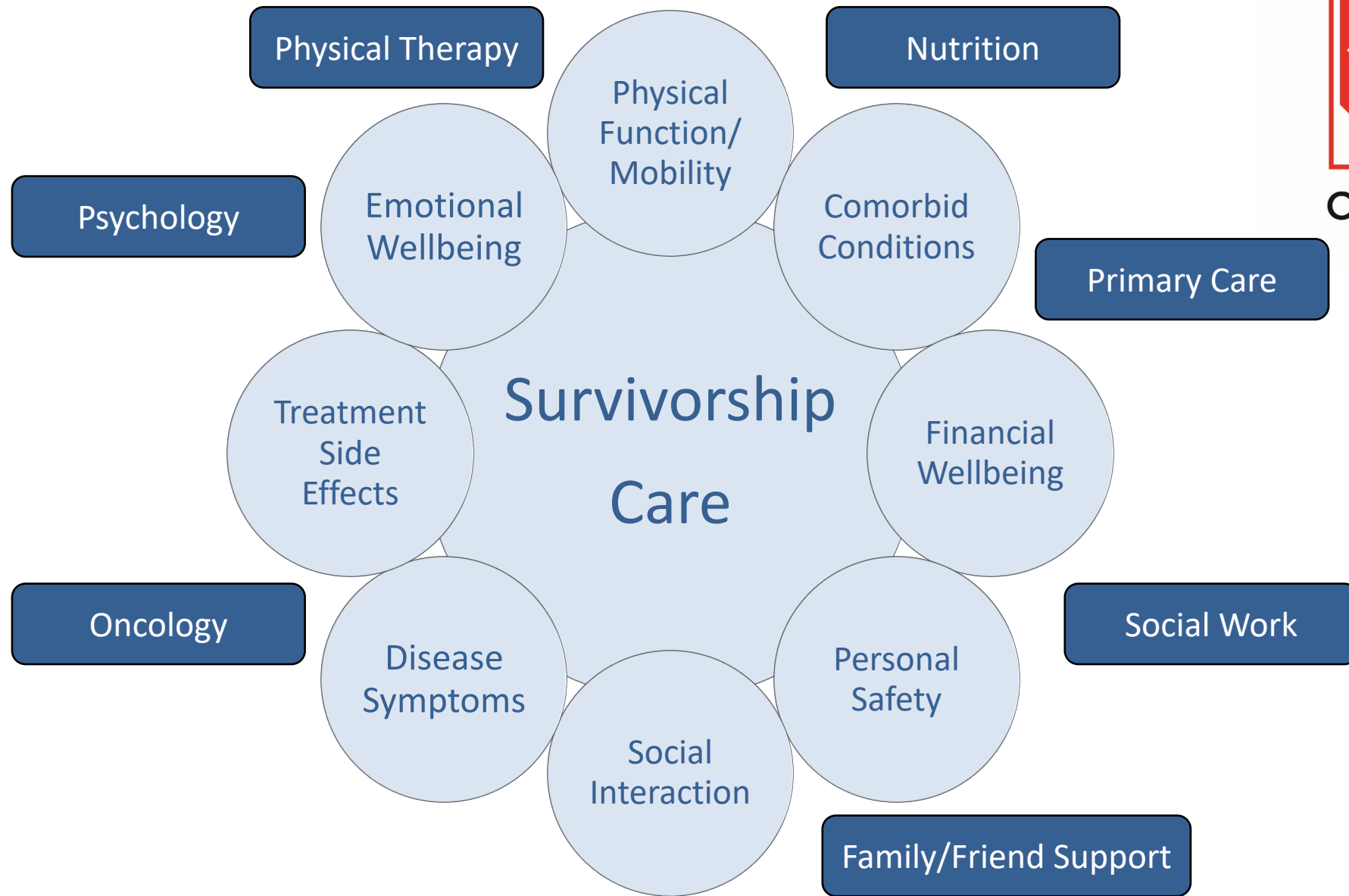
STANDARDS FOR SURVIVORSHIP CARE<sup>b</sup>

Care of the cancer survivor should include:

1. Surveillance for cancer spread or recurrence, and screening for subsequent primary cancers ([SURV-4](#))<sup>c</sup>
2. Monitoring long-term effects of cancer, including psychosocial, physical, and immunologic effects
3. Prevention and detection of late effects of cancer and therapy
4. Evaluation and management of cancer-related syndromes, with appropriate referrals for targeted intervention
5. Coordination of care between primary care providers and specialists to ensure that all of the survivor's health needs are met
6. Planning for ongoing survivorship care:<sup>d</sup>
  - ◇ Information on treatment received including all surgeries, radiation therapy (RT), and systemic therapies
  - ◇ Information regarding follow-up care, surveillance, and screening recommendations
  - ◇ Information on post-treatment needs, including information on acute, late, and long-term treatment-related side effects and health risks when possible ([NCCN Guidelines for Treatment of Cancer by Site](#))
  - ◇ Delineation of roles of all health care providers (including oncologists, primary care physicians [PCPs], and subspecialists) in long-term survivorship care with coordinated timing of care and transfer of care as appropriate
  - ◇ Promotion of adherence to healthy behavior recommendations ([HL-1](#))
  - ◇ Periodic assessment of ongoing needs and identification of appropriate resources

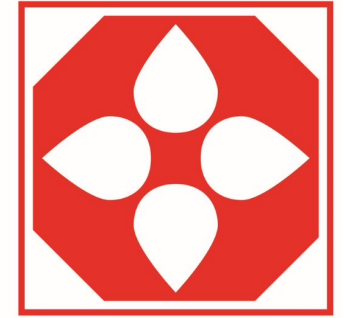


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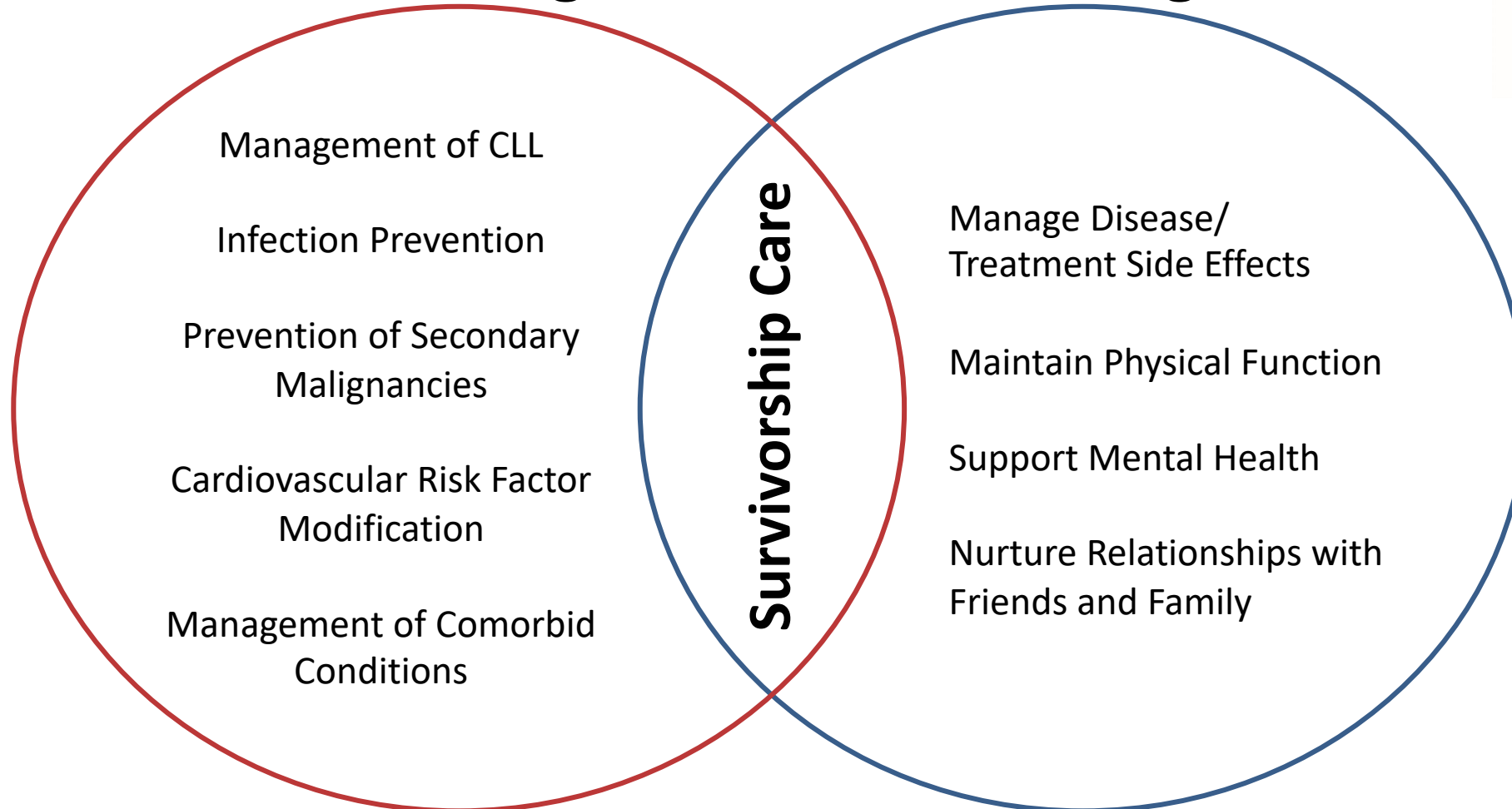
# Survivorship Care in CLL



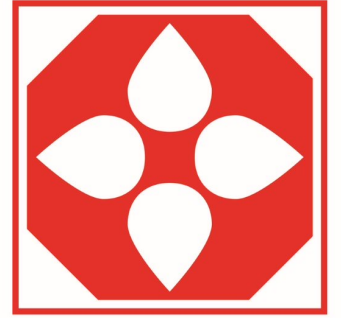
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## Surviving

## Thriving



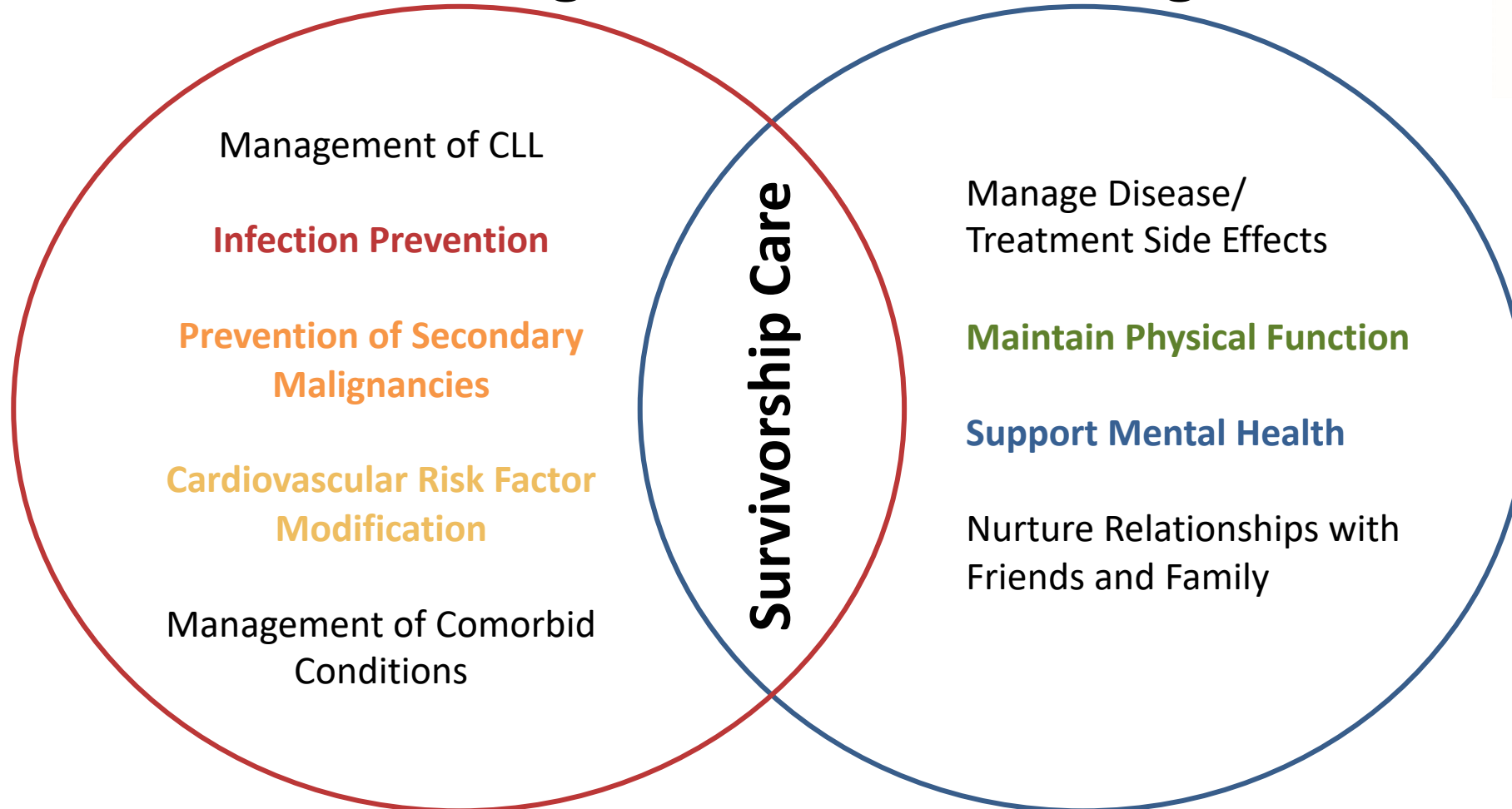
# Survivorship Care in CLL

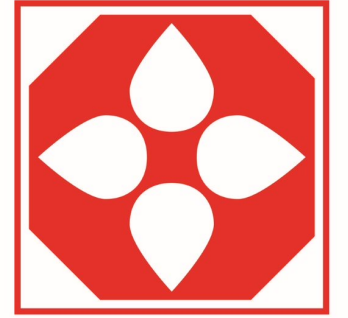


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## Surviving

## Thriving

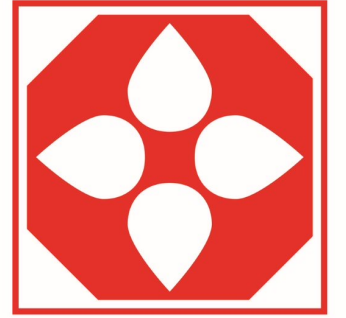




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# Infection Prevention

# Infection Prevention

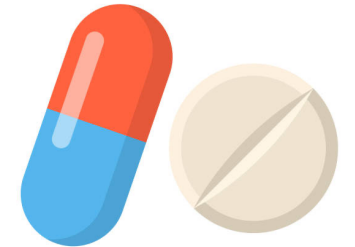
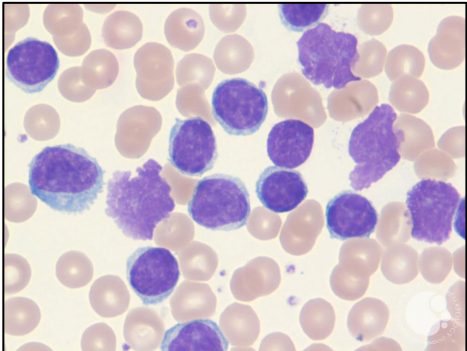


CLL SOCIETY

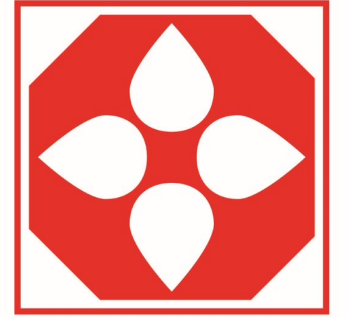
Increased Risk of  
Infection with CLL

The Disease

The Treatment



# Infection Prevention



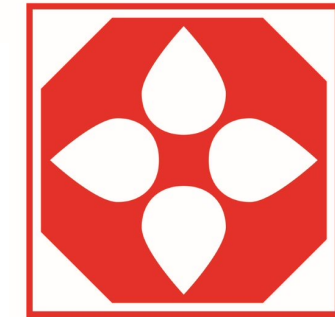
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## 1. Immunoglobulin Replacement

- Prophylactic immunoglobulin replacement (IVIg) is not recommended
- IF IgG < 500 mg/dL + recurrent infections requiring IV antibiotics or hospitalization, IVIg is recommended

## 2. Routine Vaccination for Immunocompromised





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Vaccine	Pregnancy	Indication								
		Immuno-compromised (excluding HIV infection)	HIV infection CD4 percentage and count		Asplenia, complement deficiencies	End-stage renal disease; or on hemodialysis	Heart or lung disease, alcoholism*	Chronic liver disease	Diabetes	Health care personnel Δ, §, ¶, ΔΔ
		<15% or <200 mm <sup>3</sup>	≥15% and ≥200 mm <sup>3</sup>							
COVID-19¶		Refer to footnotes								
Influenza inactivated (IIV4)Δ or influenza recombinant (RIV4)Δ		1 dose annually								
Influenza live, attenuated (LAIV4)Δ		Contraindicated			Precaution				1 dose annually	
Tetanus, diphtheria, pertussis (Tdap or Td)◇	1 dose Tdap each pregnancy	1 dose Tdap, then Td or Tdap booster every 10 years								
Measles, mumps, rubella (MMR)§	Contraindicated‡§	Contraindicated		1 or 2 doses depending on indication						
Varicella (VAR)‡	Contraindicated‡§	Contraindicated			2 doses					
Zoster recombinant (RZV)‡		2 doses at age ≥19 years			2 doses at age ≥50 years					
Human papillomavirus (HPV)†	Not recommended‡§	3 doses through age 26 years			2 or 3 doses through age 26 years depending on age at initial vaccination or condition					
Pneumococcal (PCV15, PCV20, PPSV23)**		1 dose PCV15 followed by PPSV23 OR 1 dose PCV20 (refer to footnotes)								
Hepatitis A (HepA)¶¶					2, 3, or 4 doses depending on vaccine					
Hepatitis B (HepB)ΔΔ	3 doses (refer to footnotes)	2, 3, or 4 doses depending on vaccine or condition								
Meningococcal A, C, W, Y (MenACWY)◇◇		1 or 2 doses depending on indication, refer to footnotes for booster recommendations								
Meningococcal B (MenB)◇◇	Precaution	2 or 3 doses depending on vaccine and indication, refer to footnotes for booster recommendations								
Haemophilus influenzae type b (Hib)§§		3 doses HSCT recipients only		1 dose						

Recommended vaccination for adults who meet age requirement, lack documentation of vaccination, or lack evidence of past infection

Recommended vaccination for adults with an additional risk factor or another indication

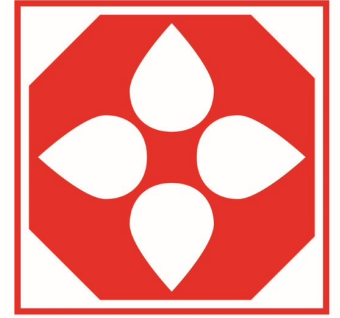
Precaution – vaccination might be indicated if benefit of protection outweighs risk of adverse reaction

Recommended vaccination based on shared clinical decision-making

Contraindicated or not recommended – vaccine should not be administered

No recommendation/not applicable

# Vaccinations for Patients with CLL

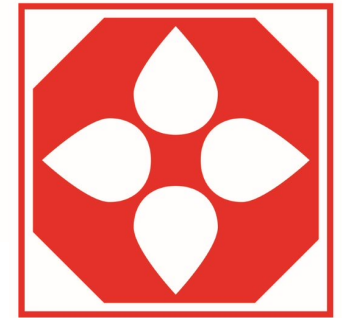


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1. Yearly recombinant influenza vaccine (Avoid live vaccines)
2. Pneumococcal vaccine series
  1. PCV20
  2. PCV15 => PPSV23
3. COVID-19 vaccine series
4. Recombinant Zoster Vaccine
5. Tetanus, diphtheria, pertussis (Tdap or Td) booster every 10 years
6. HPV Vaccine (consider  $\leq$  45 years of age)
7. RSV Vaccine (in patients  $\geq$  60 years of age)

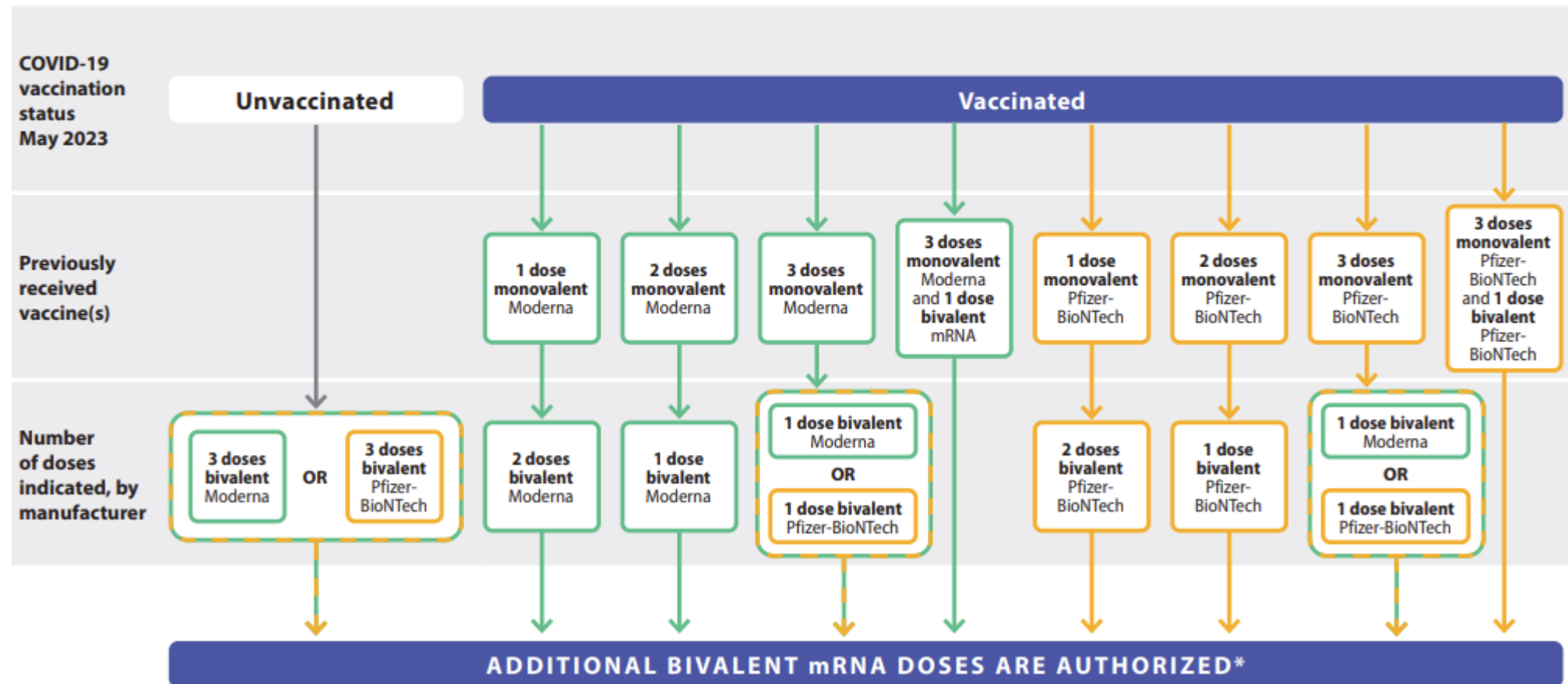
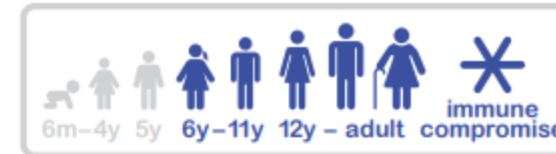
\* Ask your doctor about timing of vaccines.

# Prevention of COVID-19 Infection



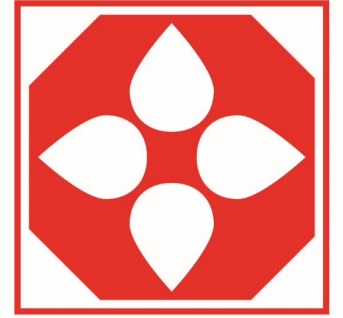
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Recommended COVID-19 vaccines for **people who ARE moderately or severely immunocompromised, aged 6 years and older**, mRNA vaccines, May 2023\*



Advisory Committee on Immunization Practices. Recommended Adult Immunization Schedule for ages 19 years or older, United States, 2023. Centers for Disease Control and Prevention.

# Treatment of COVID-19 Infection

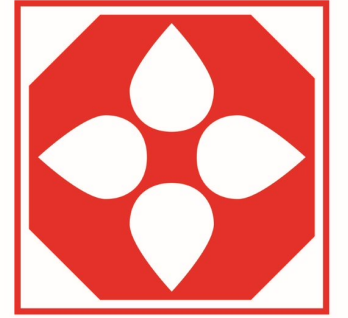


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1. Prevention
2. Outpatients:
  - Paxlovid (Nirmatrelvir/ritonavir) - preferred
  - Remdesivir (IV)
3. Hospitalized:
  - Remdesivir (IV)

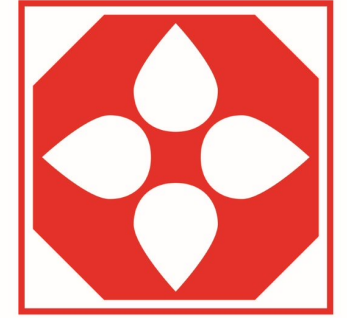
## No Longer Recommended:

- Monoclonal antibodies
- Evusheld



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# Secondary Cancer Screening



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ARTICLE OPEN

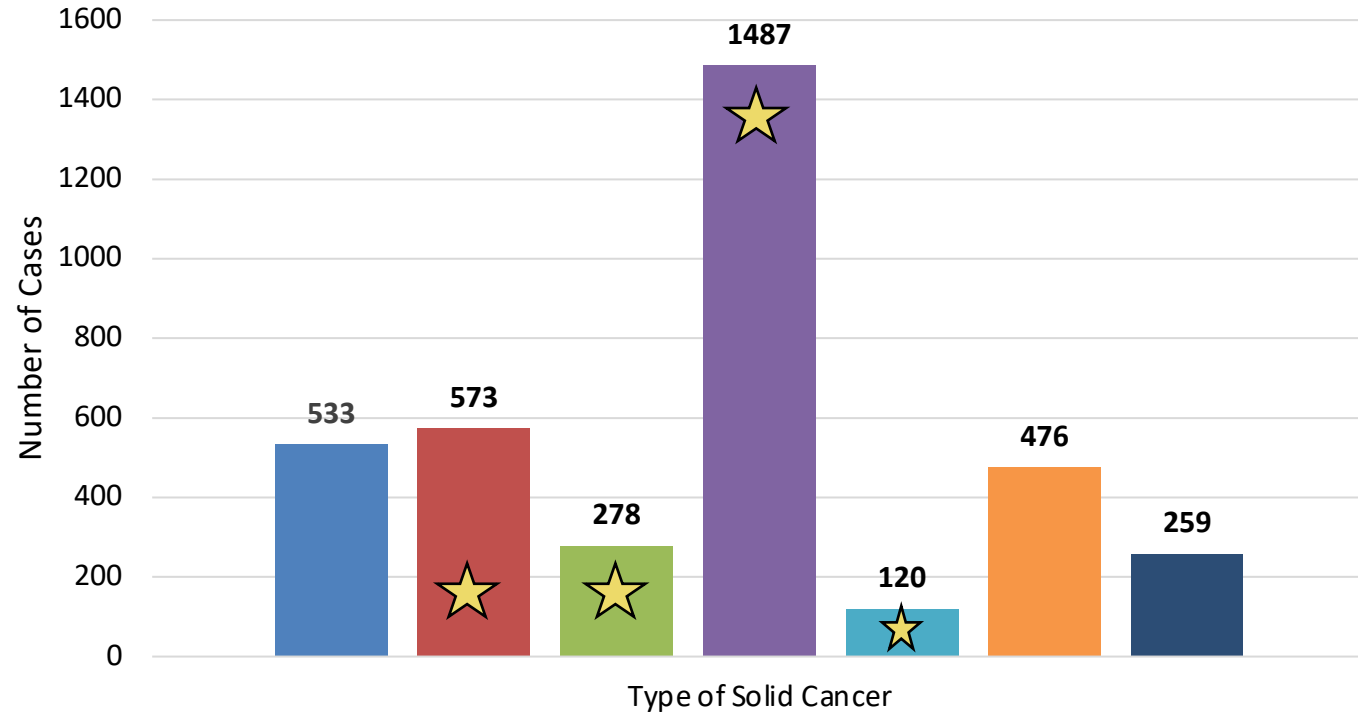
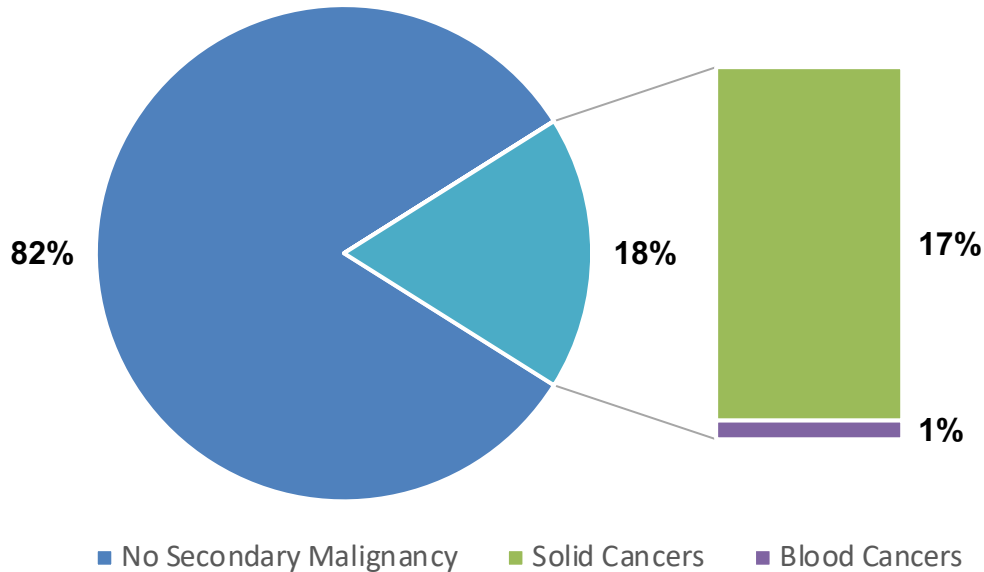
Check for updates

# Risk of second primary malignancies in patients with chronic lymphocytic leukemia: a population-based study in the Netherlands, 1989-2019

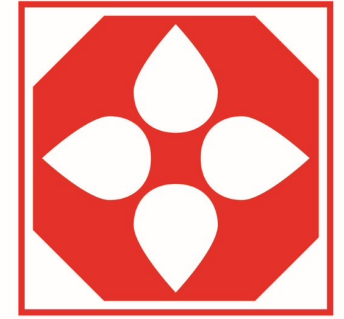
Lina van der Straten <sup>1,2,3</sup>, Mark-David Levin <sup>2</sup>, Manette A. W. Dinnessen <sup>1,4</sup>, Otto Visser <sup>5</sup>, Eduardus F. M. Posthuma <sup>6,7</sup>, Jeanette K. Doorduijn <sup>8</sup>, Anton W. Langerak <sup>3</sup>, Arnon P. Kater <sup>4</sup> and Avinash G. Dinmohamed <sup>1,4,9,10</sup>

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★ = Higher than expected case rates in general population



■ Colorectal ■ Lung ■ Melanoma ■ Non-Melanoma Skin ■ Kidney ■ Prostate ■ Breast



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ARTICLE **OPEN**

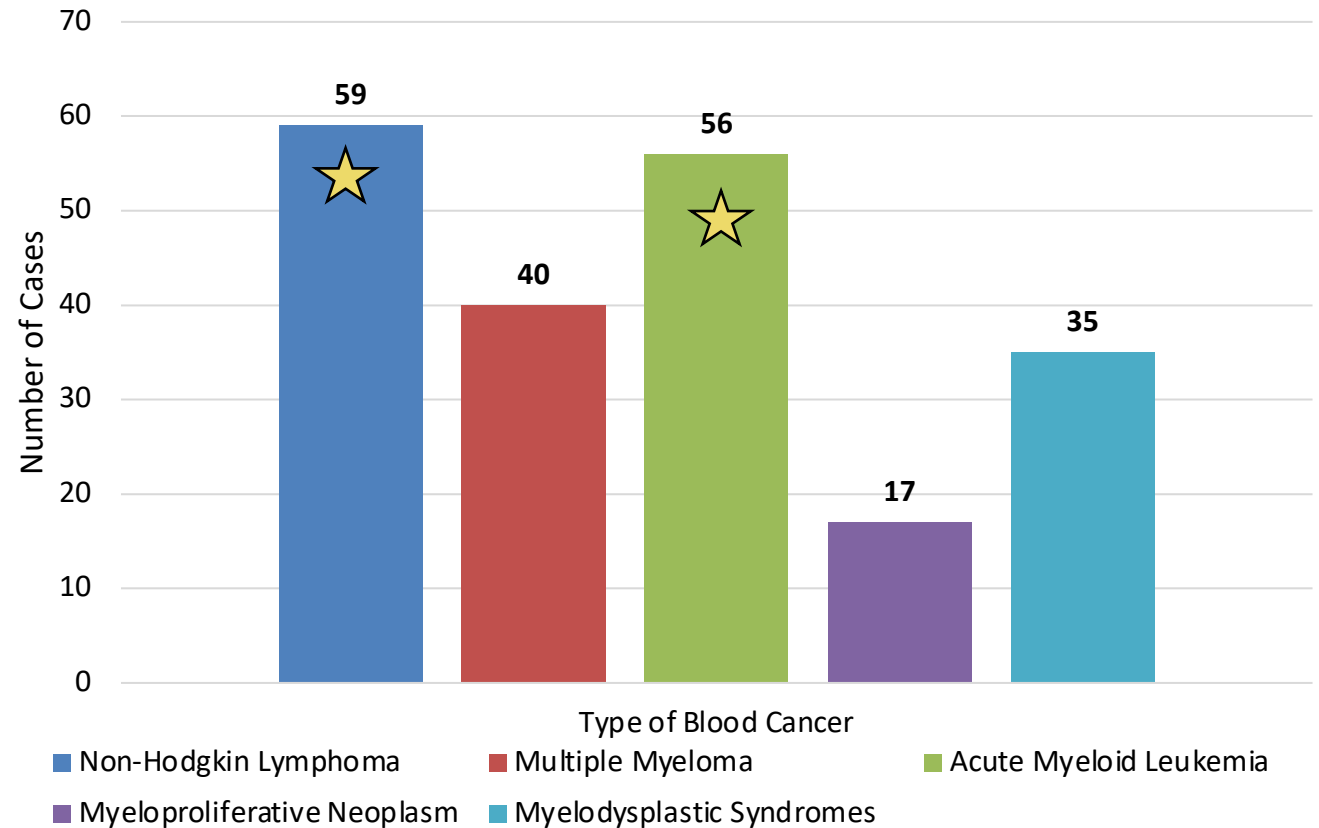
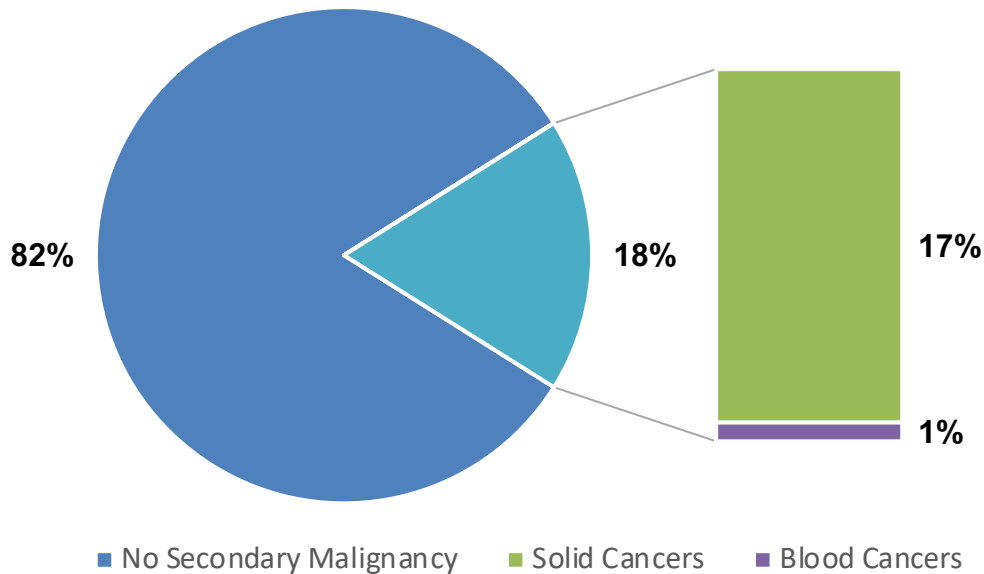
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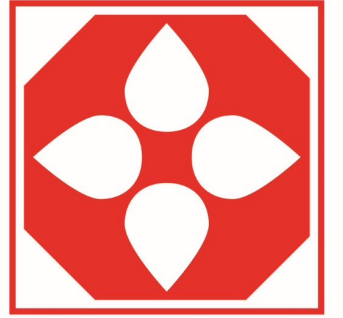
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★ = Higher than expected case rates in general population

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# Secondary Cancer Screening



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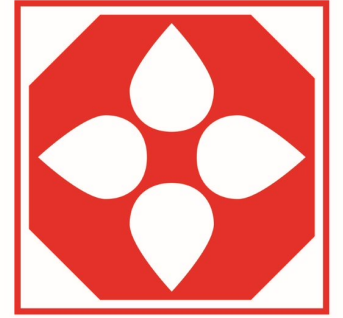
Know your family history (if possible).

Know your medical/treatment history.

Talk to your doctor about your individual cancer risk.

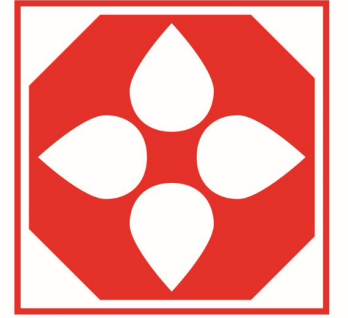


# Secondary Cancer Screening



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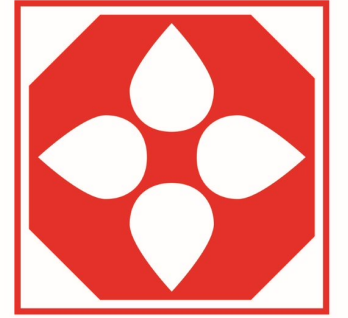
1. **Skin Cancer:** Yearly dermatology visits
2. **Colorectal Cancer:** Screening at age 45
3. **Breast Cancer:** Mammograms every 1-2 years at age 50-74, shared decision making at age 40-49 and after 75
4. **Lung Cancer:** Annual Low-dose CT scan in patients  $\geq 50$  years of age with  $\geq 20$  pack-year smoking history
5. **Prostate Cancer:** Shared decision making, if screening is performed - PSA at age 50-75 (every 1-2 years)
6. **Cervical Cancer:** Start at age 21 with pap smears, at age 30-65 can do pap smears with HPV testing every 5 years



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# Cardiovascular Health/ Risk Factor Modification

# Cardiovascular Health



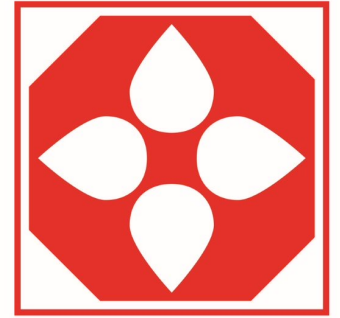
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1. Screen for pre-existing cardiac disease or emerging risk factors
  - Coronary Heart Disease
  - Heart Failure
  - Atrial Fibrillation
  - High blood pressure (blood pressure monitoring in clinic)
  - Hyperlipidemia (routine cholesterol levels)
  - Diabetes (check HgbA1c)
  - Obesity
  - Cigarette/Tobacco Use
2. Discuss your family history
3. Review prior cancer treatment history and risk for toxicity
4. Assess current diet and exercise habits

# Cardiovascular Health



## ASCVD Risk Estimator Plus



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**Current Age** <sup>i</sup> \*   
Age must be between 20-79

**Sex** \*  Male  Female

**Race** \*  White  African American  Other

**Systolic Blood Pressure** (mm Hg) \*   
Value must be between 90-200

**Diastolic Blood Pressure** (mm Hg) \*

**Total Cholesterol** (mg/dL) \*   
Value must be between 130 - 320

**History of Diabetes?** \*  Yes  No

**On Hypertension Treatment?** \*  Yes  No

**On a Statin?** <sup>i</sup>  Yes  No

**On Aspirin Therapy?** <sup>i</sup>  Yes  No

**23.9%**  
High **Current 10-Year ASCVD Risk\*\***

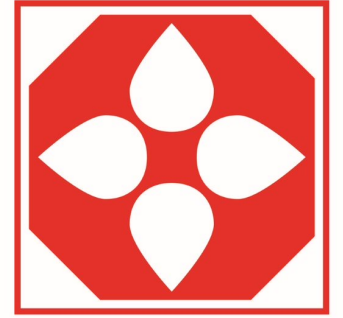
**Lifetime ASCVD Risk: 69%** **Optimal ASCVD Risk: 3.6%**

# Cardiovascular Health



AMERICAN  
COLLEGE of  
CARDIOLOGY

## ASCVD Risk Estimator Plus



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Projected 10-Year ASCVD Risk

**8.6% with Smoking Cessation, Statin Therapy, BP Medication, Aspirin Therapy**



Quit  
Smoking ⓘ



Start/Intensify Statin ⓘ



Start/Add Blood Pressure  
Medication(s) ⓘ



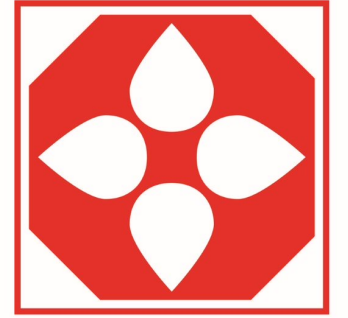
Start/continue aspirin  
therapy ⓘ

### ✓ View Advice Summary for this Patient

- **BP:** For Stage 2 HTN, initiation of antihypertensive drug therapy (with 2 agents of different classes) in combination with nonpharmalogical therapy is recommended.
- **LDL-C:** Statin initiation is indicated in the context of a clinician-patient risk discussion.
- **Diabetes:** Dietary counseling and  $\geq 150$  minutes/week of moderate intensity or  $\geq 75$  minutes/week of vigorous physical activity recommended. Metformin as first line drug to improve glycemic control to reduce CVD may be considered.
- **Smoking:** Advise patient to quit. Use combination of behavioral and pharmacotherapy. Avoid second hand smoke.
- **Aspirin:** Low dose aspirin (75-100 mg oral daily) might be considered for select patients at higher risk and age 40-70.

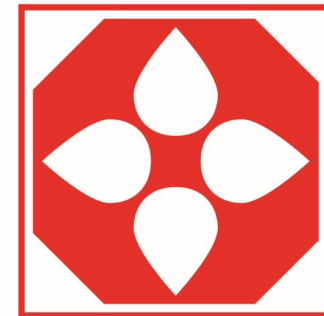
**Lifestyle:** The most important way to prevent ASCVD is to promote a healthy lifestyle throughout life. Medications to reduce ASCVD risk should only be considered part of a shared decision-making process for optimal treatment when a patient's risk is sufficiently high. Decisions around the therapies listed above are assumed to be made in the context of ACC/AHA guideline-recommended lifestyle interventions.

# Cardiovascular Health



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1. Management of chronic medical conditions
  - If you have high blood pressure → adequate blood pressure control
  - If you have high cholesterol levels → dietary changes or start statin
  - If you have pre-diabetes/diabetes → dietary changes, management of diabetes
2. Addition of protective medications
  - Start aspirin?
  - Start statin?
3. Avoid cigarette/tobacco use
4. Encourage regular exercise

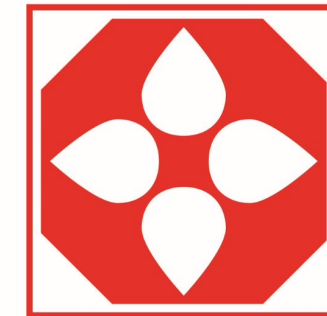


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# Bone Health

## Osteoporosis or Low Bone Mass in Older Adults: United States, 2017–2018

Neda Sarafrazi, Ph.D., Edwina A. Wambogo, Ph.D., M.S., M.P.H., R.D., and John A. Shepherd, Ph.D.



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Figure 1. Prevalence of osteoporosis among adults aged 50 and over, by sex and age: United States, 2017–2018

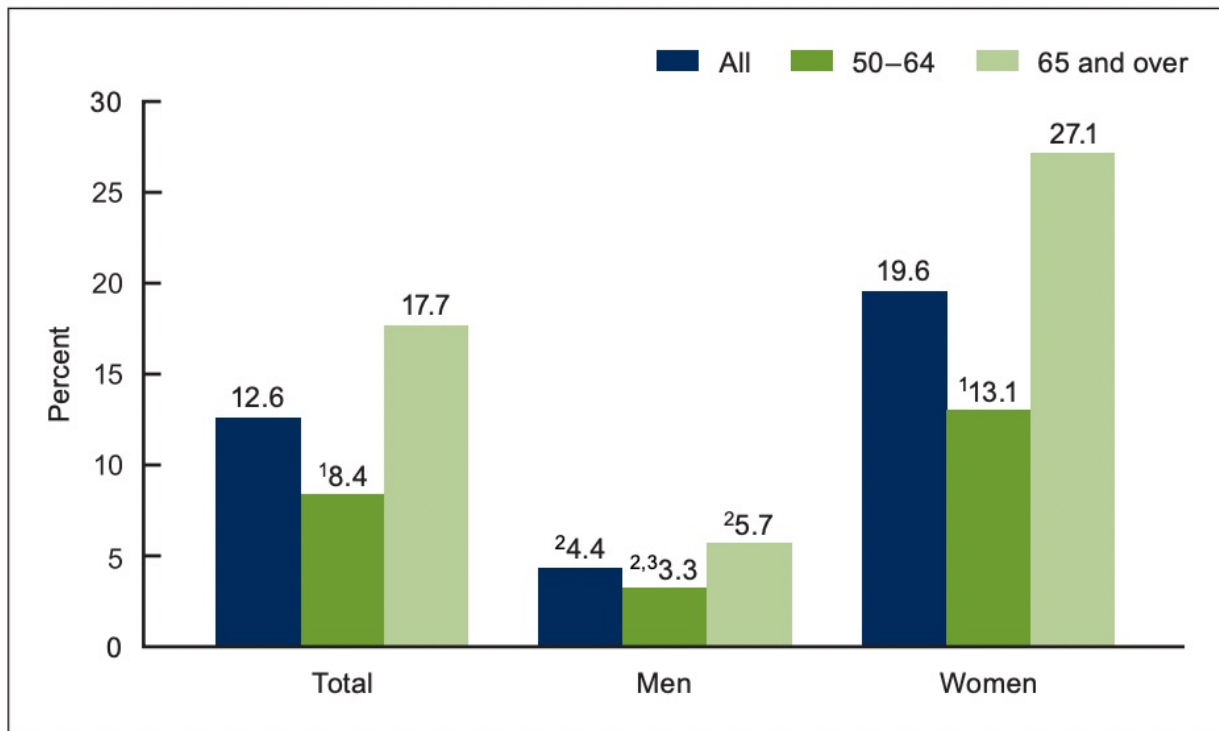
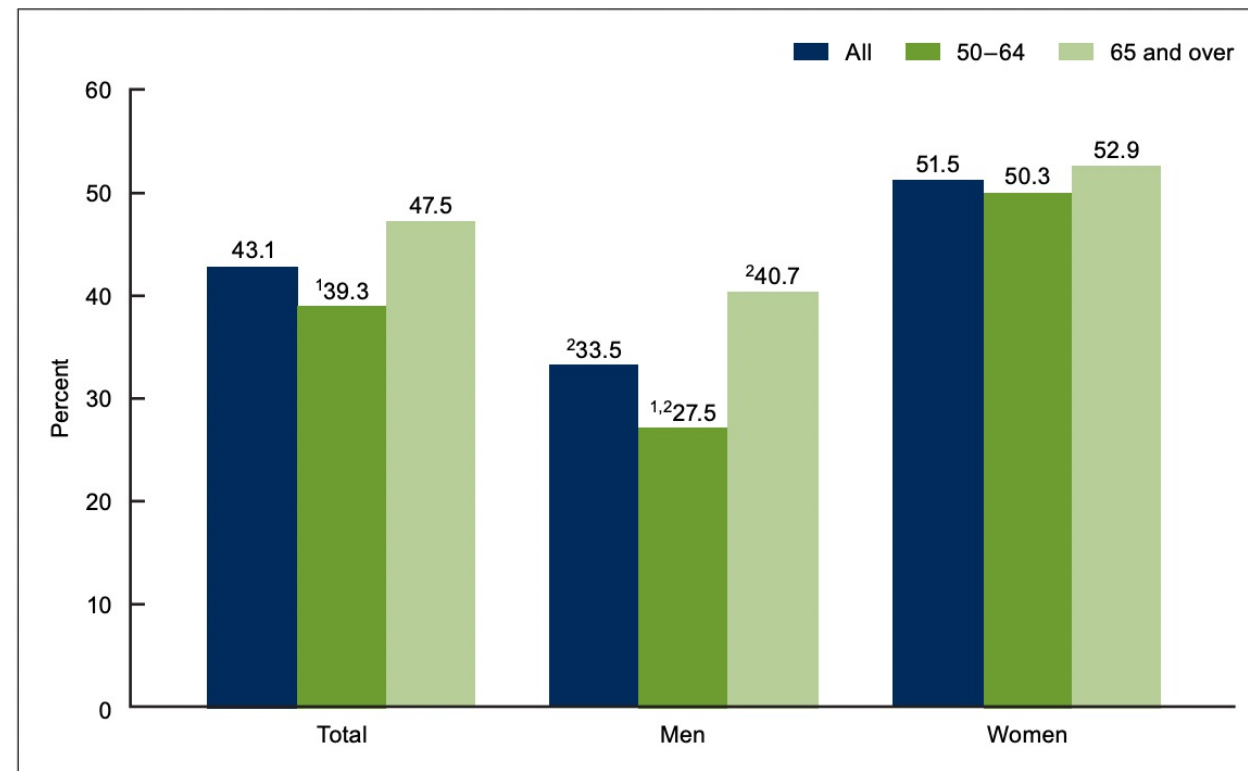
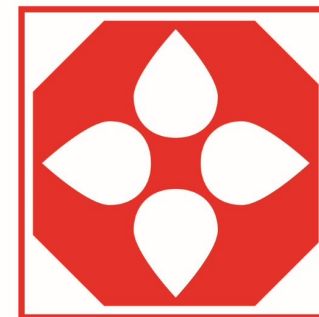


Figure 2. Prevalence of low bone mass among adults aged 50 and over, by sex and age: United States, 2017–2018





# Why Do We Care About Bone Health?



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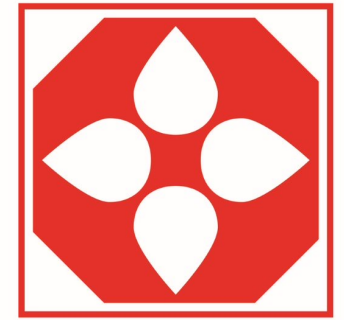
**Table 1.** Summary of Published Mortality Rates in Patients With Hip Fractures Treated in Usual Care

Author	Year	Number of Patients	In-Hospital Mortality, %	Overall 1-Year Mortality, %; Male/Female, %	1-Year Mortality of NH Patients, %	1-Year Mortality of Community Patients, %
White et al <sup>29</sup>	19				NA	NA
Keene et al <sup>23</sup>	19				NA	NA
Aharonoff et al <sup>22</sup>	19				Excluded	12.7
Leibson et al <sup>21</sup>	20				30	15
Elliot et al <sup>20</sup>	20				NA	NA
Richmond et al <sup>58</sup>	20				Excluded	11.5
Wehren et al <sup>18</sup>	20				Excluded	18.9
Roche et al <sup>7</sup>	20				NA	NA
Haentjens et al <sup>17</sup>	2007	170	6.5	18.8; NA	NA	NA
Rapp et al <sup>16</sup>	2008	4342	NA	M 58.3, F 44.8	M 58.3, F 44.8	Excluded
Von Friesendorff et al <sup>15</sup>	2008	163	NA	21; NA	NA	Na
Brauer et al <sup>1</sup>	2009	786 717	NA	M 32.5, F 21.9	NA	NA
Berry et al <sup>14</sup>	2009	195	NA	39.5; M 53.5, F 35.6	39.5; M 53.5, F 35.6	Excluded
Bentler et al <sup>13</sup>	2009	495	3	26	NA	NA

1-Year Mortality of  
~ 20-30%

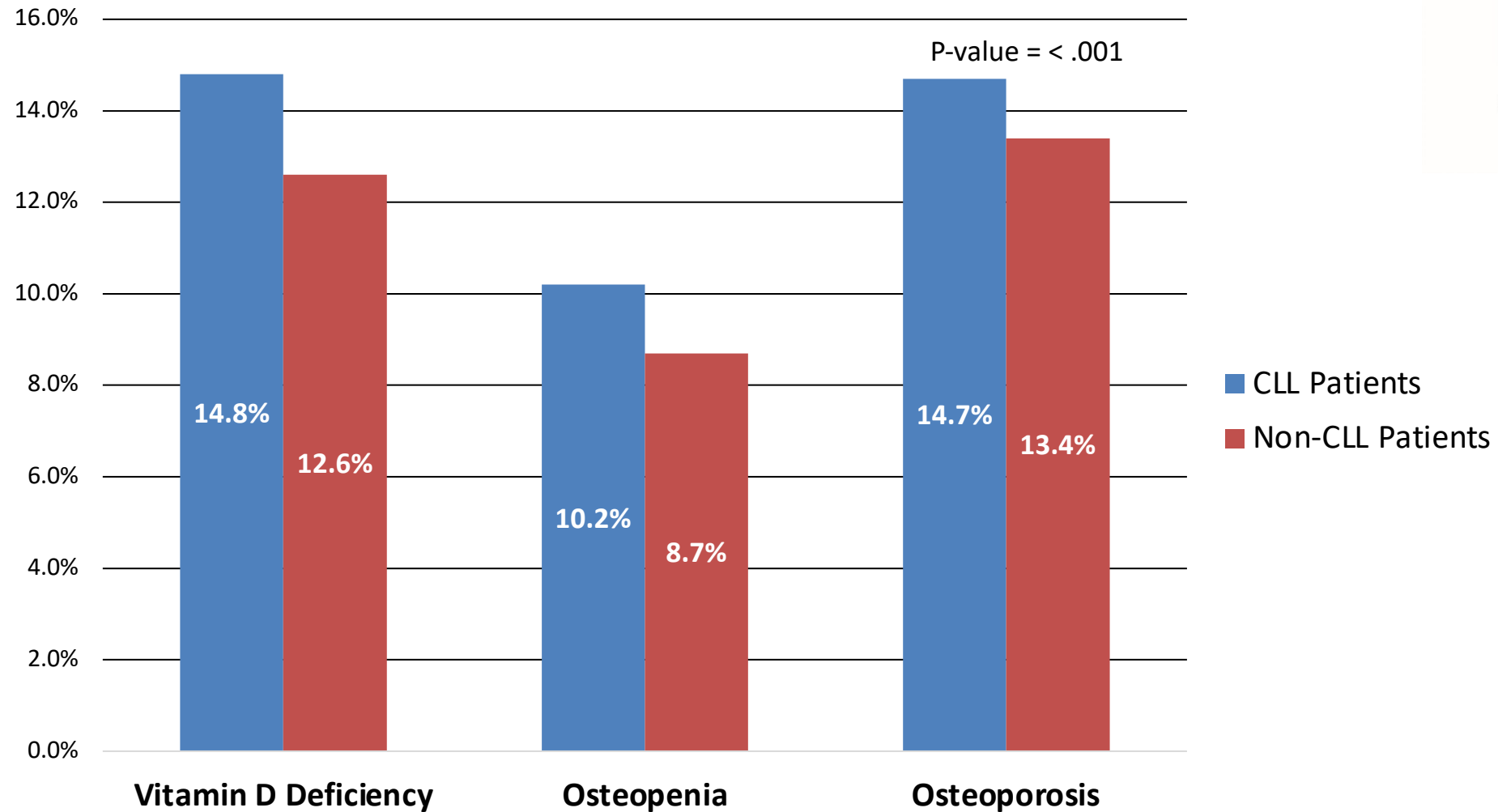
NA, not available; M, male; F, female.

Schnell et al. Geri Ortho Surg Rehab, 2010.

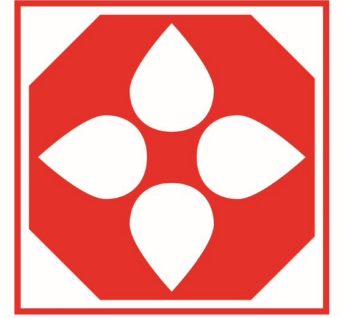


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## Prevalence of Vitamin D Deficiency, Osteopenia, and Osteoporosis



# Current Bone Health Screening



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- All women  $\geq$  65 years
- Postmenopausal women  $<$  65 with risk factors
- Men with clinical manifestation of low bone mass, history of low trauma fracture, risk factors for fracture

## Clinical Risk Factors for Fracture

Advancing Age

Previous Fracture

Steroid Use

Family history of hip fracture

Low body weight

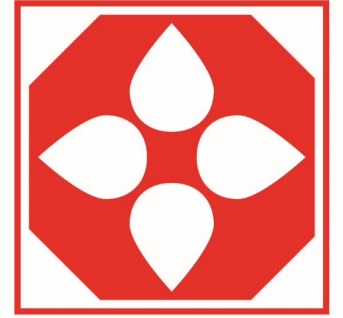
Current cigarette smoking

Excessive alcohol consumption

Rheumatoid arthritis

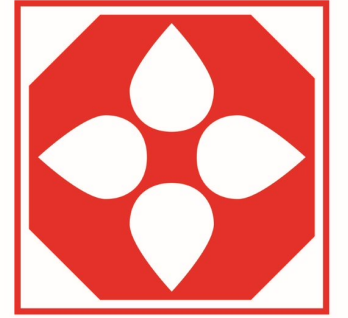
Secondary osteoporosis (hypogonadism, malabsorption, liver disease, bowel disease)

# Management of Bone Loss



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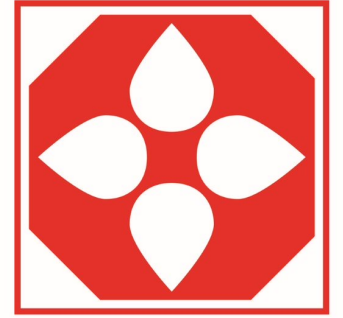
- **Normal Bone Mass** = Consider repeat bone density in ~ 10 years
- **Osteopenia (Low Bone Mass)**
  - Calcium (500-1000 mg/day) and vitamin D (800 IU daily) supplementation
  - Weight bearing exercise
  - Avoid alcohol and tobacco use
  - Consider repeat bone density in ~ 5 years
- **Osteoporosis**
  - Bone strengthening medicines (bisphosphonates or denosumab)
  - Repeat bone density in ~ 2 years



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# Mental Health

# Mental Health



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**Distress  
Fear of Recurrence**

**Anxiety**

**Depression**

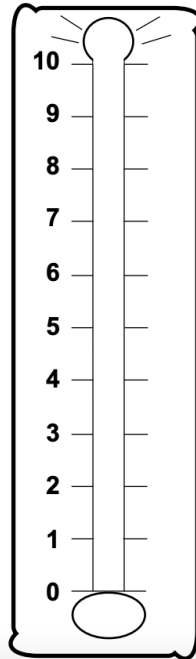
**Post-Traumatic Stress  
Disorder (PTSD)**

**NCCN DISTRESS THERMOMETER**

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

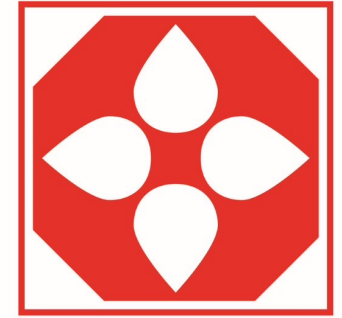
Extreme distress



No distress

**Post-Traumatic Stress Disorder Test - PC-PTSD-5 Screen**

Have you ever experienced any event(s) that was/were so frightening or upsetting that, in the past month you have...	No (0)	Yes (1)
1. Had nightmares about the event(s) or thought about the event(s) when you did not want to?		
2. Tried hard not to think about the event(s) or went out of your way to avoid situations that reminded you of the event(s)?		
3. Been constantly on guard, watchful, or easily startled?		
4. Felt numb or detached from people, activities, or your surroundings?		
5. Felt guilty or unable to stop blaming yourself or others for the event(s) or any problems the event(s) may have caused?		



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**PHQ-9 (Patient Health Questionnaire-9)**  
Objectifies degree of depression severity.

When to Use | Pearls/Pitfalls | Why Use

Ask the patient: how often have they been bothered by the following over the past 2 weeks?

Little interest or pleasure in doing things?	Not at all	0
	Several days	+1
	More than half the days	+2
	Nearly every day	+3

Feeling down.

**GAD-7 Anxiety**

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

# Mental Health

**Social Workers**

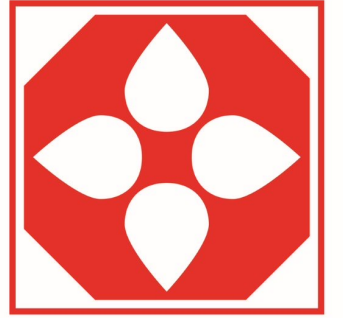
**Primary Care  
Physicians**

**Psychologists**

**Family/Community**

**Psychiatrists**

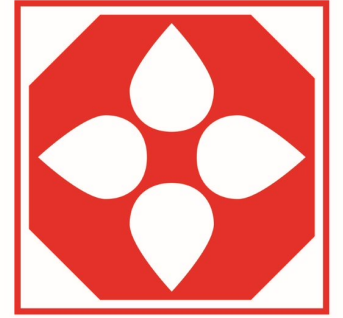
**Oncology Team**



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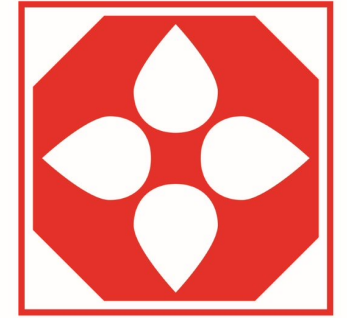
# Mental Health



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1. Talk to your oncology team regarding prognosis or risk for disease progression
2. Establish with a mental health provider (if needed)
3. Pay attention to lifestyle changes that may improve your overall health and well-being (ex: sleep and exercise)
4. Journaling or find a hobby
5. Spend time with friends/family/support system
6. Connect with other cancer patients/survivors

# CLL Society Support Groups



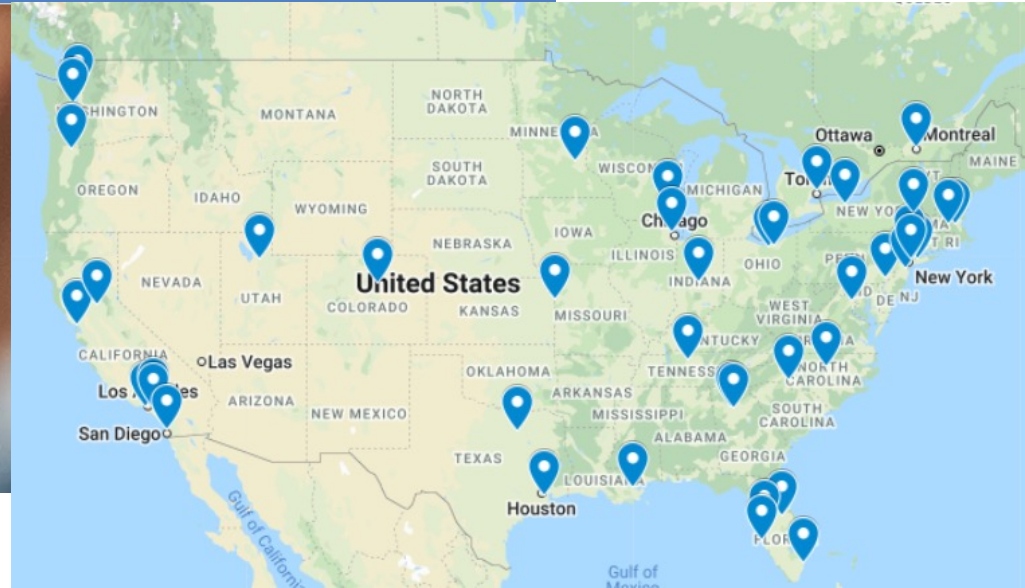
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## CLL-Specific Patient Support Groups

Over 3,000 CLL patients and caregivers are currently registered to meet monthly in our approximately 40 CLL-specific support groups across the United States and Canada under the care and guidance of CLL Society-trained facilitators who uphold standards of inclusiveness and privacy.

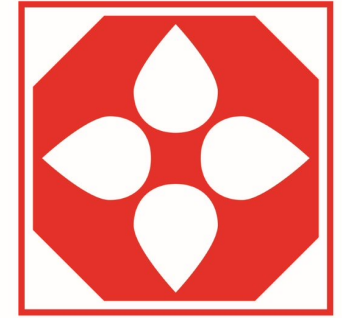
CLL Society's CLL-specific support groups are a place of camaraderie and strategy sharing among CLL patients and caregivers as well as a hub of learning and swift conduits for CLL breaking news and cutting-edge research-supported treatment information.

[Sign up today!](#)



<https://cillsociety.org/support-groups/>

# Leukemia & Lymphoma Society



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LEUKEMIA & LYMPHOMA SOCIETY®

ABOUT LLS PATIENTS & CAREGIVERS RESEARCHERS & HEALTHCARE PROFESSIONALS DARE TO DREAM PROJECT HOW TO HELP

SEARCH DONATE EN ESPAÑOL

## MENTAL HEALTH AND CRISIS SERVICES

**SUPPORT RESOURCES**

- Information Specialists
- Clinical Trial Support Center (CTSC)
- + Financial Support
- LLS Podcast
- Online Chats

Please note that these resources are regularly reviewed to ensure that links still work correctly and that the resources listed continue to be helpful to our visitors. If you find that a link isn't working or information is incorrect, please email [infocenter@lls.org](mailto:infocenter@lls.org). If you would like for us to consider adding your organization to this resource, please [complete and submit this form](#).

**988 Suicide & Crisis Lifeline**

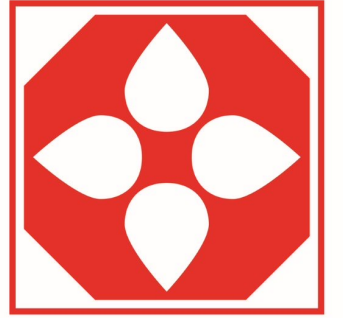
**Contact:** 988 or 1-800-273-8255 (1-800-273-TALK)

**Population Served:**  
Anyone thinking about suicide or worried about someone in distress, in the U.S.

**Mission**

Chat

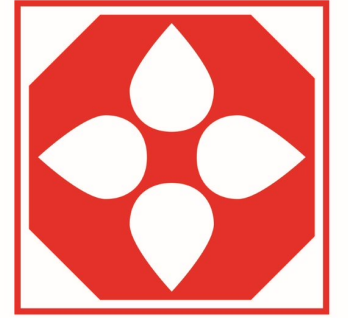
# Additional Recommendations



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1. Engage in physical activity.
2. Maintain a healthy diet high in vegetables, fruits, and whole grains.
3. Drink alcohol sparingly.
4. Discontinue use of cigarettes, tobacco products, and e-cigarettes.
5. Practice sun safety (use SPF at least 30, avoid tanning beds, avoid sunburns, wear hats/coverage when outside).
6. Strive for 7-9 hours of sleep regularly.

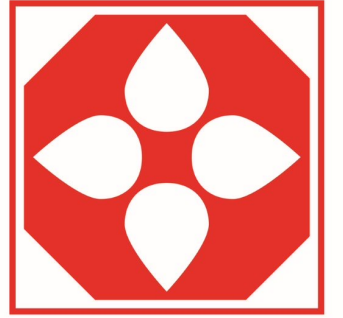
# Conclusions



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- **Patients with CLL can/do live long, rich lives!**
- Remain up-to-date on vaccinations to prevent disease.
- Establish care/follow-up with primary care team regularly for age-appropriate cancer screening, management of risk factors, and comorbid conditions.
- Discuss cancer-related or treatment-related fears with oncology team.
- Seek out assistance from mental health professionals when needed.
- Join cancer support groups or engage in community activities.

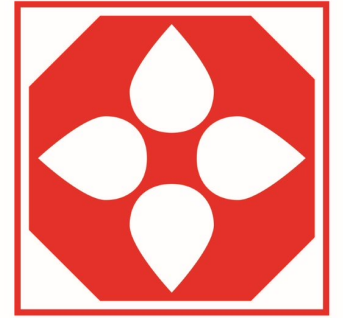
# Poll Question



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This Program Was Made Possible  
Through Generous Donors Like You  
and Grant Support From



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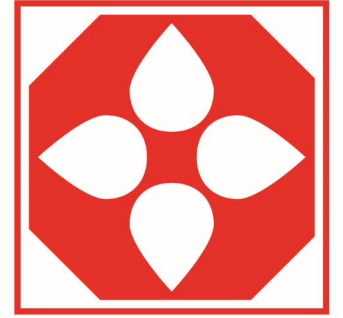
abbvie

AstraZeneca



# Thank You for Attending!

Please take a moment to complete our **post-event survey**, your feedback is important to us



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If your question was not answered, please feel free to email [asktheexpert@cllsociety.org](mailto:asktheexpert@cllsociety.org)

Join us on September 27<sup>th</sup> for our next webinar on why policy matters for CLL/SLL patients and caregivers

CLL Society is invested in your long life. Please invest in the long life of the CLL Society by supporting our work

**[cllsociety.org/donate-to-cll-society/](https://cllsociety.org/donate-to-cll-society/)**