# CLL Ireland Patients Forum

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BCNI INVESTIGATOR

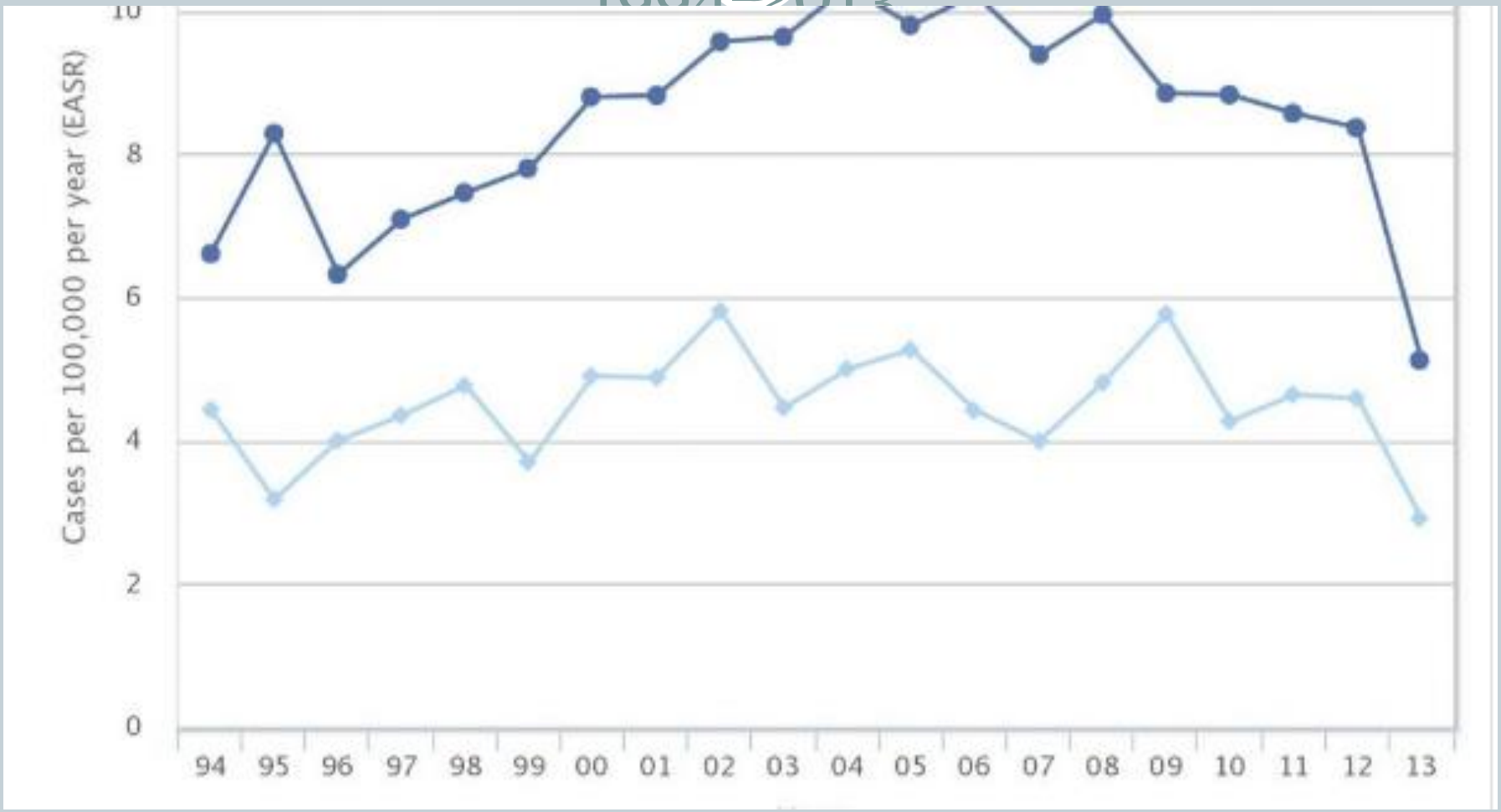
# CLL

- What is it?
- How common is it?
- How do we know how common it is?
- Is there research going on?
- Why does research matter
- Basics of the Full Blood Count
- What does a CLL cell do and how does it do it?

# CLL – what's in a name?

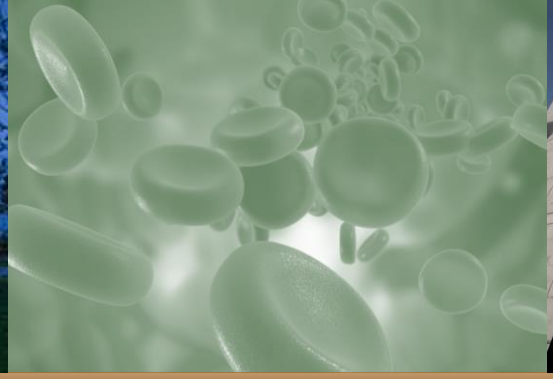
- *Chronic*
- *Lympho*
- *cytic*
- *leuk*
- *aemia*

# New diagnoses of CLL in Ireland
# National Cancer Registry Ireland Data
# 1994-2013

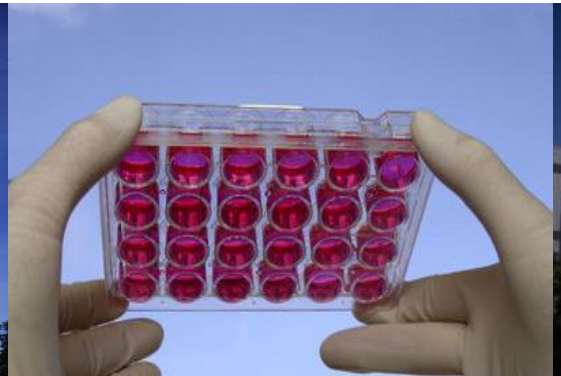


# New diagnoses of CLL in Ireland
# National Cancer Registry Ireland Data

- Who are the NCRI?
  - Collaboration with BCNI
- Incidence
  - Its about new cases
- Prevalence
  - Reflects survival



# BLOOD CANCER
## NETWORK IRELAND
## (BCNI)



# BLOOD CANCER NETWORK IRELAND (BCNI)

1. Extended Data registration for Blood Cancers 2017

2. Biobanking – what does it mean for CLL

3. Clinical trials for new drugs

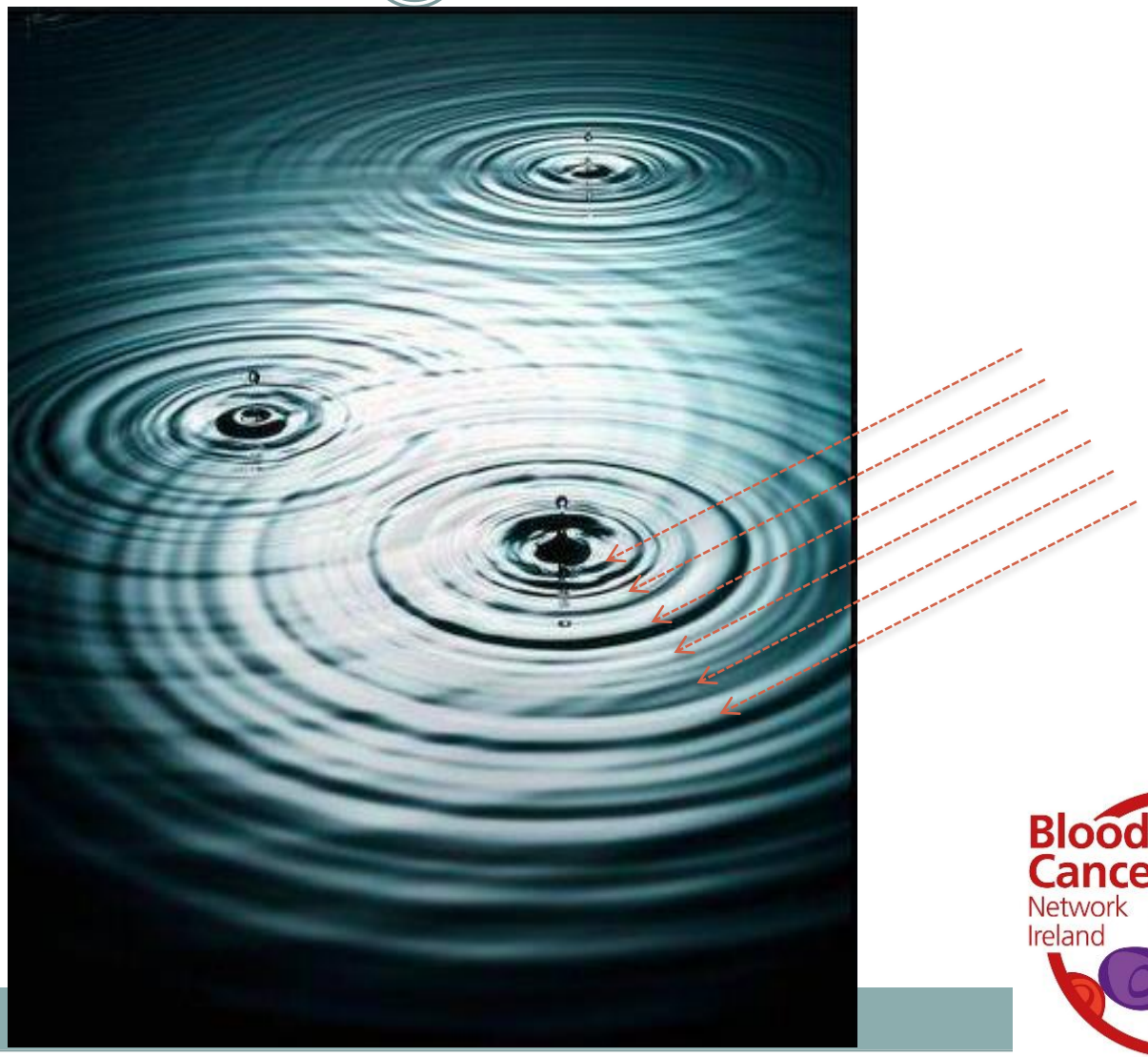
# Wider impacts – leveraged progress

Biobanking

Clinical Trials

Enhanced Blood Cancer Registration

The overlapping circles of benefit

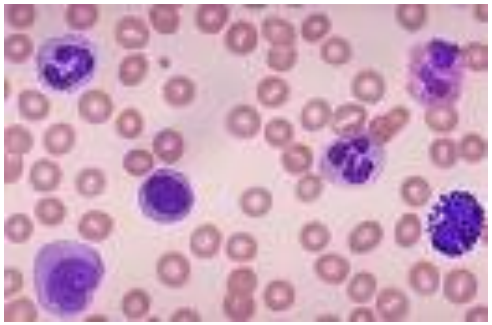


Blood Cancer Network Ireland

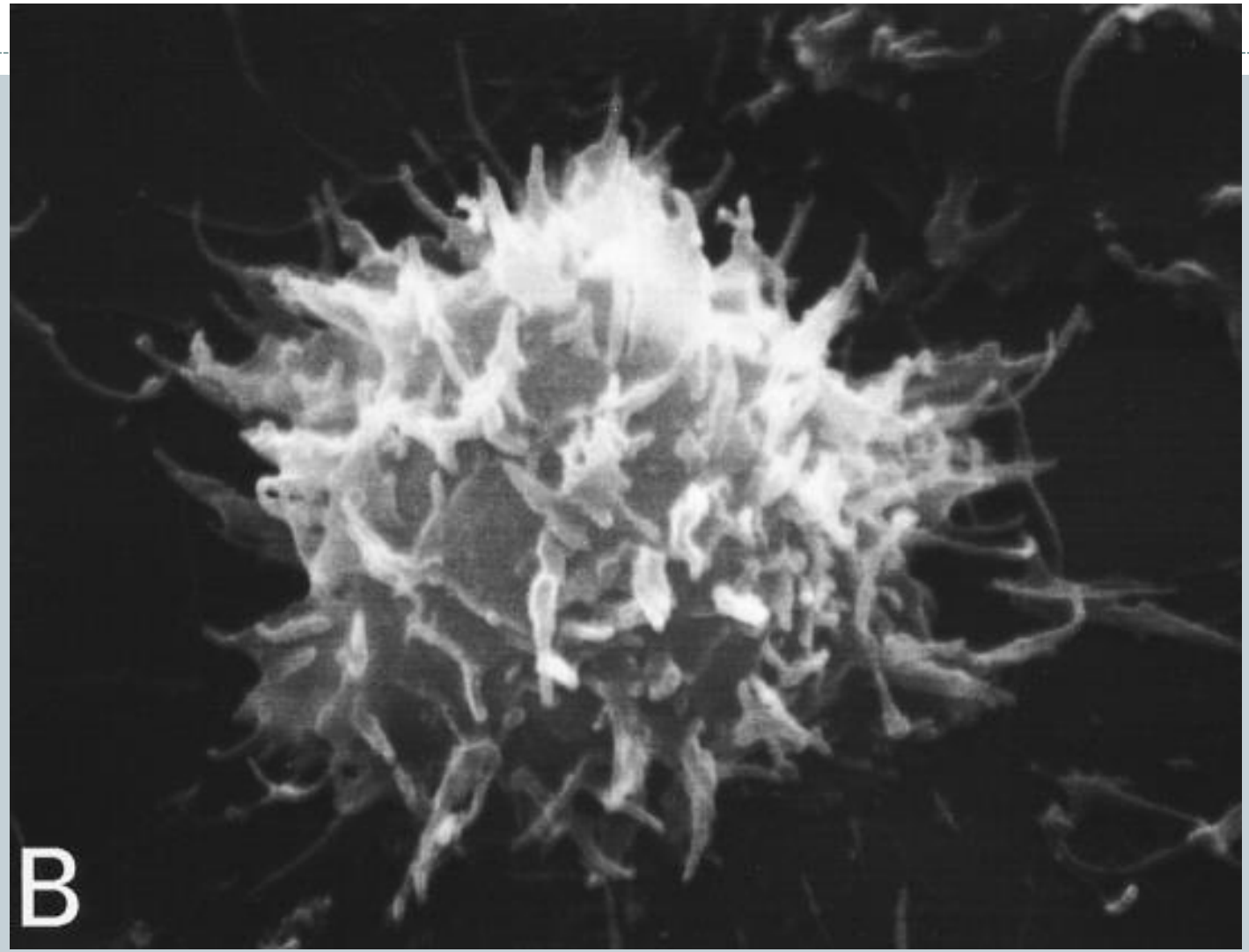
# Full Blood count

- Red cells
- White cell
  - 5 different types of white cells
  - Focus on lymphocytes and neutrophils
- Platelets

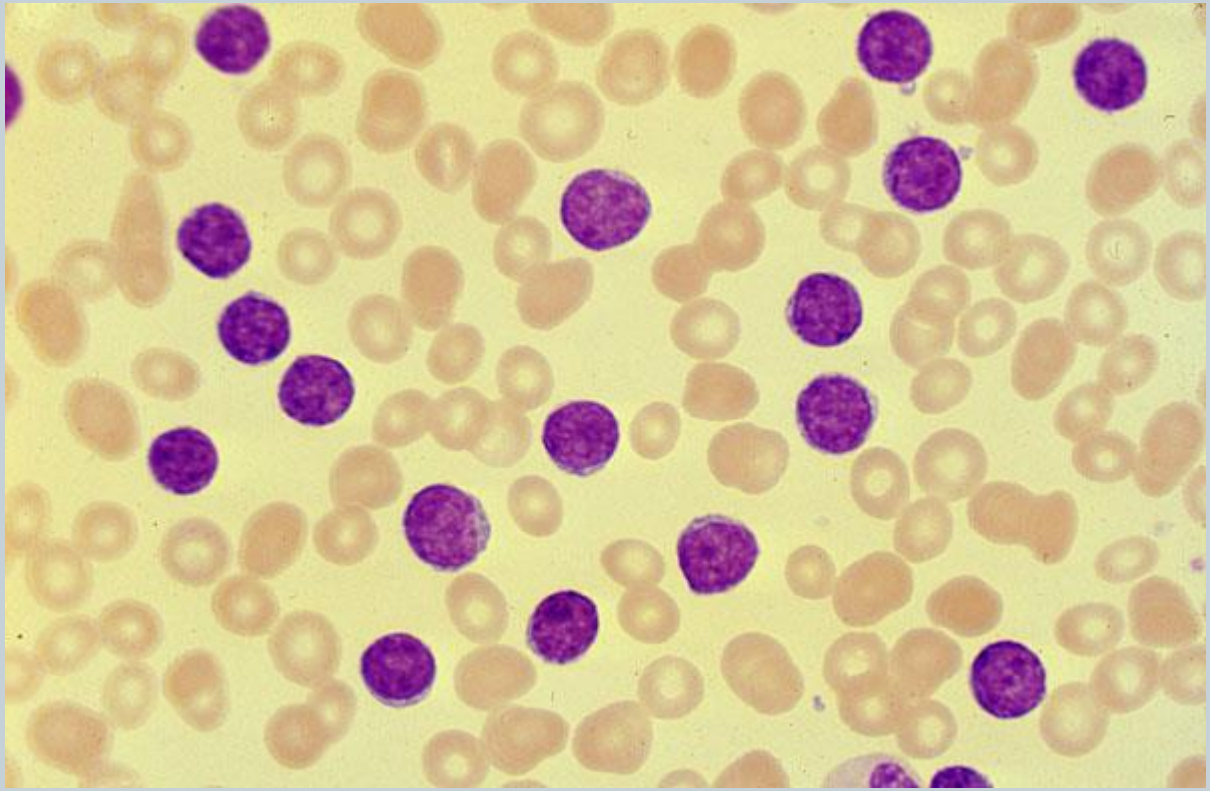
# Types of white cells



# What does a lymphocyte really looks like?



# CLL

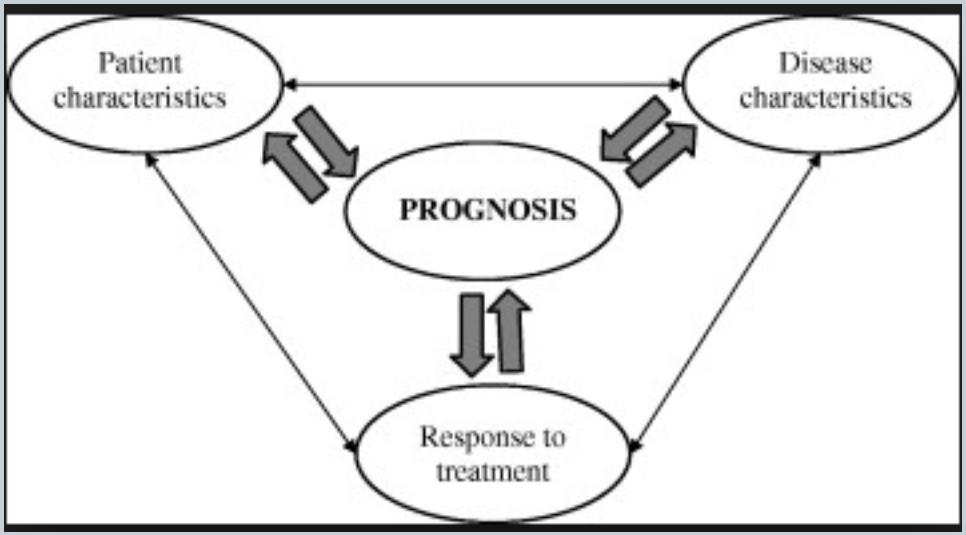


# CLL – assessing prognosis

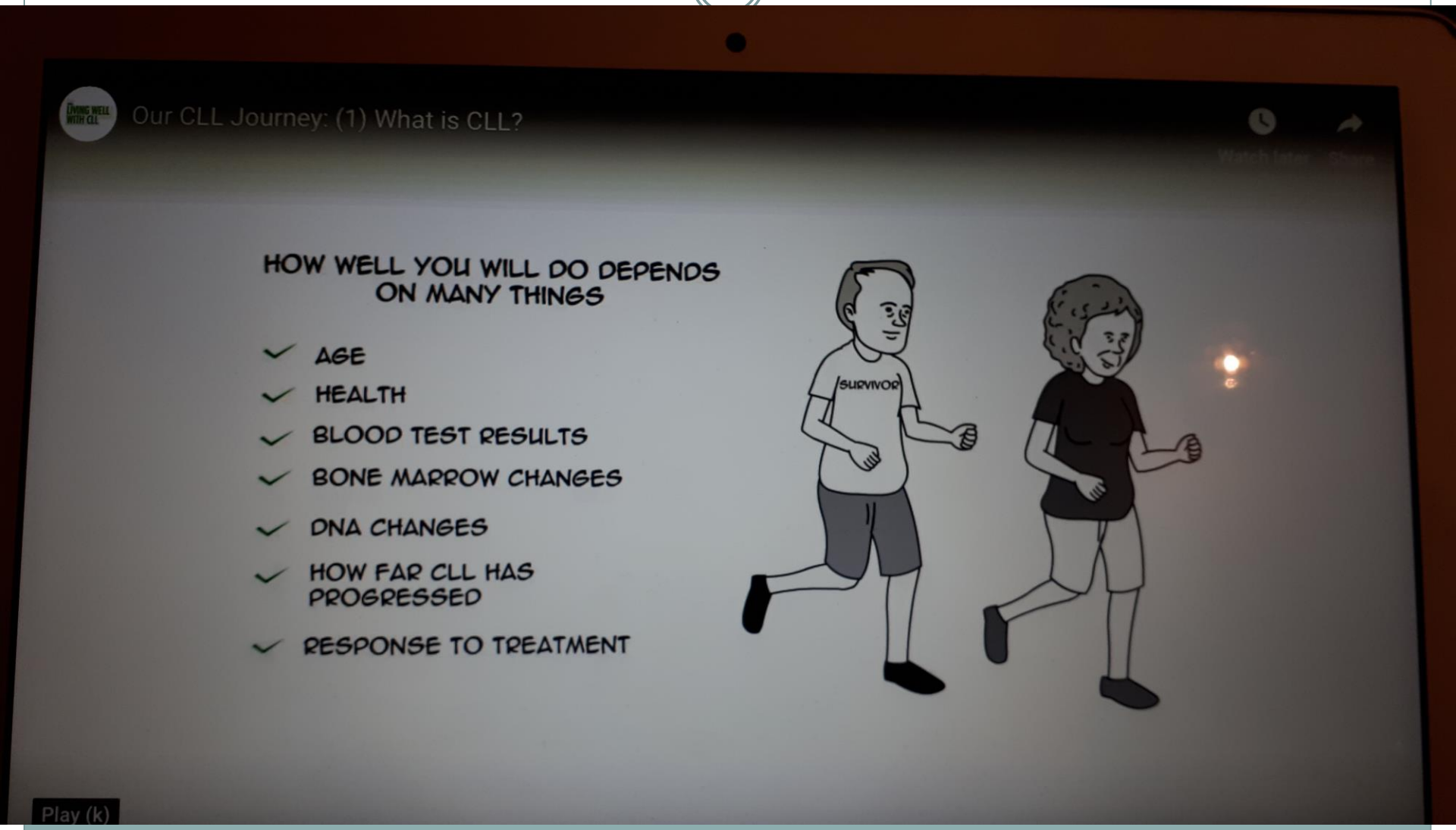
- What is prognosis?
- How accurate is it?
  - Population level
  - Individual level

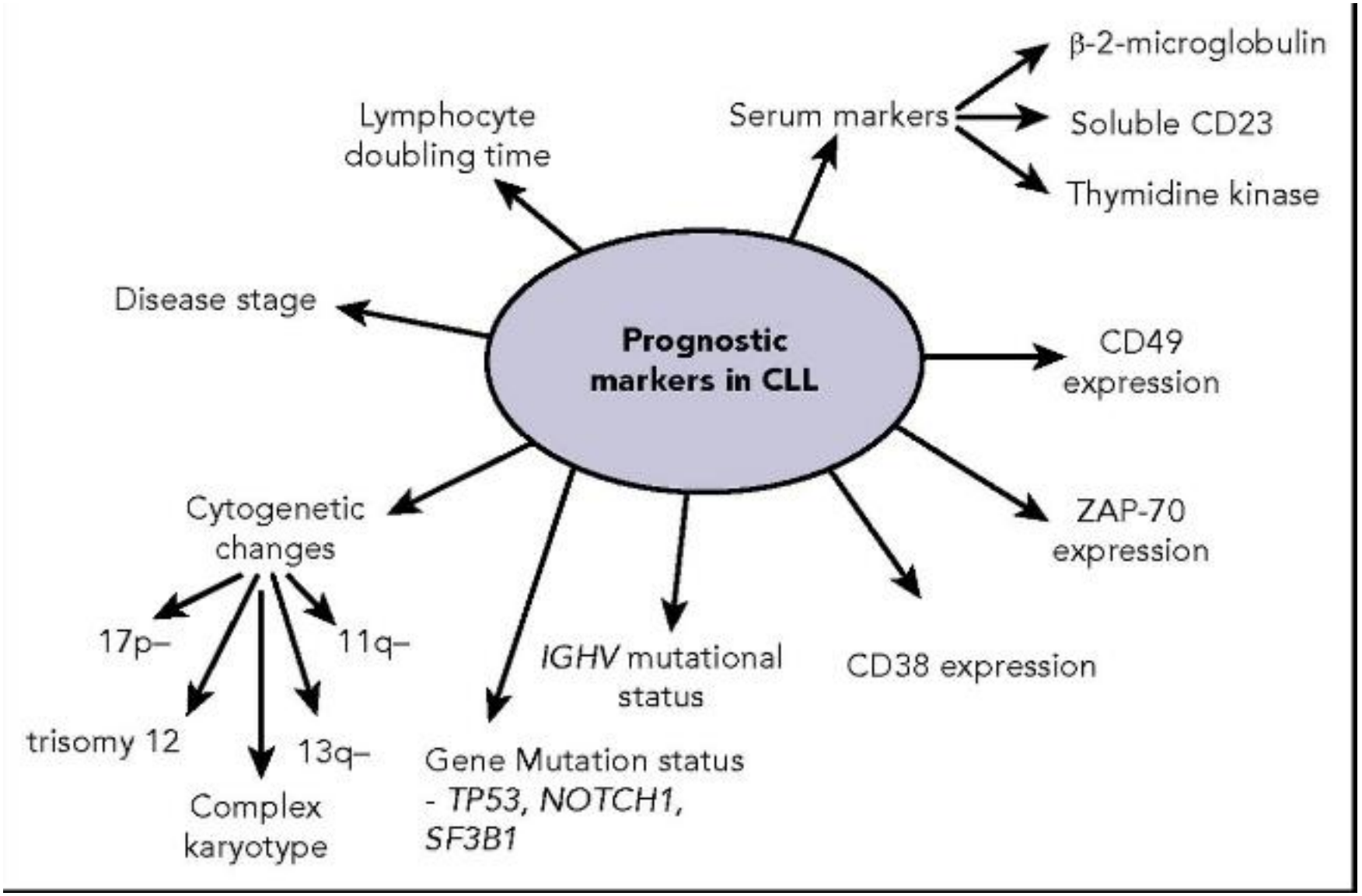
- What do we use to help predict it?
  - Mutated and Unmutated CLL
- Characteristics on the CLL cell that we can exploit (CD20)
- Antibodies
- The unseen Multidisciplinary team in your corner
- Dealing with uncertainty

# How do deal with assessing your prognosis

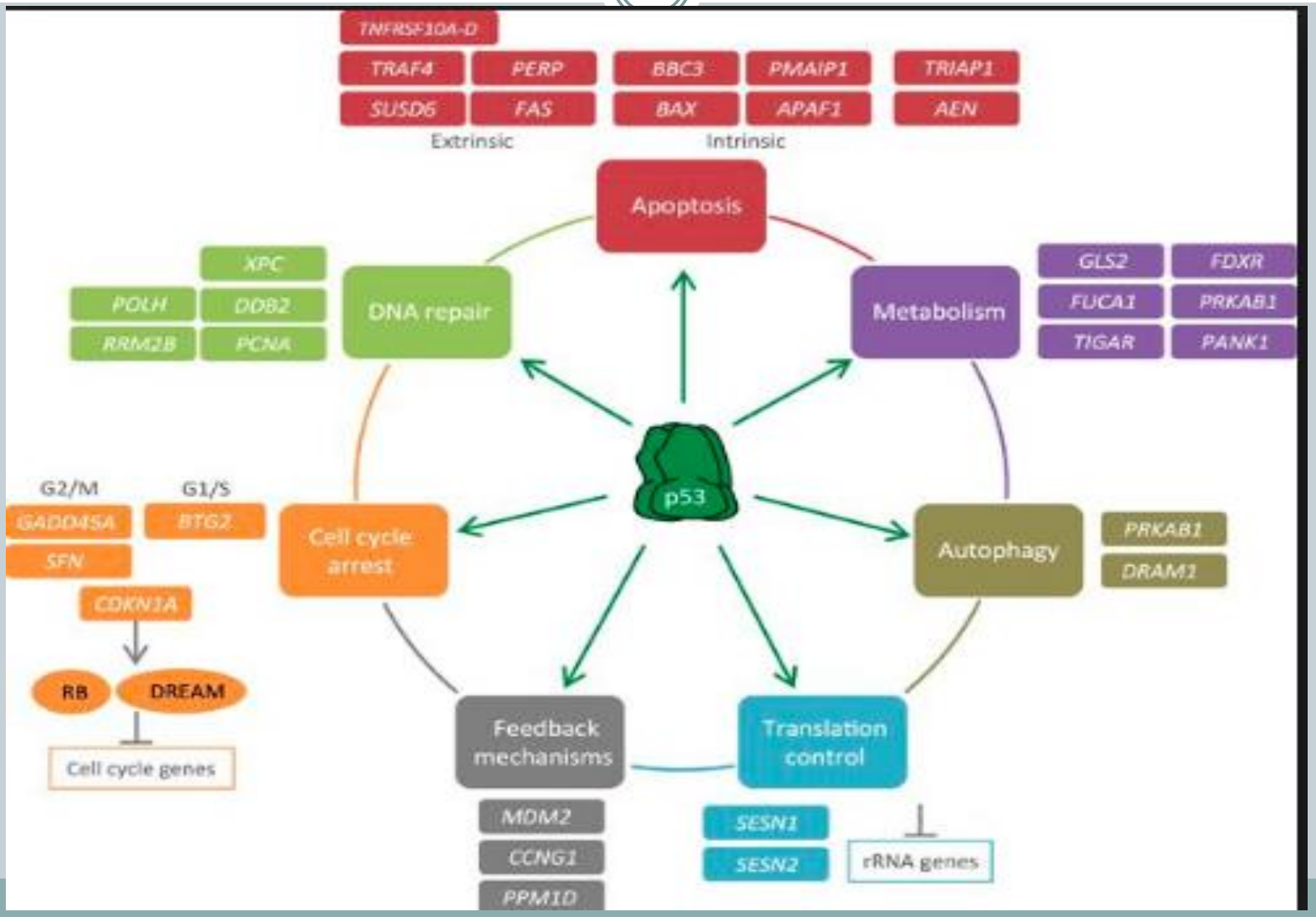


# From the excellent CLL Ireland Website

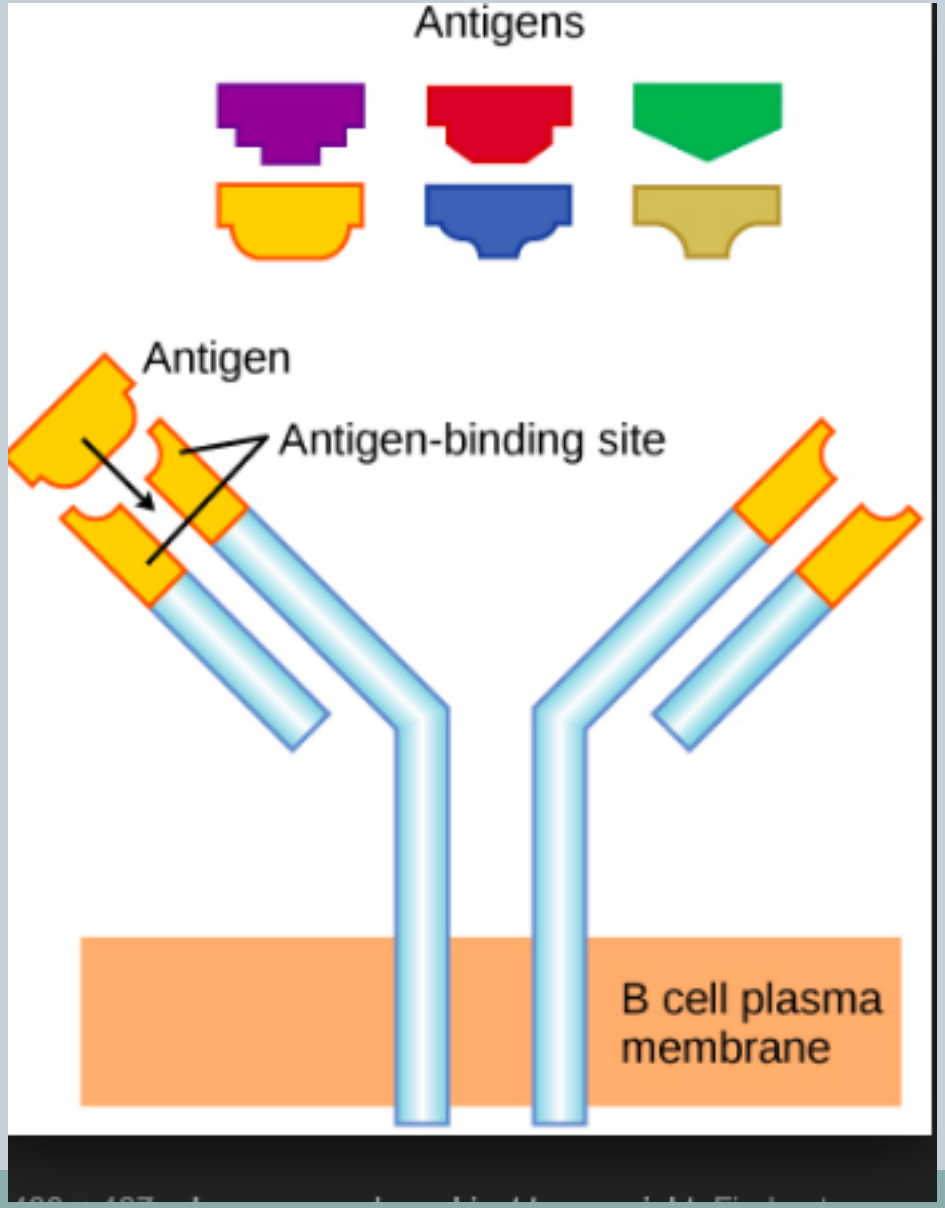


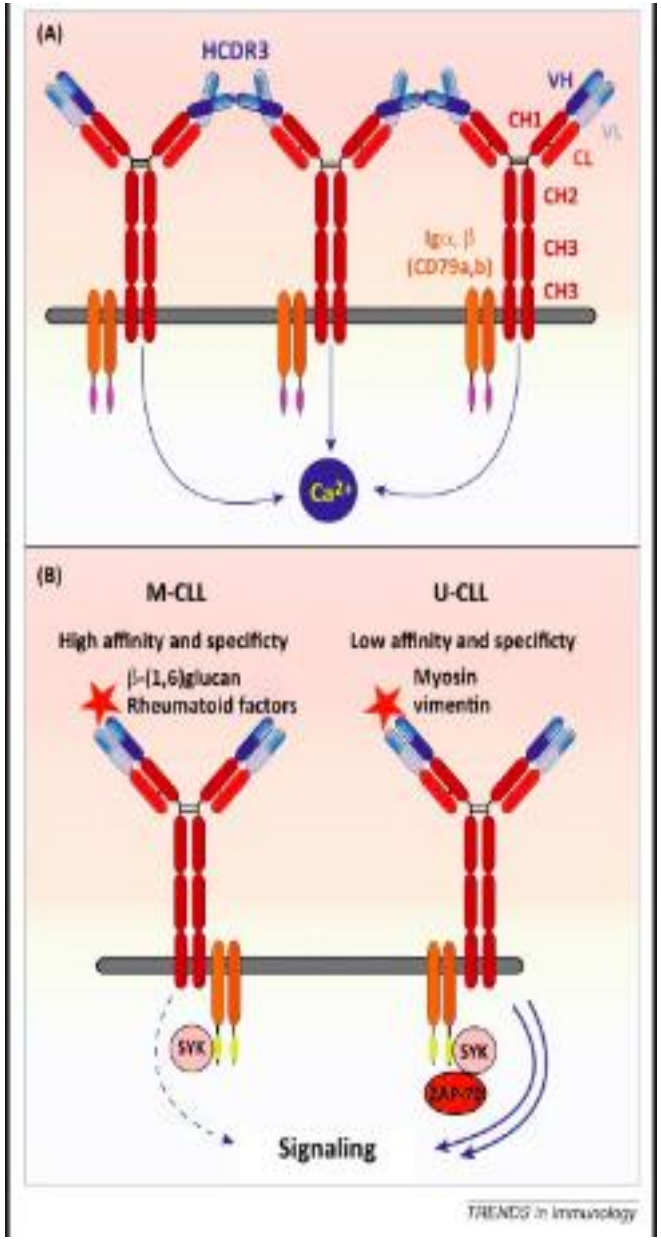

Prognostic markers in CLL
Lymphocyte doubling time
Serum markers
β-2-microglobulin
Soluble CD23
Thymidine kinase
Disease stage
CD49 expression
Cytogenetic changes
17p–
11q–
trisomy 12
13q–
Complex karyotype
Gene Mutation status - TP53, NOTCH1, SF3B1
IGHV mutational status
CD38 expression
ZAP-70 expression

# P53 (17p deleted)

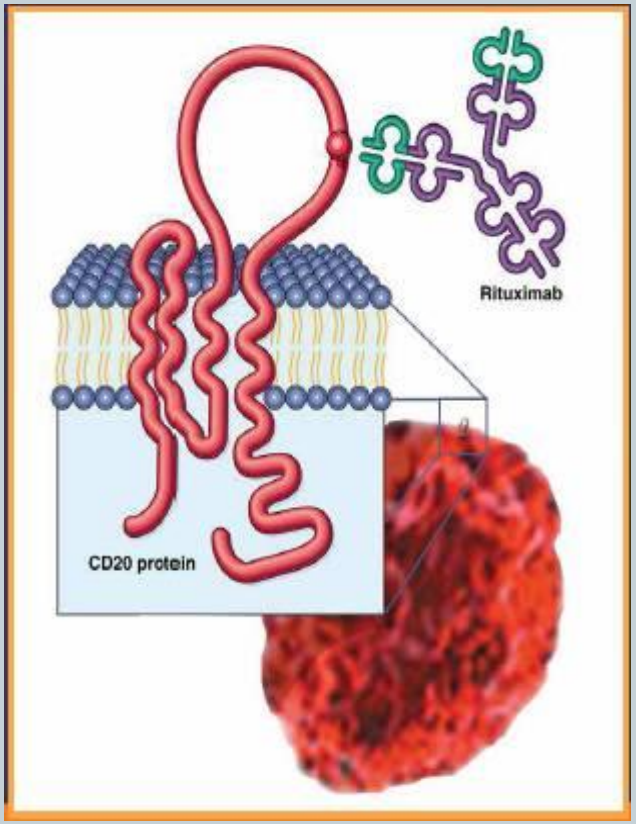


# Mutated and unmutated

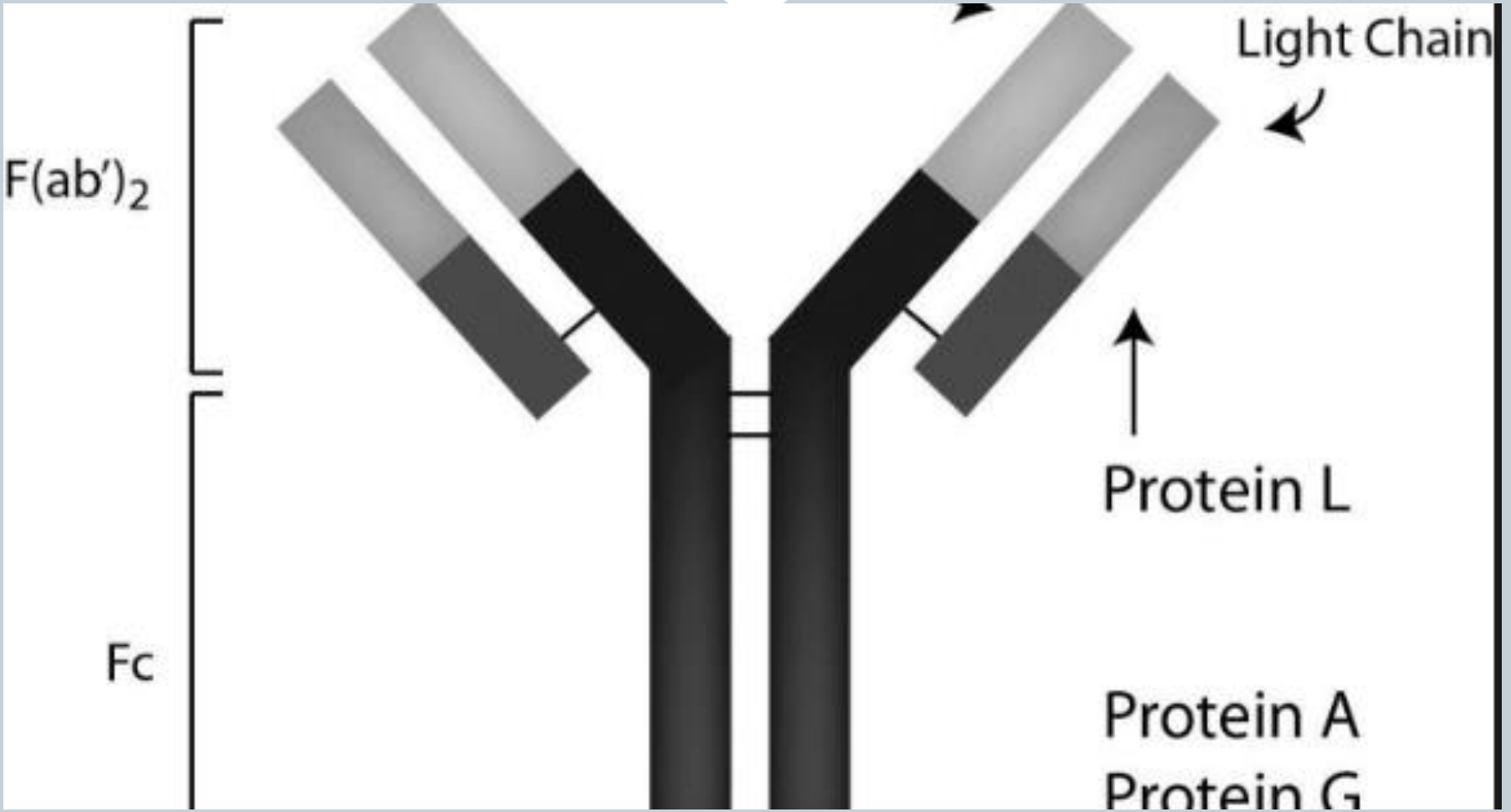



(A)
HCDR3
VH
CH1
VL
CL
CH2
Igα, β
(CD79a,b)
CH3
CH3
Ca2+
(B)
M-CLL
U-CLL
High affinity and specificty
Low affinity and specificty
β-(1,6)glucan
Rheumatoid factors
Myosin
vimentin
SYK
SYK
ZAP-70
Signaling
TRENDS in Immunology

# CD 20 on a lymphocyte



# What's an antibody?



# Blood film

- Why/when you might have to wait
- Analyser’s and Humans in the laboratory
- Your Multidisciplinary Team in Your Corner

# Dealing with the information

- Psychological health and well being
- Managing uncertainty