



# CLL LIVE: Self Care



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MN

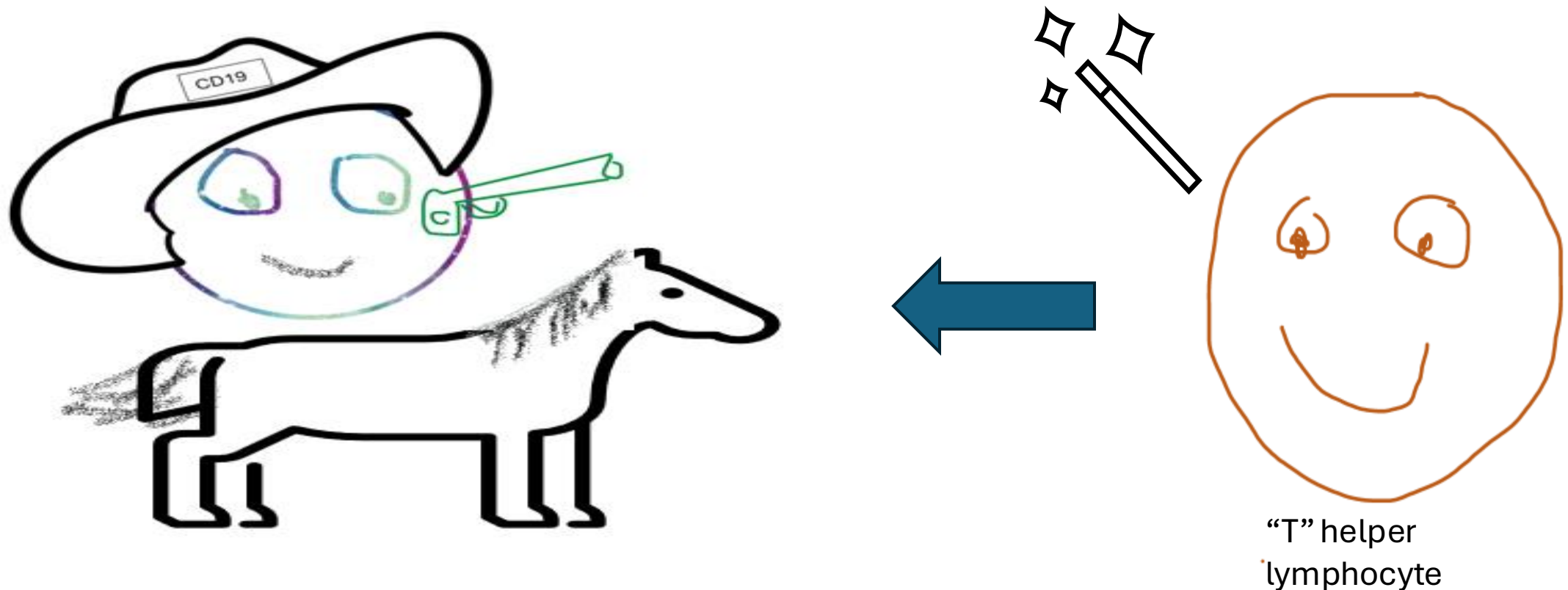
Nurse Practitioner  
Cross Cancer Institute  
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# Objectives

- Simplify understanding re the role of a B lymphocyte
- Identify steps to enhance immunity and protection from illness
- Review CLL secondary cancer risks and provide surveillance recommendations
- Acknowledge anxiety and suggest mitigation strategies

# CLL is a “B lymphocyte” malignancy

- These cells are part of our immune system
- They produce antibodies (immunoglobulins) in response to bacteria, virus or parasites




# I have too many Bs, why am I immune compromised?

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These lymphocytes are  
functionally incompetent

- Less lymphocytes to  
change into antibody  
producing cells/memory  
cells/plasma cells
- So less IgG/IgA production  
increases risk for severe,  
recurrent or persistent  
infections





How can I  
quantify my  
risk for  
infection

- 
- Disease burden
  - Secondary immune deficiency
  - Treatment effects
  - Environmental awareness

# Disease Burden



# Disease burden – imagine our bone marrow



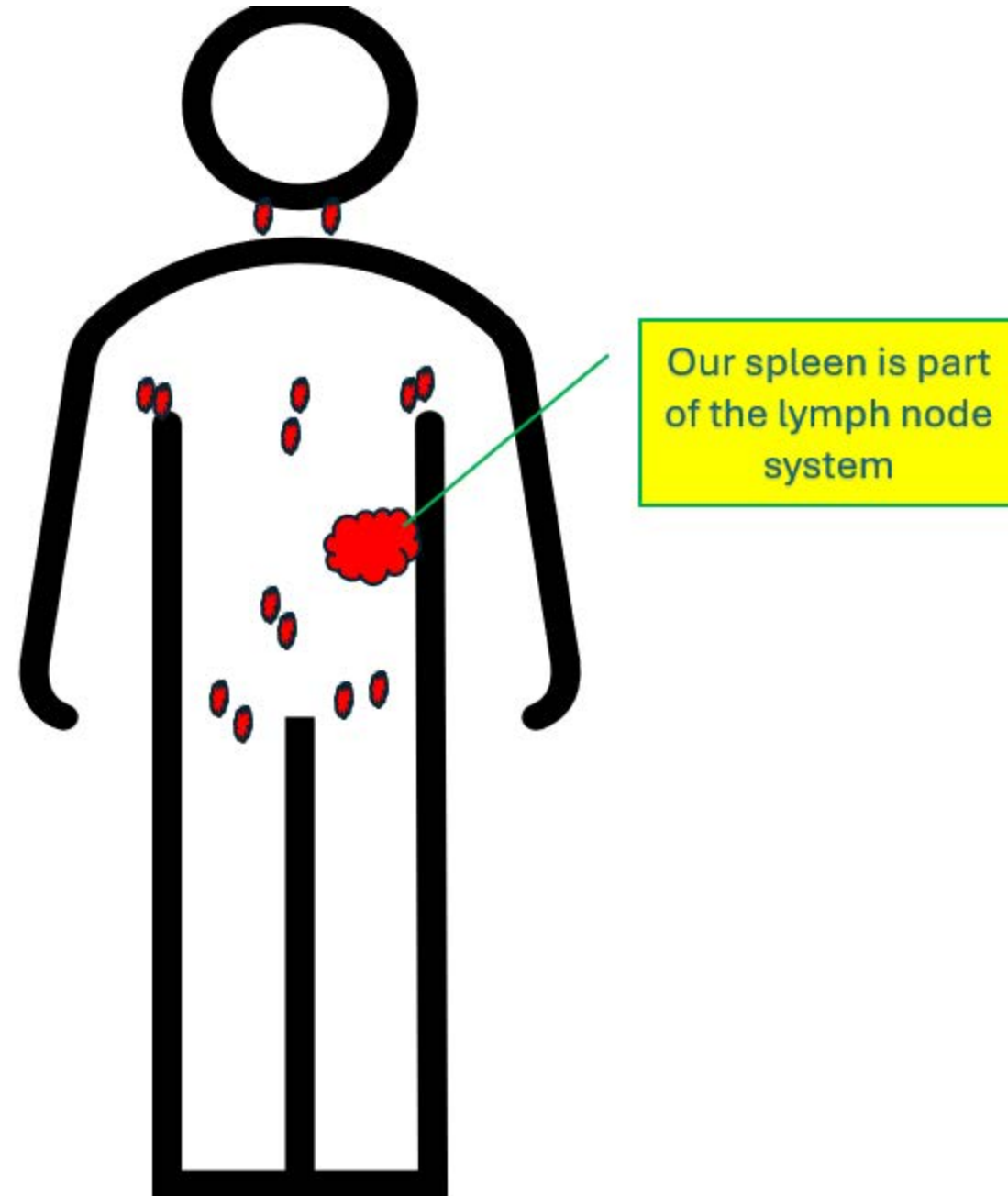
# Immune Deficiency





# Splenomegaly

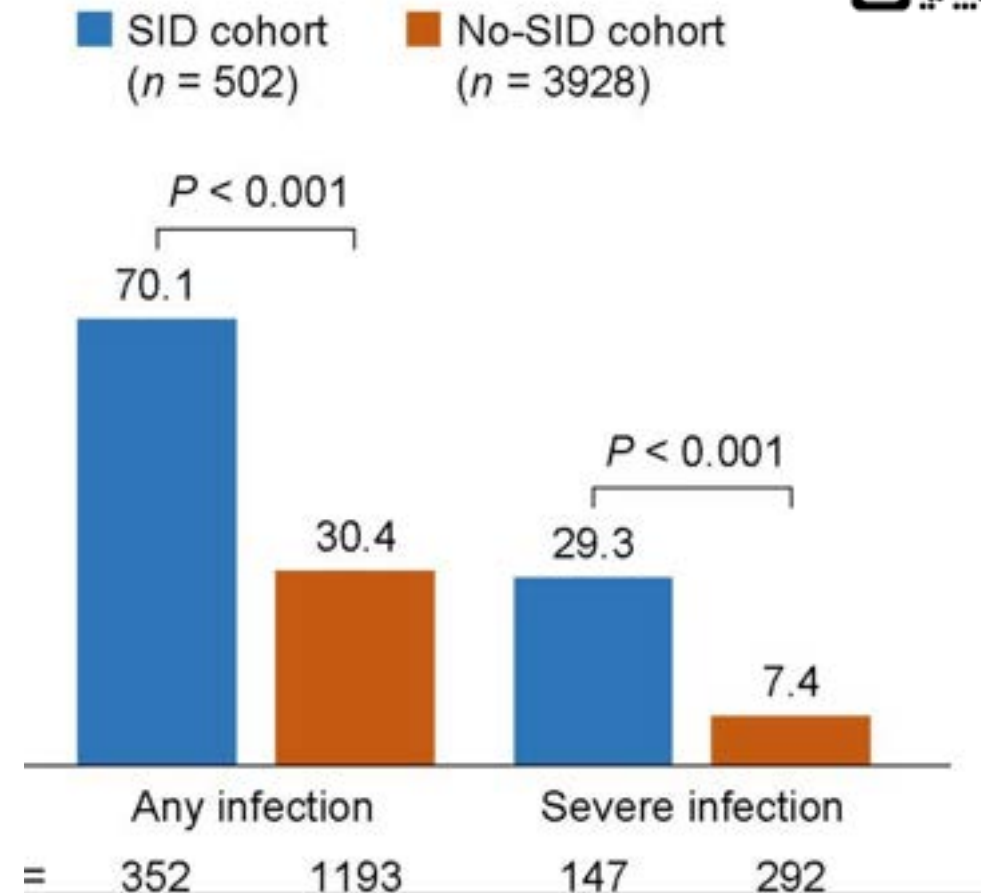
- Role of spleen in infection
- Known risk for ‘encapsulated organism’ infections when removed
  - *Haemophilus influenzae* type b,
  - *Neisseria meningitidis*, and
  - *Streptococcus pneumoniae*.



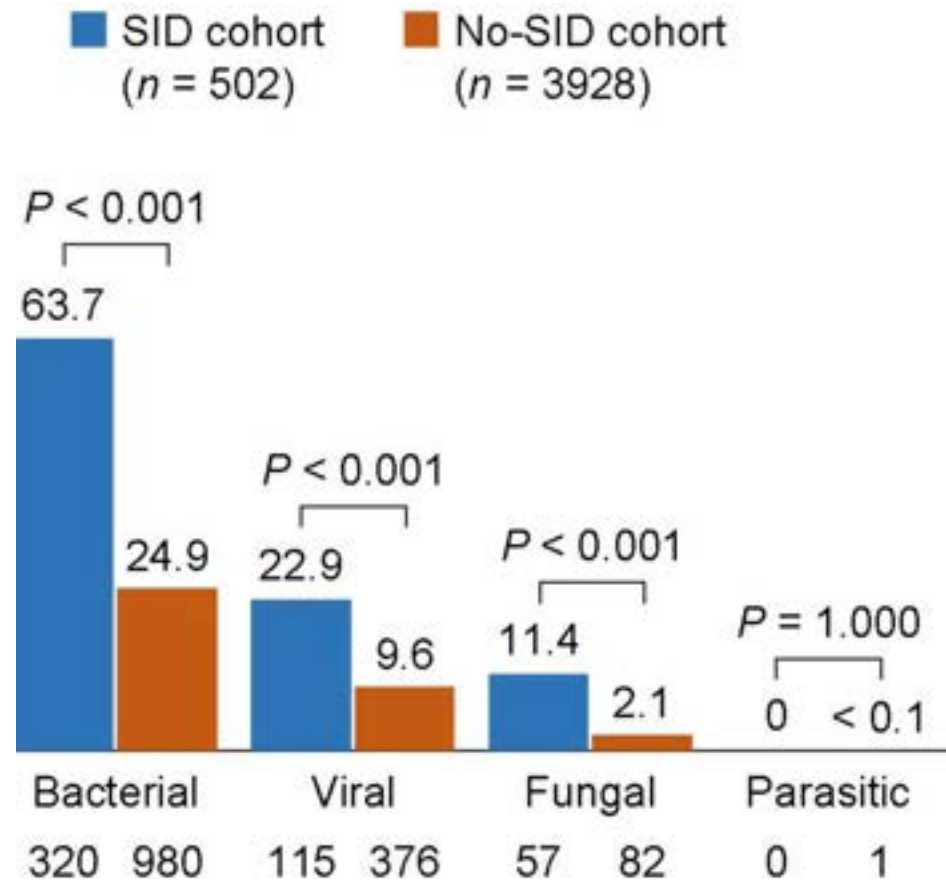
# Disease burden: Low Immunoglobulin levels



- Low levels of immunoglobulin is called “immune deficiency”
- When its CAUSED by CLL – we call it secondary immune deficiency (SID)
- Risk for infection exists EVEN IF normal IgG levels but admittedly lower

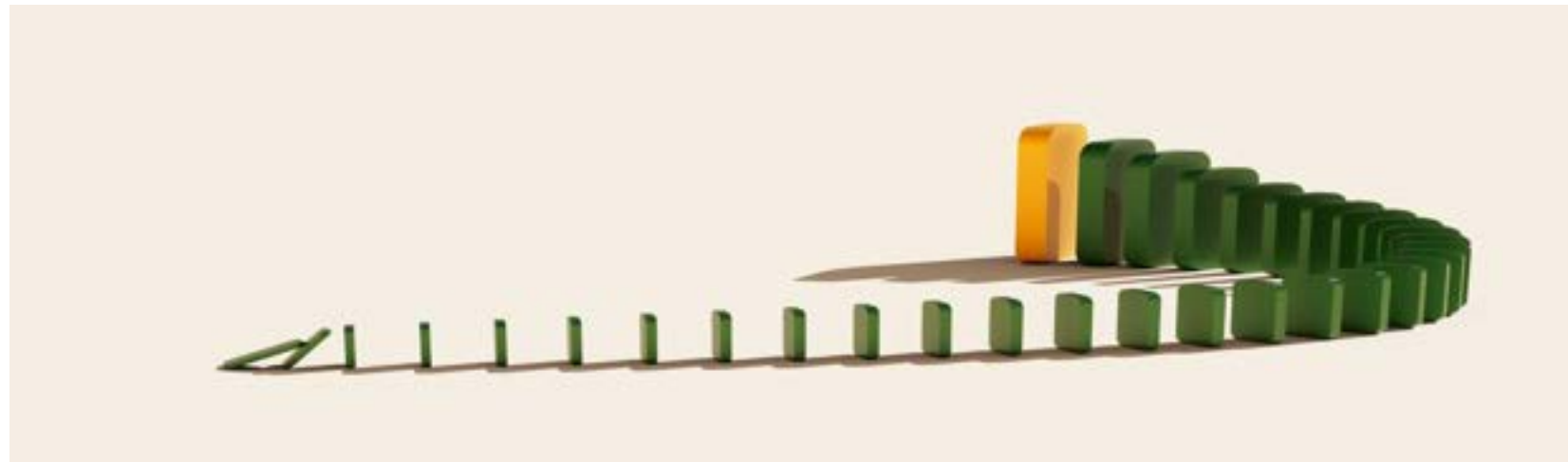


# Multiple causes infection



# Frequency and severity of infections

- If you have NORMAL IgG levels and you are STILL having frequent infections
  - Especially upper respiratory or nasal/throat infections (sinopulmonary infections)
- IgG subclasses



# IgG Replacement Therapy



## **Intravenous (in the vein)**

- Hospital based
- Time
- Travel
- Dose 0.4g/kg q3-6 weeks

## **Subcutaneous (under the skin)**

- Home – less absence work
- Self administer, flexibility
- Cost saving to health system
- Less infusion time
- Reported improved patient satisfaction, QOL
- Improved stability serum IgG levels
- Dose 0.1 – 0.15g/kg weekly

	AB/ON	BC	QC	Atlantic Provinces
Reduced IgG or subclasses	Less than lower limit of normal on TWO separate occasions	Level not defined	IgG< 2 g/L post B cell targeted treatment, chemotherapy or splenectomy	“low” level immunoglobulin
Routine replacement for primary prevention	No	No	No	No
Infection specifications	<ul style="list-style-type: none"> <li>• Invasive life-threatening infection in last year</li> <li>• Recurrent severe infections</li> <li>• Clinically active bronchiectasis</li> <li>• Immunodeficiency specialist recommendation</li> </ul>	Recurrent bacterial infection	Severe, unusual or recurrent infection	Life threatening or recurrent clinically significant infections
Harmon et al. Immunoglobulin utilization in Canada 2023 Allergy Asthma Clin Immunol				

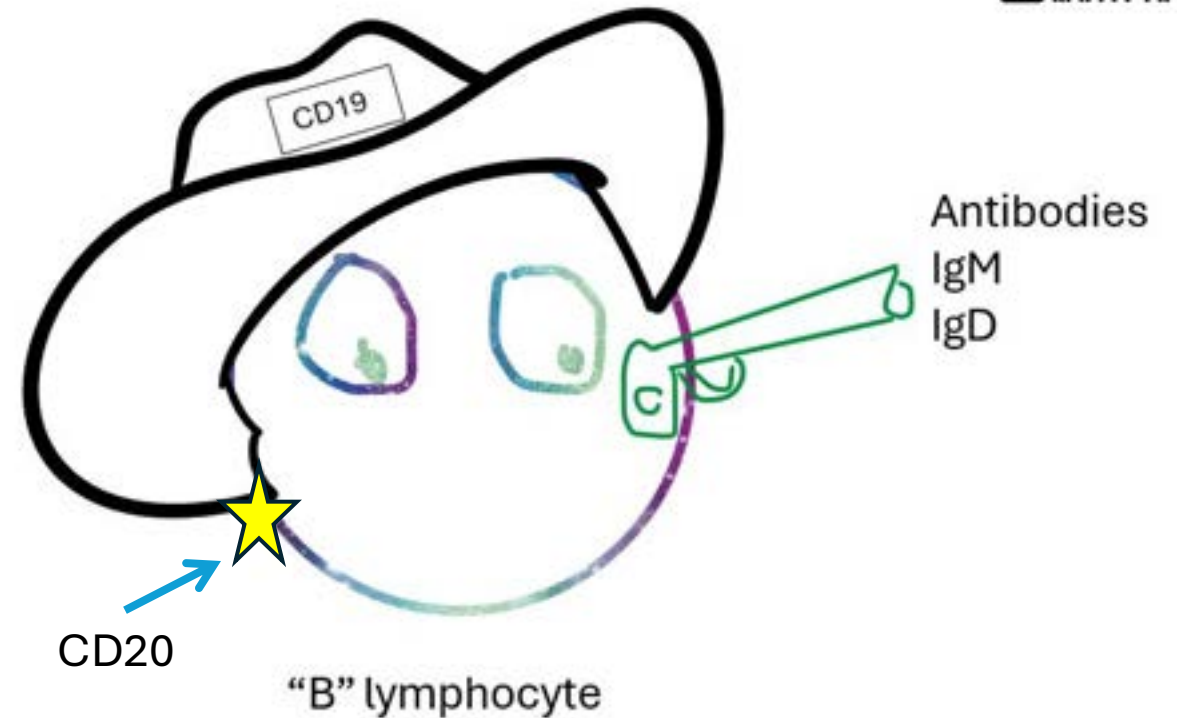
# Treatment Effects





# Your treatment

- Some treatment may help restore immunity (per Dr.Spencer talk)
- Some treatment may further impair immunity
  - CD20 is a marker found on B cells prior to becoming a mature plasma cell
    - antiCD20 therapy in last six months
    - Rituximab/Obinutuzumab



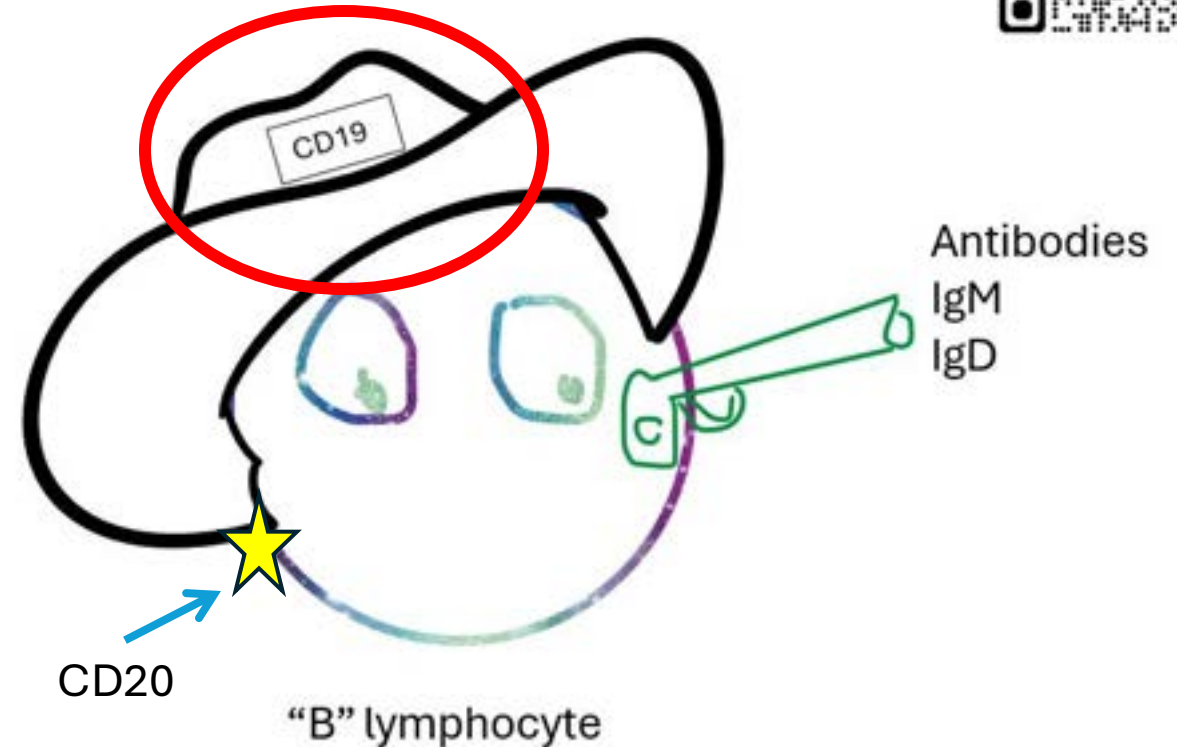


# Treatment of the future



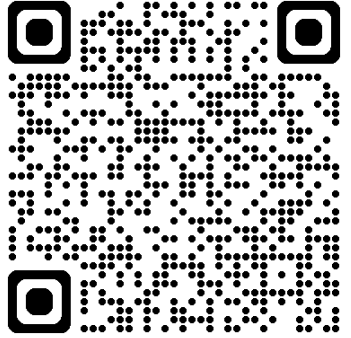
## CAR-T cell therapy

- CD19 target found on “B” and plasma cell
- There are a few CD19 negative plasma cells out there as some immunity is preserved post CAR-T
- Rates of IgG replacement post CAR-T reported at 31-60% long term



# Environmental Awareness





# Assess the environment

- Crowds
- Singing
  - increased spread of virus in closed environment,
  - duration of hours spent
- Close proximity to unwell persons
  - planes without ability to distance/ensure long term protection
- Known people who are unwell also in attendance
  - Inform people about your status

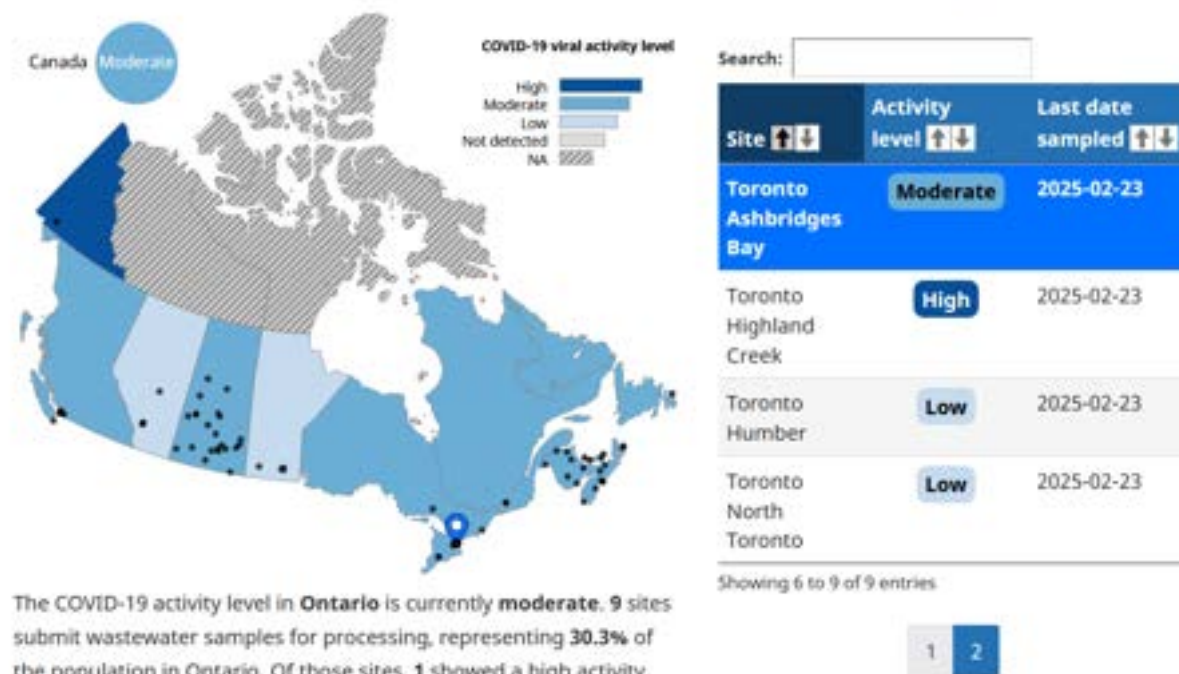
Nakashita et al Singing Is a Risk Factor for Severe Acute Respiratory Syndrome Coronavirus 2 Infection: A Case-Control Study of Karaoke-Related Coronavirus Disease 2019 Outbreaks in 2 Cities in Hokkaido, Japan, Linked by Whole Genome Analysis. Open Forum Infect Dis. 2022 Mar 23;9(5):

# Awareness: of Risk

## National overview

Figure 1. Current wastewater COVID-19 viral activity levels in Canada

Zoom or tap regions to see respiratory virus activity levels in Canada. Map data is available in .csv format.

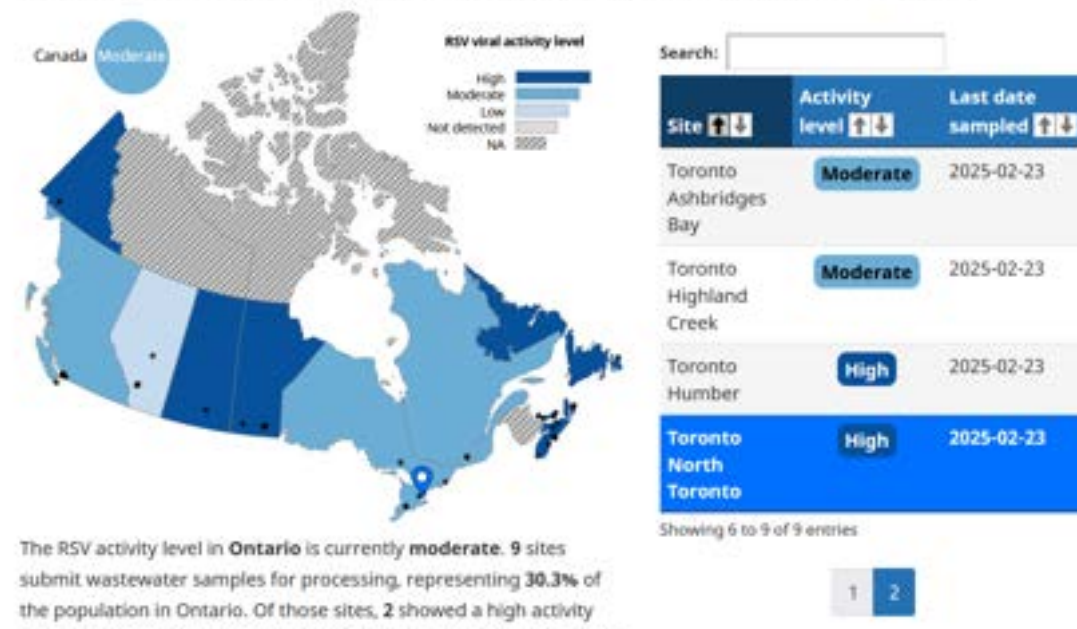


The COVID-19 activity level in Ontario is currently moderate. 9 sites submit wastewater samples for processing, representing 30.3% of the population in Ontario. Of those sites, 1 showed a high activity level, 1 showed a moderate activity level and 2 showed a low activity level, as of February 23, 2025.

## National overview

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The RSV activity level in Ontario is currently moderate. 9 sites submit wastewater samples for processing, representing 30.3% of the population in Ontario. Of those sites, 2 showed a high activity level and 2 showed a moderate activity level, as of February 23, 2025.

<https://health-infobase.canada.ca/wastewater/>

# You are sick....when to take action

- Is there ability to swab for Influenza or COVID?
  - Treatment early for Influenza
  - Treatment early for COVID
    - May be funded if you are on CLL therapy. Contact your provider
- Duration of symptoms
  - Progressing
  - Stable and not getting better



# Protection : Vaccination

- COVID
- Influenza
- Pneumo20 – pneumococcal pneumonia protection
- RSV – respiratory syncytial virus
- Shingrix
- No live vaccines (MMR, yellow fever)

# Prevention: Alternative therapy

- No benefit has been found to reduce frequency of respiratory illness by taking COLD-FX <sup>1</sup>
- No randomized studies of vitamin C benefitting CLL
- Use of gel or saline based nasal spray 2-6x daily with COVID infection has been shown to reduce duration of illness by nearly 2 full days<sup>2</sup>

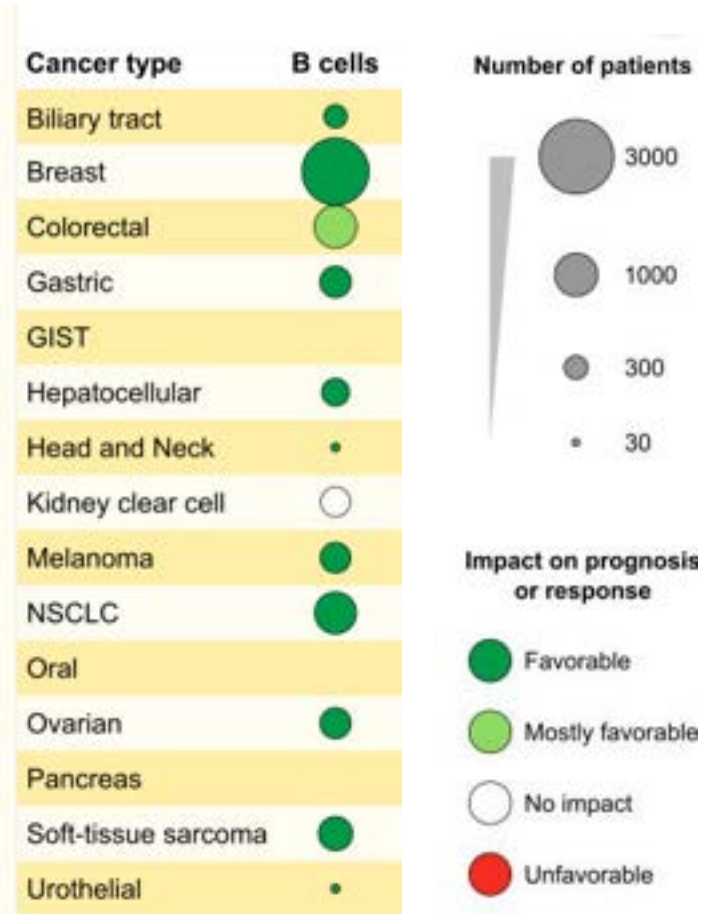
1. High, K. P. et al. (2012). A randomized, controlled trial of Panax quinquefolius extract (CVT-E002) to reduce respiratory infection in patients with chronic lymphocytic leukemia. *The journal of supportive oncology*, 10(5), 195–201.
2. Little, Paul et al. (2024). Nasal sprays and behavioural interventions compared with usual care for acute respiratory illness in primary care: a randomised, controlled, open-label, parallel-group trial. *The Lancet Respiratory Medicine*, Volume 12, Issue 8, 619 - 632

# B cells and Cancer



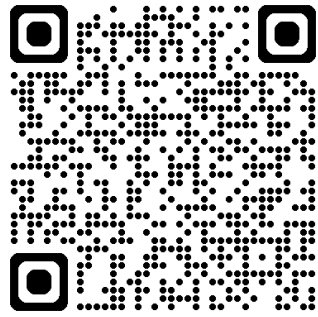


# B cells also play a role in cancer



- Exact concrete ‘mechanism’ of action is still missing and theorized
  - some routes enhance cancer
  - some routes reduce cancer
- The more B cells are found in and around a malignancy the better outcomes
- The more varied those B cells are, the better the outcome

# So... if more is better... less/less functional B cells =



## **Who was included?**

- Netherlands 1989-2019 population study of all CLL diagnosed patients in this time frame through national registry data
- 24,815 CLL patients
- Available BTKi (e.g. Ibrutinib) post 2014
- Venetoclax post 2017

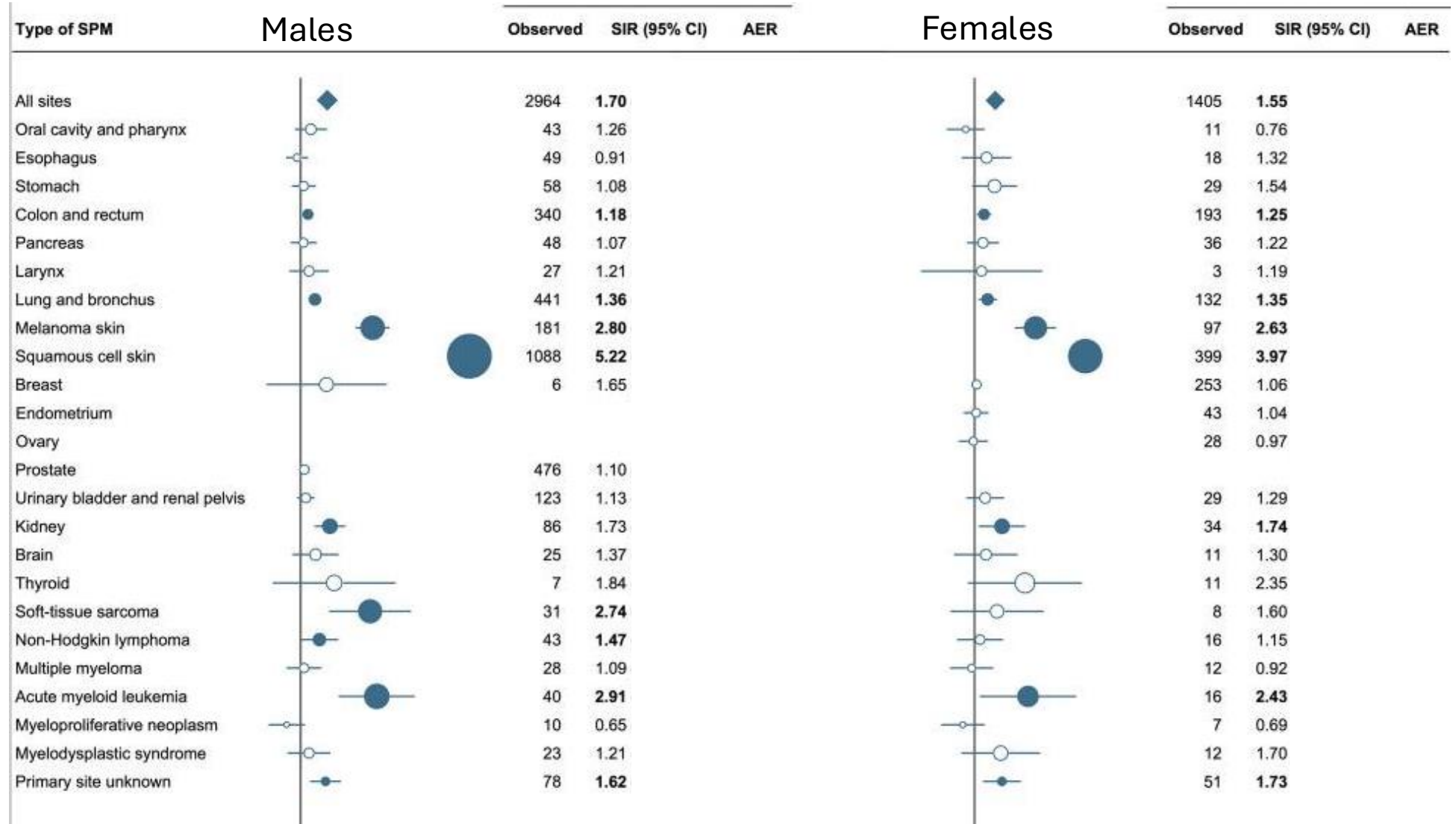
## **Higher risk of cancer**

- Squamous cell skin cancer
- Melanomas of the skin
- Lung/bronchus cancer
- Colon/rectal cancer
- Prostate/Breast
- Soft tissue sarcoma
- Lymphoma
- AML
- Thyroid cancer

# How high is the risk?

SIR=  
Standardized  
Risk ratio

If 1=norm  
2 = twice as  
likely  
etc



van der Straten L, et al. Risk of second primary malignancies in patients with chronic lymphocytic leukemia: a population-based study in the Netherlands, 1989-2019. Blood Cancer J. 2023 Jan 13;13(1):15

# Other countries

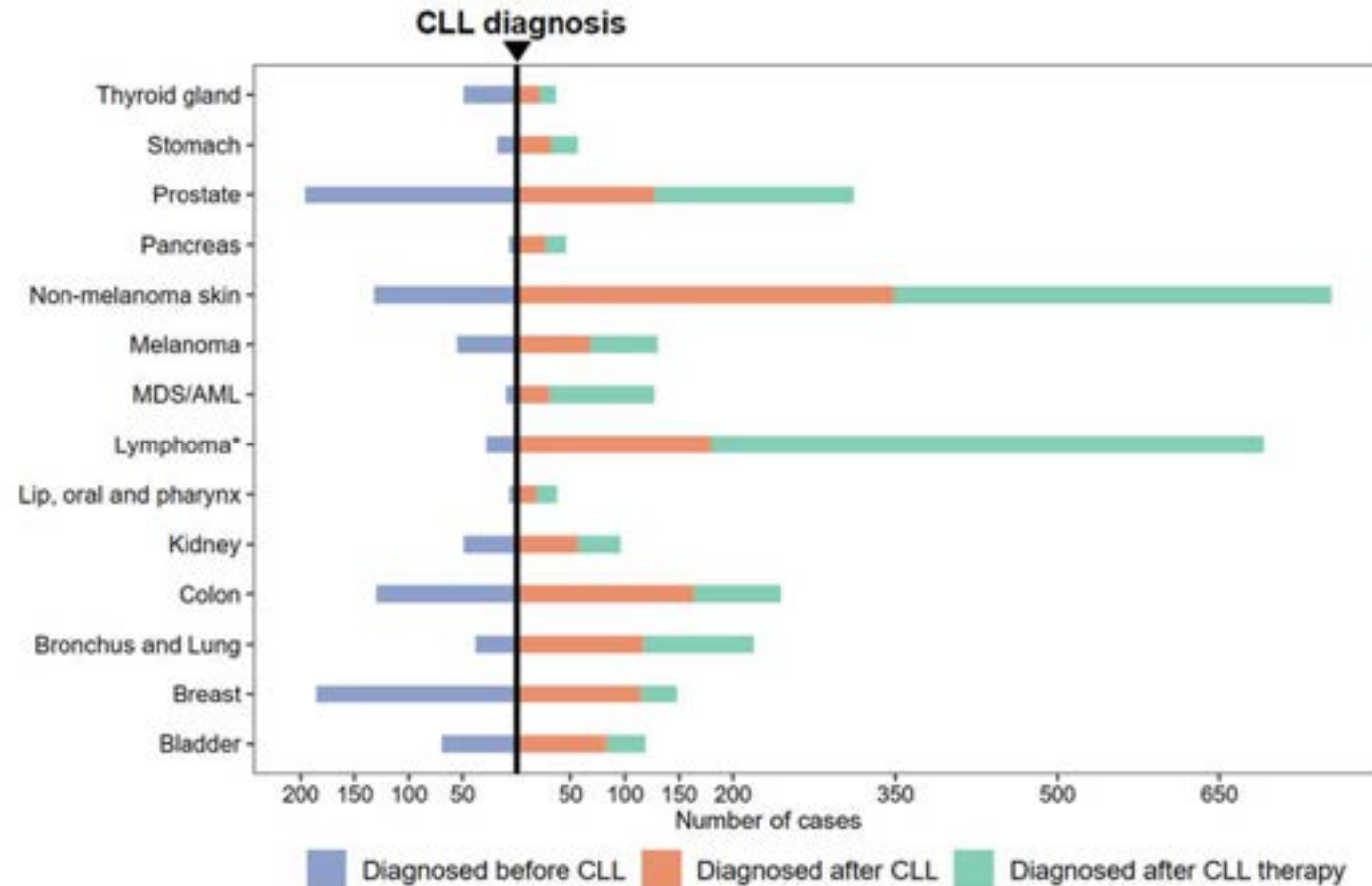


## European data (ERIC data)

- 19,705 patients from 85 different centers in 28 countries with CLL/SLL/MBL
- Diagnosed from 2000 to 2016
- Data collection 2020 - 2022
- 21% had a second malignancy
  - 15.7% solid tumor
  - 4.2% other hematological malignancy
  - 1% had both

Chatzikonstantinou, T et al. Other malignancies in the history of CLL: an international multicenter study conducted by ERIC, the European Research Initiative on CLL, in HARMONY. eClinicalMedicine, Volume 65, 2023, 102307

# When do these cancers get diagnosed?



**Fig. 1:** Other hematological and non-hematological malignancies and their relation to CLL diagnosis and CLL therapy initiation. \*Including Richter transformation. AML, acute myeloid leukemia; MDS, myelodysplastic syndrome.

# CLL treatment can also contribute to cancer risk



**SPM = second primary malignancy**

Table 4. . Patients developing SPMs after treatment initiation, by treatment regimen<sup>†</sup>.

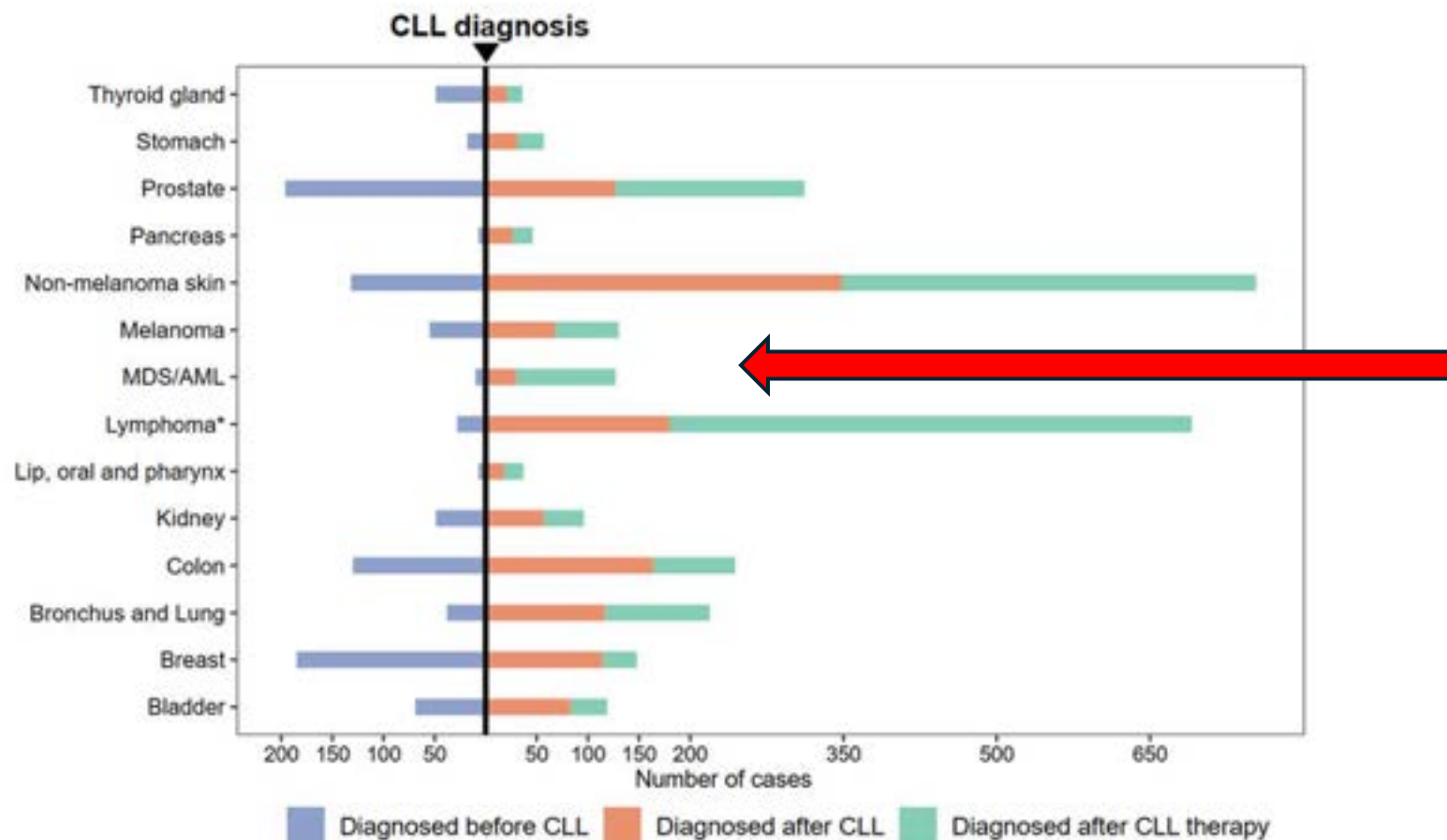
	Anti-CD20 (n = 137)	Anti-CD20 + chemotherapy (n = 278)	Targeted oral agent (monotherapy or with anti- CD20) (n = 122)
Patients with CLL developing a SPM, n (%)	29 (21.2)	80 (28.8)	19 (15.6)

- U.S. Population study (SEER) from 2010 – 2016 followed to Dec 2019 (3053 people)
- A significantly lower percentage of people treated with targeted therapy developed a second primary cancer

Ailawadhi S, Ravelo A, Ng CD, Shah B, Lamarre N, Wang R, Eakle K, Biondo JM. Assessment of second primary malignancies among treated and untreated patients with chronic lymphocytic leukemia using real-world data from the USA. J Comp Eff Res. 2024 Feb;13(2):e230119



# AML/MDS linked to past treatment



2.6% were treated with FC+-R and developed AML/MDS within 5 years after treatment  
And NONE of the patients treated with only a novel agent developed AML

Fig. 1: Other hematological and non-hematological malignancies and their relation to CLL diagnosis and CLL therapy initiation. \*Including Richter transformation. AML, acute myeloid leukemia; MDS, myelodysplastic syndrome.

# Screening







The official journal of the College of Family Physicians of Canada

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## Cancer screening in Canada

**What's in, what's out, what's coming**

Genevieve Chaput, M. Elisabeth Del Giudice and Ed Kucharski

Canadian Family Physician January 2021; 67 (1) 27-29; DOI: <https://doi.org/10.46747/cfp.670127>

# What to watch for



Source: NCI Visuals Online. Skin Cancer Foundation.  
[www.cancer.gov](http://www.cancer.gov).

**MELANOMA**  
CANADA

Learn the **ABCDE's**  
& Spot **Melanoma**

**ASYMMETRY**  
One half of the mole does not match the other

**BORDER**  
Mole edges are ragged, notched, uneven or blurred

**COLOUR**  
Variety of colours may be present. Shades of black, brown, tan, sometimes with blue, grey, red, pink or white

**DIAMETER**  
Mole has grown in size and is larger than 1/4 inch

**EVOLUTION**  
Mole has changed in the past few weeks or months. It may be itchy, scaling or bleeding

## Find a Dermatologist Near You

Access to a list of rapid access clinics, mole mapping clinics and other skin cancer specialists across Canada. Additional resources from the Canadian Dermatology Association are provided.

SEARCH NOW →



# MelanomaCanada.ca

- Scroll to bottom of [melanomacanada.ca](https://melanomacanada.ca)
- To find this link to find a dermatologist near you  
Includes a list of rapid access clinics by province or ask your oncologist for a referral

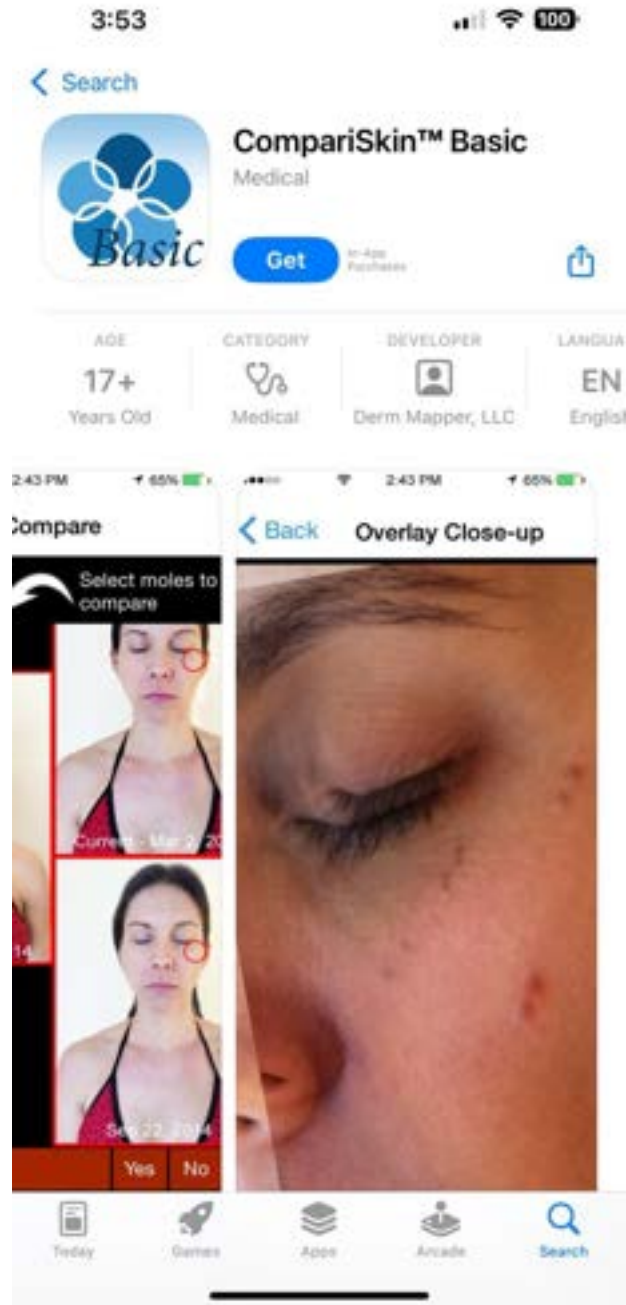




## Mole Mobile

- Travels across AB, BC, ON, QC starting May yearly
- Free skin checks and directs supports if something suspicious identified
- Can sign up for notification re tour stops
- No appointments, first come first served
- Must be Canadian citizen (provincial ID required)
- Does not require provincial health care card

# Free app CompariSkin- Basic



# Colorectal

- 40 – consider FIT testing
- Age 50- 74 FIT every 2 years, or flexible sigmoidoscopy every 10 years
- 75+ Screening not recommended

## Does not apply to

- previous polyps,
- inflammatory bowel disease,
- first degree relative with colon cancer
- blood in stool or symptomatic
- families with hereditary syndromes predisposing to colon cancer (Lynch syndrome, familial polyposis)

# Lung

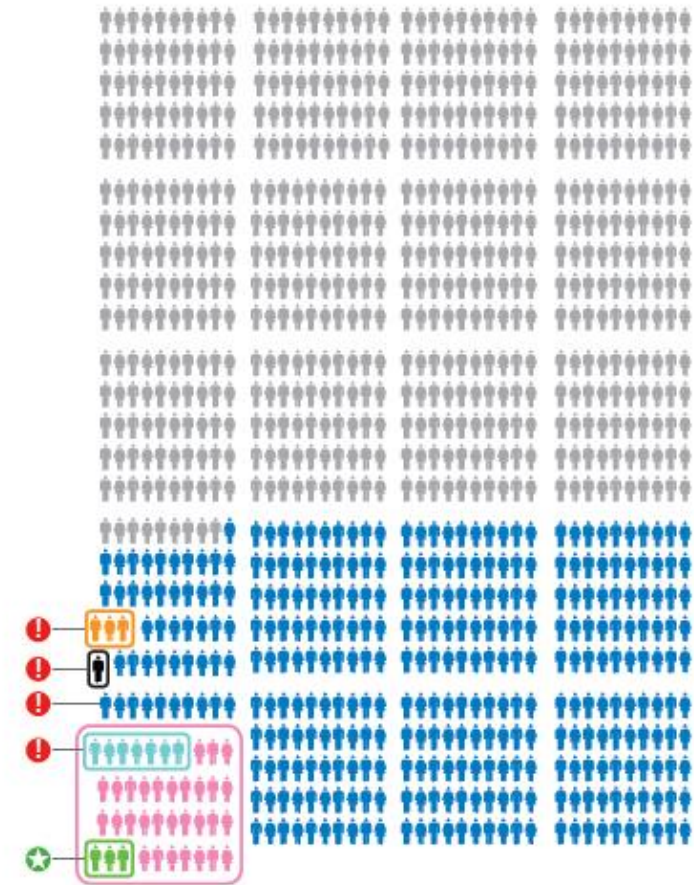
Step 1: calculate # of packs per day  
multiply by number of years smoked

Step 2: If this # is greater than 30 and  
still smoking or quit less than 15 years  
ago

- Age 55 -74 low dose CT scan  
recommended up to 3 times

Screening with a Chest X ray is not recommended

[Lung Cancer— 1000-Person Tool – Canadian Task Force  
on Preventive Health Care](#)



609	will have a negative low-dose CT scan result	
40	will be diagnosed with lung cancer	
351	will have a positive scan result and find out after further testing that they do not have cancer (false positive)	Harm
7	of the 40 diagnosed lung cancers would not have caused illness or death (overdiagnosis)	
3	will have major complications from invasive follow-up tests	
1	will die from invasive follow-up testing	
3	fewer people will die from lung cancer (vs. when screening with chest x-ray)	Benefit

# Prostate Screening

- PSA – not recommended at any age due to high incidence of false positives – even if digital rectal exam was completed
- No benefit in screening which included high risk groups (those with first degree relative with prostate cancer)
- No PSA value completely excludes prostate cancer
- Only a small proportion of prostate cancer causes symptomatic disease or death whereas the majority is slowly progressive and not life threatening.

## BENEFITS

1 out of every 1,000 men will escape death from prostate cancer because they were screened with PSA.

## HARMS

178 out of every 1,000 men screened with the PSA test will have an unnecessary biopsy to confirm they do not have prostate cancer

21 out of every 1,000 men who undergo prostate biopsy will have complications severe enough to require hospitalization.



# Breast

- Under age 50 – not recommended
- 50 to 74 – every 2 – 3 years mammogram recommended
- MRI/CT/ultrasound not routinely recommended

- Does not apply to
  - family history of breast cancer,
  - known genetic risk (BRCA1 or 2)
  - symptomatic persons (lump)

## **Cervical**

- PAP test every 3 years for women age 25 -69 asymptomatic who have ever been or are sexually active
- Over age 70 with 3 negative PAP in last 10 years, screening can cease

## **Ovarian**

- No recommendation for ultrasound or blood testing at this time (asymptomatic women)

Side effects

treatment

Secondary Cancers

Anxiety

Infection

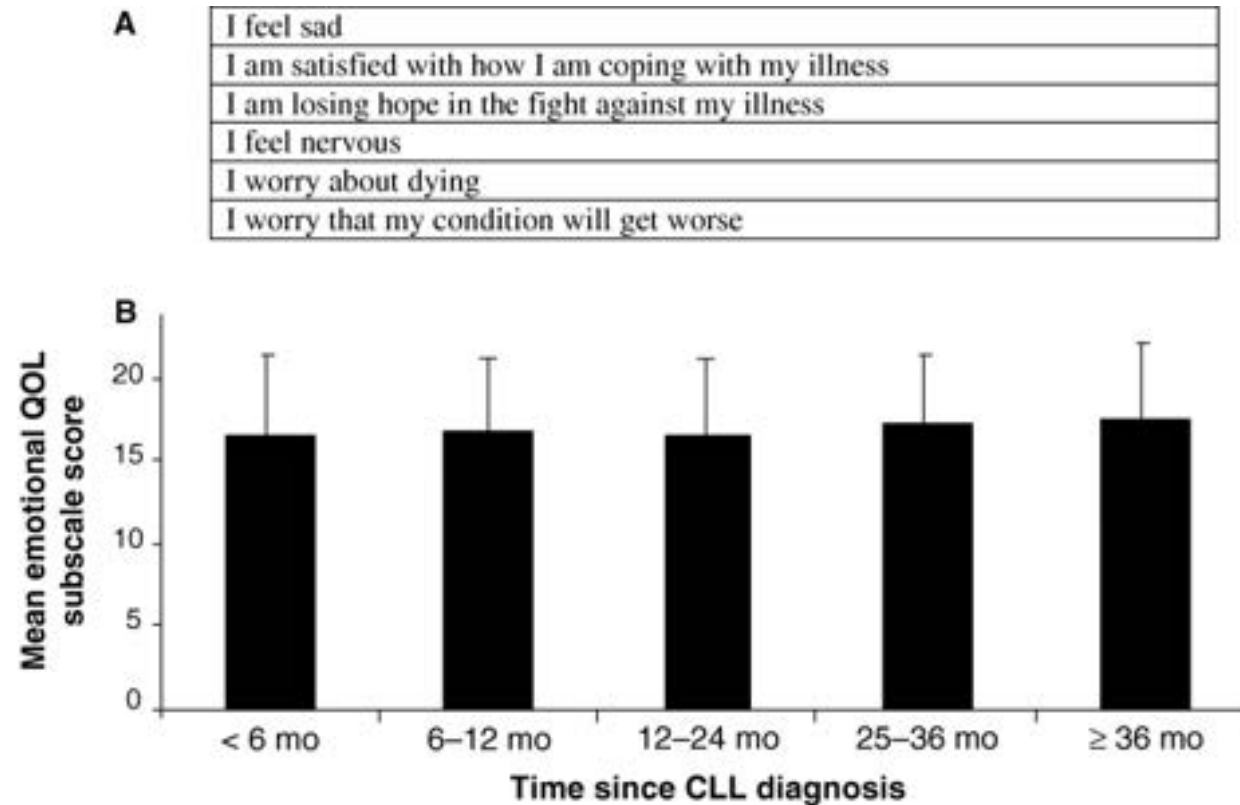
UNKNOWN

# Distress is a real thing

- N=1482 International online survey of CLL patients with QOL assessment (FACT-G, Brief Fatigue Inventory)

“emotional distress experienced by newly diagnosed patients is not a transient phenomenon that ‘gets better with time’”

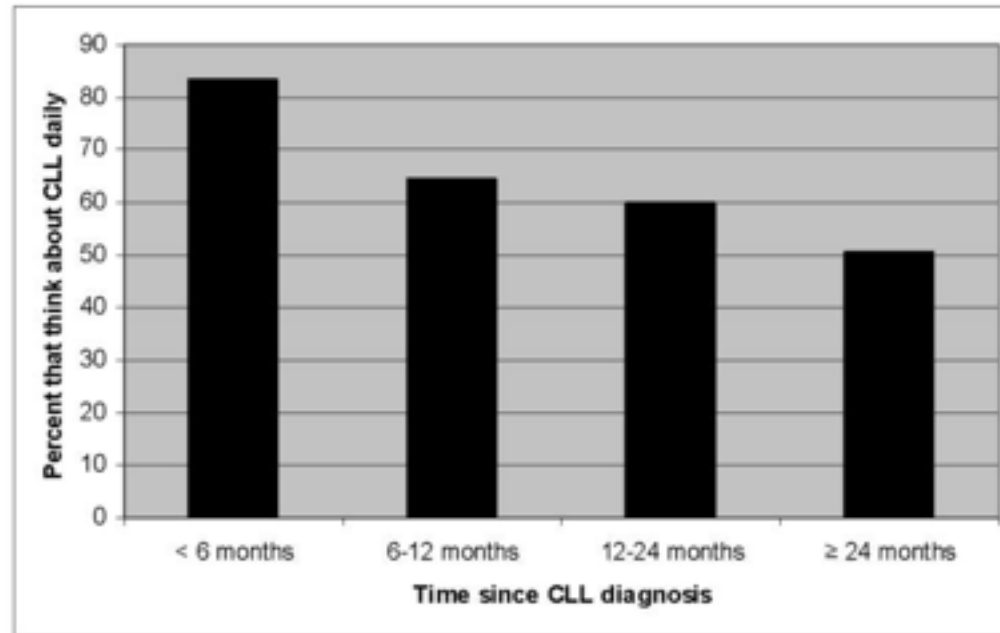
# 3 years out....no change emotional QoL



Quality of life in chronic lymphocytic leukemia: an international survey of 1482 patients

Shanafelt, Br J Haematol, Volume: 139, Issue: 2, Pages: 255-264, First published: 25 September 2007, DOI: (10.1111/j.1365-2141.2007.06791.x)

And 56% of patients surveyed think about their CLL every day even 2 years out....



Offering more frequent monitoring in the first six months after diagnosis may help alleviate anxiety

Fann, J. Hutch News Stories, The cancer waiting game, 2016

# Does treatment relieve anxiety

- Survey 105 CLL patients divided into two groups
  - active treatment
  - watch and wait
- Depression and Anxiety and QOL surveys
- No difference between depression, anxiety and physical or mental quality of life

# UnMET needs in CLL


Received: 19 January 2021 | Revised: 20 July 2021 | Accepted: 27 July 2021

DOI: 10.1002/pon.5800

ORIGINAL ARTICLE

WILEY

## Unmet supportive care needs, anxiety and depression in haematology patients during watch-and-wait

Marieke D. C. Damen<sup>1</sup>  | Peter E. Westerweel<sup>2</sup> | Mark David Levin<sup>2</sup> | Aline J. Pelle<sup>3</sup>



# Top Unmet needs

Where can I help?

%	Unmet need	Domain
18	Being informed about things you can do to help yourself to get well	Health-needs
18	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	Health-needs
17	Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse or friends need it specialist) if you, family or friends need it	Health-needs
16	Uncertainty about the future	Psychological-needs
16	Being informed about your test results as soon as feasible	Health-needs
16	Feelings of sadness	Psychological-needs
15	Being informed about cancer which is under control or diminishing (i.e., remission)	Health-needs
14	Being treated like a person not just another case	Health-needs
13	Fears about the cancer spreading	Psychological-needs

# Collaboration

- If able, sign up to access your electronic chart
- Come prepared to your appointment
- Have your questions ready – consider a journal
- Document symptoms concretely AND DURATION so better prepared
  - Napping? Duration?
  - Drenching sweats how many nights per week?
  - Frequency and duration of infections
  - Weight loss
  - If on treatment – blood pressure, racing heart, dizzy spells

# Re frame your CLL therapy plan

- Traditional – Watch and Wait
- Active Surveillance/Routine Surveillance
- On Treatment
- Between treatments

**W&W**

**M&M**

**M&M**

# M&M

- M – monitor
  - Labs, symptoms, physical findings
  - Science
- M – Move On
  - Don't let this diagnosis derail your plans moving forward
    - Retirement
    - Vacations
    - Special occasions
  - If you find yourself ruminating on CLL - have a pack of M&M's and review the notes from your previous appointments and organize your thoughts for your next appointment in your journal



*“It’s not how much money we make that ultimately makes us happy between nine and five. It’s whether or not our work fulfills us. Being a teacher is meaningful.”*

Malcolm Gladwell



Thank YOU for giving me this  
opportunity to add **meaning** to my life today.

Nan